

## FAMILY PARTNERSHIP MODEL AS A FRAMEWORK TO ADDRESS PSYCHOSOCIAL NEEDS IN PEDIATRIC CANCER PATIENTS

### FAMILY PARTNERSHIP MODEL COMO ENFOQUE PARA ATENDER LAS NECESIDADES PSICOLÓGICAS DE LOS PACIENTES DE ONCOLOGÍA PEDIÁTRICA

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#### Abstract

**Objectives:** To summarize recent scientific literature on the psychosocial needs of pediatric cancer patients and their families and the existing psychological interventions to address these needs. To outline the features of the Family Partnership Model, an intervention that has proven effective in other chronic pediatric problems and may be also helpful in this field.

**Methods:** The most recent papers regarding the psychological needs of children with cancer and the interventions to meet them were reviewed. The principles of the Family Partnership Model as a method to enhance care and meet these children's needs were discussed.

**Results and conclusions:** Although significant psychopathology in children with cancer is relatively rare, psychological late effects such as subclinical PTSD in the survivors and their parents continue to be concerning. Renowned experts in this field have suggested that intervention frameworks useful for this population should provide tailored psychological support to families of children with cancer. Besides, the importance of interventions that can be delivered by health care professionals outside of mental health (e.g. physicians, nurses and teachers) have been highlighted. The Family Partnership Model is a holistic, family-centered and strengths-based approach that provides effective support specifically tailored to children's and

#### Resumen

**Objetivos:** Resumir la literatura científica más reciente sobre las necesidades psicológicas de los pacientes de oncología pediátrica y sus familias y las intervenciones psicológicas existentes para atender dichas necesidades. Describir los principales rasgos del *Family Partnership Model*, una intervención que ha probado su eficacia en otros problemas pediátricos crónicos y podría ser también útil en este área.

**Método:** Se revisaron los artículos más recientes sobre las necesidades psicológicas de los niños con cáncer y las intervenciones diseñadas para cubrirlas. Se discuten los principios del Family Partnership Model como método para mejorar la atención psicológica de este tipo de pacientes.

**Resultados y conclusiones:** Aunque los trastornos psicopatológicos en niños con cáncer son relativamente raros, las consecuencias psicológicas a largo plazo, como el Trastorno de Estrés Postraumático que puede estar presente a nivel subclínico en los supervivientes y sus familias, siguen siendo preocupantes. Renombrados expertos en este campo han sugerido que las intervenciones eficaces para esta población deberían proporcionar apoyo psicológico adaptado a las necesidades específicas de los niños con cáncer y sus familias. Además, se ha destacado la importancia de las intervenciones psicológicas que pueden ser llevadas a cabo por profesionales de la salud no especialistas en salud mental (por ejemplo médicos, enfermeras

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families' needs. As it meets the most recent recommendations made by experts and has proven helpful in the treatment of child with other chronic illnesses, we think it is a really promising intervention framework.

**Key words:** Pediatric psychooncology, pediatric cancer; posttraumatic stress disorder, psychological interventions; family therapy.

y profesores). *El Family Partnership Model* es un enfoque holístico, centrado en la familia y basado en los puntos fuertes y competencias del paciente que proporciona apoyo psicológico específicamente diseñado a las necesidades de estos pacientes y sus familias. Como cumple las recomendaciones más recientes hechas por los expertos y ha demostrado su eficacia en el tratamiento de niños con otras enfermedades crónicas, consideramos que es una intervención prometedora.

**Palabras clave:** Psicooncología pediátrica, cáncer infanto-juvenil, trastorno de estrés post-traumático, Intervenciones psicológicas, terapia de familia.

## INTRODUCTION

Cancer is the second-leading cause of death in infancy in developed countries, after accidents. Nonetheless, as life expectancy is greater, childhood cancer is now regarded as a chronic disease with which children and their families may cope indefinitely. With increasing rates of survival, there has been a parallel increase in the concerns for the quality of life of children who survive. In this way, more and more attention is being paid to the medical and psychological late effects of this illness.

On the other hand, there are relatively few intervention studies to guide our advocacy and delivery of care as clinicians<sup>(1)</sup>. In order to shed light on this issue the aims of our study are: first, to review the existing literature on psychological needs of children with cancer and their families and the psychological interventions that have proven effective to address these needs; second, after reviewing the recommendations made by experts in this field in order to develop psychological interventions more helpful for this population, to outline the main features of the Family Partnership Model, a method

that has been effective in the treatment of psychological needs of children with chronic illnesses other than cancer and it may be also helpful in the case of these children and their families.

## PSYCHOSOCIAL NEEDS OF PEDIATRIC CANCER CHILDREN AND THEIR FAMILIES

Authors such as Patenaude and Kupst<sup>(2)</sup> have highlighted that although substantial progress has been made in a relatively short period, we are only beginning to understand what the psychosocial needs of patients and their families are and how to address them. These authors comment that as methods of treatment for cancer have improved and as length of survival has increased, the needs of children and families have changed.

