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Interdisciplinary Model of Attention for Children Undergoing Hospitalized Surgical Procedures

Renata Panico Gorayeb[1], Maria de Fátima Galli Sorita Tazima[2], Flávio de Oliveira Pileggi[2], Maria Angela Marchini Gorayeb[1], Ricardo Gorayeb[1] and Yvone A.M.V. Vicente[2]
[1]*Psychology, Department of Neurology, Psychiatry and Medical Psychology, School of Medicine of Riberao Preto, University of Sao Paulo,*
[2]*Pediatric Surgery, Department of Surgery and Anatomy, School of Medicine of Riberao Preto, University of Sao Paulo*
Brazil

1. Introduction

In this chapter we aim to present a model of comprehensive care for hospitalized children in a public Brazilian university hospital. This service is provided by a team of pediatric surgeons, psychologists, nurses and social workers, all of who specialize either in pediatrics or in the surgical procedures of the pediatric surgical clinic.

As part of their continuing education, these professionals regularly participate in conferences and courses specific to developments in maternal/pediatric care, therapeutic coping techniques in the realm of maternal/pediatric care, and the major diseases that affect children in this age group.

The team is responsible for the care of children and adolescents aged 0-18 years, of both sexes, who require either outpatient or inpatient medical and surgical care. In this chapter we will discuss the provided surgical care and the specific details of its treatment, care, and guidance, for both the child and the child's family, in bio-psycho-social aspects.

The interdisciplinary approach has been emphasized in recent years by promoting a broader understanding of the patient, his or her medical condition, and its context, demonstrating that this joint service improves the diagnosis, prognosis and quality of life of the patient.

The main objectives of this interdisciplinary model of care are:

- To wholly assist the patient and his or her family, caring for their bio-psycho-social needs
- To assist the patient and his or her family in acquiring a better understanding of the diagnosis and prognosis of each condition

- To promote the understanding, development and acceptance of invasive procedures and hospitalization
- To help understand the cognitive and affective aspects of disease perception and their influences on the quality of life of patients and their families, supporting the diagnosis and treatment compliance, thus providing greater progression

Based on these objectives, the Pediatric Surgery Team of the University Hospital of the Faculty of Medicine of Ribeirão Preto of the University of São Paulo (HCFMRPUSP) developed a protocol of integrated care for patients and their families. Through this protocol, all children and families who will experience a surgical procedure are treated in consultation with an interdisciplinary team composed of surgeons and psychologists in order to provide guidance and explanation of the possible conflicts related to the surgery for both the child and the family.

This model was developed from concepts described in several papers cited in the international literature, especially Canada, USA, France and China, which aimed specifically at the orientation of these patients for the procedures they will be undergoing, desensitization to invasive procedures, child-parent coping strategies, treatment and prognosis, as well as interdisciplinary interaction.

2. How pediatric illness can interfere with the family dynamic

Illness represents a modification of the bio-psycho-social scheme in a very particular and individual way, known in healthcare literature as one of the main factors that affect anxiety levels, quality of life, and individual behavior.

In the case of children, it is emphasized that they are in the process of building their own representations of reality and they do so through the summation of all their experiences.

Within the many objective and subjective lived experiences in the developing child's life, the importance of the relative and reactive models provided by adults during the child's early social environment stands out. The younger the child, therefore, the greater the influence of the behavioral patterns and coping mechanisms displayed by the child's adult references.

In the case of illness, which is not represented by any distinctive cognitive or affective form, the child is strongly influenced by the actions of those individuals who provide it with emotional support because these adults are significant role models who will utilize their own prior associations to deal with the new reality of their child's health.

The manner in which children therefore deal with this new reality is oftentimes reflective of their parents' coping mechanisms and the way their parents deal with the anxiety that stems from fear and uncertainty about their child's diagnosis/prognoses.

The new reality creates uncertainty about how, and if, these adults will or will not be capable of reasonably and appropriately recoding the experience of surgery and/or hospitalization for their children to understand.

For parents, the expectation surrounding the responsibility they feel to maintain the health and wellbeing of their children transforms the surgical procedure into a trigger of extreme anxiety.

The child's exposure to the risks of a hospitalization or surgery may induce negative fantasies and fearful reactions in both the parents and the child, exacerbating a natural reaction of anxiety and possibly causing a dysfunctional or pathological reaction of anxiety, and consequently a possible behavioral disruption.

The difficulty in understanding the procedure to be performed on the child, or even the hospital context to which the child will be exposed, the possibility of injury, loss or separation from the child, the anesthetic risk, and especially the fear of prognosis are some of the reasons these parental feelings are evoked.

For the infant, who is still in full development of its impressions, the principal sentiment is fear of the unknown, the pain, and the risk of separation from its attached adults, such as the mother.

Upon admission, everything surrounding the child is new and often scary. The child finds itself in a new routine with environmental and social restrictions and is often exposed to procedures that cause pain and/or discomfort.

These potentially anxiety-inducing changes are more intense during hospitalization due to the environmental restrictions, the hospital routine, and the prognosis, among other factors.

However, the process becomes more complex during surgery. There will also be an invasive intervention that includes anesthetic procedures, being that various studies show that surgery, and anesthesia in particular, are stimuli that trigger stress and anxiety because they can be symbolically associated with the fear of loss.

These factors may lead to behavioral changes in the child during and after hospitalization, such changes being more frequent in children who have not constructively addressed and coped with the stress they experienced.

In pediatric surgery, anxiety can be observed both in the child and in the parents, so that parental coping techniques, the representation of their anxiety and consequently the manner in which they deal with the child, can help or hinder the team's work and the child's recovery.

Very anxious parents exacerbate their child's inappropriate behavior, often hampering treatment and even the child's prognosis. For this group, with greater difficulty in coping with fear and anxiety, the child's behavior often changes during and after hospitalization, encouraging behaviors that are disturbing, such as nail biting and enuresis, and emotional, such as tantrums and night terrors. The same changes can also occur in the parents.

Note that empowering both children and adults to face and cope with the illness and proposed surgical procedure provides a way to deal with the information and can reduce fears and the implicit risks of a hospitalization. It is known that the quantity and quality of information received by the family and by the patient influence their trust in the team and consequently reduce anxiety and behavioral changes, which improves adherence to treatment.

In this way, we emphasize the idea that when information and psycho-emotional support are provided to patients and their families there is often an improvement in the acceptance of the proposed procedures and, especially, an increased confidence in the team.

This work is done in order to allow patients and their parents to understand the context of their clinical situation with detailed quantitative and qualitative information about the treatments and proposed procedures.

Therefore, when the whole family can be prepared and supported by a psychological intervention, damage to the child's behavior and the family's anxiety can be reduced.

This procedure is done by encouraging better a better compliance with the treatment as a whole, which shows that parental anxiety and pediatric behavioral changes, recognized in literature as the main factors that influence a child's health during the post-operative recovery, can be managed.

The work of this team, carried out by a clinical psychology specialist professional in conjunction with surgeon colleagues, all looking for a better pediatric recovery, confirms and reinforces the literature about the importance of interdisciplinary work in planning a pre-operative preparation for the child and family before a medical intervention.

Thus, we present the protocol that is necessary for providing comprehensive interdisciplinary care to the hospitalized child, especially in the case of a surgery. This work is done as much for the children as for their caregivers.

3. Interdisciplinary care protocol for pediatric surgery at HCFMRPUSP

This protocol was structured on a 2002 survey that aimed specifically to evaluate parents' understanding of their child's illness and the surgical procedures to be performed. We sought to investigate what were the principal doubts, fears, fantasies, and anxieties experienced by parents with regard to the risks and the diagnosis, as well as the hospitalization itself.

This work was carried out in order to understand what were the preconceived notions of the general population and also to assess the level of understanding and anxiety in the parents, before and after hospitalization of the child. In children, we analyzed changes in behavior before and after hospitalization, assembling comparative measurements.

The results of this study show data that compare to the related literature, where one can observe, through research tools, that:

- Maternal anxiety was significantly reduced, by around 30% on average, one month after the surgery when the mother received psycho-affective care and guidance before and during the surgical procedure of her child. Mothers without this care and guidance display an average reduction of 8% in levels of anxiety. These data point to a conclusion that psychological intervention leads to a better adjustment in the way that the mother/caretaker represents and copes with the illness, which she consequently passes on to the child.
- The mothers' levels of informed understanding, measured by correct information about the diagnosis, prognosis, and care for the child, before and after the surgery, were much more comprehensive in the group receiving psychological treatment, at 80% about activity restrictions after surgery and 100% about home care, while these figures respectively, were 50% and 40% in the group of mothers who did not receive guidance.

Further, the adequacy and retention of the information relayed by the pediatric surgeons, of a total of 40 general questions about the treatment, displayed a 67.5% satisfactory response rate in the group that was treated with psychological intervention, whereas the group that only received the usual guidance displayed a 30% satisfactory response rate. The same was true for the unsatisfactory response rate, where the control group who received no further guidance answered 22.5% of questions unsatisfactorily, demonstrating inadequacy in the care of the children, while the psychologically guided group did not offer any inadequate responses. Attention should be paid to the potential risks in the post-operative home-care of children whose families were not cared for and guided in an interdisciplinary manner.

- The frequency of unwanted children's behavior such as bedwetting, nail biting, insomnia, night terrors, and overuse or re-attachment of comfort objects (pacifier, bottle) was also lower in the group of children who were given therapeutic space to express their concerns and be guided in a more appropriate coping mechanism to deal with the fear of hospitalization and possible separation from their protective parental figures.

In this way, it was determined that the reception and guidance of the caregivers and the children is beneficial for the family, which produces a more relaxing work environment for the professional, which in turn also provides for fewer minor complications, due to the parents' better understanding of appropriate post-operative homecare and of the measures to be taken in the hospital itself.

Therefore, since 2002, this model protocol has been used by the interdisciplinary pediatric surgery team at HCFMRPUSP, with constant improvements made with respect to the integration of the group for the best possible care for the child and family and seeking to promote a less aversive process for those involved in pediatric surgery.

In this model of care, all children entering the Department of Pediatric Surgery at HCFMRPUSP after a medical screening to assess their clinical needs are referred for a psychological evaluation so that their psycho-emotional and social needs can be perceived in a more global way.

The first meeting assesses the parents' and the child's previous understanding of the health issue and the need for clinical or surgical treatment. Also assessed are the psycho-emotional resources for coping with clinical questions and hospital situations to which they will be submitted.

When the child's visit to the hospital requires only clinical, and not surgical, procedures, the child and its family are evaluated by a psychologist in their understanding of the diagnosis, treatment, and prognosis, as well as their methods of coping with the particular situation.

During this assessment, the family group receives additional information about ways to manage the child's behavior in order to favor the treatment and are offered, when necessary, invitations to join support groups for chronic illnesses or individual counseling when the child and/or parents present difficulties in accepting the course of action proposed by the professionals.

Following the chapter is an outline of the protocol for psychological preparation of the pre-surgery child that is used at HCFMRPUSP.

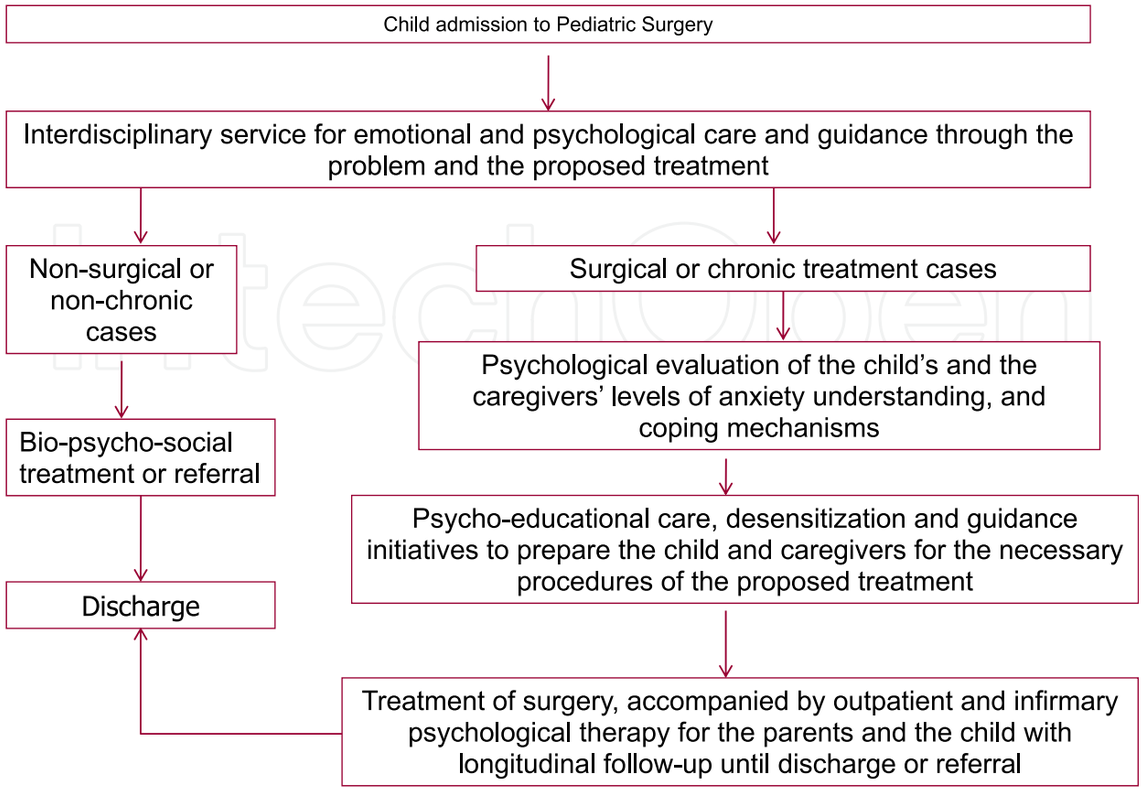


Table 1. Protocol for psychological preparation of the pre-surgery child - HCFMRPUSP

Also assessed during this meeting are the issues of the child's global development, and necessary referrals are made to ensure the best possible neuro-psycho-motor development. Only after all these issues have been met and forwarded to the appropriate clinical follow-up services can the child be discharged from the Pediatric Surgery Interdisciplinary Team.

When the child has an organic impairment that requires surgical treatment, the care of the team, in addition to that which is listed above, also includes an interdisciplinary reception and guidance where the illness, procedures, processes, treatments and invasive interventions are clarified in simple and didactic terms, first by the medical team and later by the psychological team.

In this context, parents/caregivers and children are guided through questions about the child's health, the treatment processes, and the hospitalization. During this first meeting of the child to be operated on, a psycho-emotional assessment of the parents and the child about the diagnosis, the pre-operative, operative, and post-operative procedures, and the hospitalization is performed in order to explain and reduce any doubts or possible negative fantasies regarding the experience.

It is often the case that this work is not concluded after only one session, and returns become necessary so that the staff, the child, and the parents are all aware, accepting, and comfortable with the procedures and its possible risks and benefits.

The process of Psychological Intervention is applied to the child and its parents through psycho-educational guidelines, or information for caregivers and children.

For these sessions, verbal instructions, didactic play materials, such as teaching material understandable to laypeople or hospital toys, and real hospital equipment are used as technical resources that may promote desensitization to procedures that may occur during the doctor visits and on the day of the surgery.

The handling of these materials is stimulated so that the real medical procedures will have been previously simulated in a play environment, seeking to promote desensitization of potentially anxiety-inducing situations that parents and children will experience.

Also provided are clarifications of the doubts and eventually presented inappropriate illusions. As part of the psychological intervention process, the most anxious parents and children visit the pediatric pre-anesthesia room of the surgery center and also the recovery room, where they receive a demonstration and explanation of the procedures that will occur there, which are presented by the team's psychologist.

If the child experiences any difficulty in interacting with the medical staff, returns are scheduled weekly or biweekly, except in the case of an emergency surgery, until the child is able to recover from its fear and illusions and interacts appropriately with the team during its evaluations and clinical procedures, which are often invasive.

What occurs, therefore, is an adaptation of the child to the members of the team and to the hospital equipment through successive exposure, as well as a systematic desensitization by reciprocal inhibition, through relaxation technique training, in the cases where the child exhibits resistance to being examined or to remaining calm in the hospital environment.

When an emergency or urgent surgery is required, the child is hospitalized and this procedure of desensitization to the team and the treatment is performed intensively in the infirmary.

4. The psychological focus on interdisciplinary care in pediatric surgery

The psychologist works together with the interdisciplinary team, both on an outpatient basis and in the infirmary.

The following take place in the clinic:

- Pre-operative group therapy that guides and prepares patients and parents for surgery;
- Therapy for families and patients suffering from syndromes and malformations;
- Orientation and guidance for children and parents with difficulty accepting or understanding processes, procedures, diagnoses and/or prognoses;
- Clinical therapy for children and adolescents who complain of daytime and nocturnal enuresis, encopresis, chronic constipation, and colon management;
- Guidelines for parents for the management of their children's behavior.

The specific objectives of the orientation and psychological counseling are:

- To guide and inform parents and patients about the disease and the procedures to be performed during the surgery and hospitalization;
- To promote desensitization to the procedures and to the hospital setting;
- To create awareness of the emotional family aspects that can interfere with adherence to pediatric treatment and to improve the quality of life of the patient and the family.

The following are used as educational materials for working with children and families:

- Playful/didactic hospital supplies that replicate those actually used in real procedures;
- Life-size cloth dolls of that represent a child of approximately one (1) meter in height with internal organs that replicate the human body;
- Real hospital equipment

The orientation and guidance therapy is performed primarily in groups, optimizing in this way the care offered to patients despite the high demand of the clinic. This form of care matches the data published in literature that demonstrates that group activities, beyond permitting a greater comprehensiveness of care, assists the patient in identifying with other people with the same needs, providing a space for clarification of doubts and exchange about similar situations between families.

For these pre-operative guidance and orientation groups, three meetings are generally held, following the procedures described below.

- **1st Meeting –** Parents (Informational meeting)

Informational meeting with the parents about the illness, hospitalization, and surgery of their children, as well as the goals of the group meetings with the children. The objective of this first meeting is for the parents to have a better understanding of their children's illness and the procedures that will be performed by the team, at the same time becoming aware that their children are not the only ones affected by the problem, so that they may thus act more appropriately toward the children's doubts.

- **2nd Meeting –** Children

This meeting is aimed at assessing the children's level of anxiety and understanding, as well as the children's own awareness of their health problem, the proposed treatment, and finally their reaction to the hospital. The order of activities is:

- Introductions and meeting of the children and staff;
- Evaluation of the knowledge and understanding of the children of their own disease;
- Creating awareness that other children are suffering from the same problem;
- Fun activities with hospital toys that promote desensitization to hospitalization;
- Investigation into the expectations of hospitalization and surgery;
- Explanation in a playful and didactic manner, provided by the doctor with the aid of mannequins, about the procedures which the children will go through during hospitalization (pre-anesthetic fasting, venous access, surgery, dressings, care and post-operative changes);
- Orientation about the sequence of surgery, return visits, and discharge;
- Final fun activity where the children simulate hospitalization.

- **3rd Meeting –** Parents and Children

The goal of this meeting is to evaluate the degree of comprehension of information received and to visit the hospital, in the following order:

- Investigation into the absorbed information and, when necessary, more illustrative repetition of anything not understood;
- Explanation in a fun and didactic manner, provided by the nurse in charge of pediatric surgery, with mannequins and hospital equipment, about the procedures and stay in the infirmary;

- Familiarization with the hospital accommodations (bedroom, infirmary playroom, outdoor playground, pre-anesthetic room and recovery room) where the doctor and nurse discuss what happens in each environment; Interactive activities that provide information about the affinity between pairs of children, so that staff can properly select pairs that should be roomed together;
- Closing play with the staff.

In the infirmary, follow-up care and treatment of patients seen in preoperative groups or individually in the clinic is continued, and also, when necessary new treatments are initiated, using the same criteria from the clinic for patients that begin their treatment through a transfer from another center.

5. Importance of interdisciplinary care in pediatric surgery

Over 13 years of work (1998-2011) improvements has been observed, with the procedures that were adopted, both for pre-operative preparation and for the treatment of chronic patients.

For out-patient follow-ups and in the infirmary, the improvements were in the affective development of emotional conflicts, fears, illusions, prejudices against the disease; facilitation of desensitization to procedures and to the hospital setting; lower levels of anxiety in both patients and parents, who demonstrated awareness and comfortableness regarding the procedures; hospitalizations with fewer complications and faster recoveries.

This data shows the importance of the performance of an interdisciplinary staff in the treatment of a pediatric surgery patient and his/her family.

The importance of intervention procedures aimed at the pre-operative preparation of children and their families is increasingly recognized. We should stress the need for this process to be carried out by a specialist in psychology who does not only stop to provide information about clinical procedures.

It is necessary that intervention programs provide conditions in which the parents and children can express their fears and anxieties about the situation that they are experiencing so that they can understand it more effectively.

Psychological Intervention, performed by a professional who is qualified to identify the emotional characteristics of parents and children in a systematic manner and with interdisciplinary support, can reduce the harmful effects to the child-family-professional bonds and can also reduce the undesirable aspects of hospitalization and surgery and consequently support the healthy development of the child.

The presence of a psychology professional together with the surgical team is fundamental when attempting to provide effective treatment to pediatric patients and their families, providing them with an effective understanding of procedures, better interaction with the staff, greater adherence to treatment, and consequently fewer risks to the emotional development of the child as a result of hospitalization.

This team believes that the interdisciplinary treatment in pediatric surgery is of utmost importance, because surgery is a time of crisis for parents and children, during which they are frightened and concerned about the necessity of a surgical intervention.

While the child is afraid of the unknown, of pain and of separation from their loved ones, the adults, in turn, fear the inherent risks of the invasive procedures, illness, and the possible poor prognosis and the treatments to which the child may be submitted.

Therefore, we believe that a staff trained in the care of both children and caregivers, and able to deal with the children's and adults' fears and illusions about their reality, is very important for the proper development of the measures taken and actions necessary in each case.

Our experience supports the national and international published literature that is very rich in articles about the importance of humanizing clinical care with a child and family during illness, especially with those that require hospitalization and who are submitted to invasive procedures, aimed specifically at the preparation of these patients for the procedures they will be undergoing. Here can be mentioned the studies of desensitization to invasive procedures, child-parent coping strategies, treatment and prognosis, as well as interdisciplinary interaction.

From these considerations the importance of guidance and counseling programs for children, when subjected to surgery, as well as for parents, can be emphasized, for both the literature and the real experience reported here show that these interventions are effective in the reduction of anxiety in mothers and children, providing better conditions for confronting stressful situations, and lower rates of behavioral changes in children after surgical procedures.

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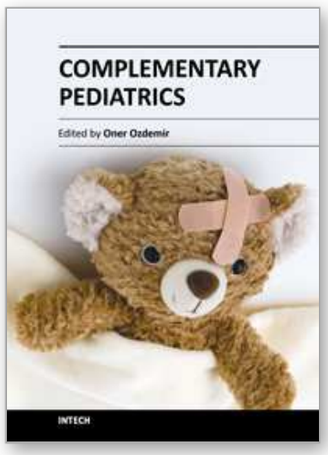
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Phone: +86-21-62489820
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