Pediatric cancer children have to adjust to complex treatment regimes (hospitalizations or isolation) which imply separation from parents and absenteeism from school, among others. On the other hand, treatments such as bone marrow transplants or chemotherapy usually imply painful procedures and disturbing side effects. Most side effects (nauseas, vomiting

or hair loss) are reversible. Nonetheless, other such as sterility, developmental delay or brain damage can be permanent. This latter aspect is the most important risk factor for mental disorders in children with chronic illnesses<sup>(3)</sup>. Children with brain tumours have gross motor, sensory and neurocognitive deficits that require the expertise of a clinical psychologist with experience in neuropsychology. Specific memory and attention problems are also associated with cranial irradiation and certain types of chemotherapy for leukaemia. Children treated before the age of five years are particularly vulnerable to long-term cognitive difficulties<sup>(4)</sup>. Similar to other groups of children with chronic illness, children and adolescents at highest risk for peer difficulties are those whose treatment affects the Central Nervous System or who have obvious changes in physical appearance<sup>(5)</sup>. As length of survival increases, the need for management of late effects (for example, neurocognitive deficits, infertility, or cardiotoxicity) is quickly becoming a burgeoning area of study<sup>(2)</sup>.

Treatment is often associated with anticipatory anxiety, phobias and other conditioned responses (nauseas, vomiting) that may interfere with the adherence to treatment<sup>(6)</sup>. Eating disorders (hyperphagia, anorexia), sleep disorders (insomnia, nightmares), enuresis, encopresis, hypochondria and health concerns, among others, have also been described<sup>(6)</sup>. Many authors have also found diminished social skills compared to their peers<sup>(7-9)</sup>.

However, data from the first major cohort of childhood cancer survivors indicate that psychological adjustment was within normal limits as measured using standardized questionnaires<sup>(3)</sup>. Survivors of childhood cancer do not demonstrate high levels of depression<sup>(10,11)</sup>. Besides, the depressive symptoms seen in pediatric cancer patients during treatment are often indicators of a normal response to the

distressing circumstances of diagnosis and treatment<sup>(12)</sup>.

Current thinking suggests that traditional or general measures of psychopathology and well-being may not have captured the specific and persistent experiences of childhood cancer survivors and their families<sup>(1)</sup>. According to Meyer and Fuemmeler<sup>(13)</sup>, to better capture the adjustment and resiliency of children and families to the cancer experience, young investigators in pediatric psychoncology will need to become proficient at developing, validating, and evaluating measures relating to quality-of-life issues and adaptive functioning in the context of survivorship and acute treatment.

The conceptualization of childhood cancer and its treatment as traumatic has gained increasing support in the growing literature on medically related posttraumatic stress. The fourth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association<sup>(14)</sup> added experiencing a life-threatening medical condition or observing it in a close affiliate (e.g., family member) as a qualifying event for PTSD.

It is noteworthy that although PTSD rates in childhood cancer survivors are low (5%–10%)<sup>(15-17)</sup>; high rates of PTSD and PTSS are reported for survivors of childhood cancer when they are young adults (15–21%)<sup>(18,19)</sup>. For parents of childhood cancer survivors, rates of PTSD or partial PTSD range from 5% to 25% with subclinical PTSD being common as well<sup>(20-24)</sup>. Mothers and fathers were found to have significantly higher levels of PTSS than were parents of never-ill children<sup>(25)</sup>. Internalizing symptoms commonly afflict these caregivers<sup>(24)</sup>. Posttraumatic stress symptoms (PTSS) such as intrusive thoughts, physiologic arousal, and avoidance have been documented in mothers and fathers of childhood cancer survivors<sup>(26)</sup>. Data also indicate PTSS in siblings of survivors<sup>(27)</sup>.

On the other hand, more and more attention is being paid to the psychological needs of the staff who work with these patients. Most of the studies claim that among the situations that cause most distress in medical personnel are caring for hospitalized children and caring for terminally-ill patients. The latter one is considered the most anxiety-provoking situation by medical staff. Doctors and nurses are often overwhelmed by this situation up to the extent that some of them are diagnosed with the "Burnout Syndrome". This syndrome is characterized by physical symptoms (insomnia, unspecified somatic complaints, fatigue, headaches...); psychological symptoms (sadness, anhedonia, anxiety...) and behavioural ones (e.g. "depersonalization" defined as impairment in the human treatment that is given to the patient).

Specific training given to hospital and community staff which highlights the psychological issues that affect sick children contributes to the holistic care of the child. In order to prevent the burnout syndrome in medical staff two measures have been described: firstly, it has been emphasized the importance of training the staff in the management of their own emotions regarding the palliative care situations. On the other hand, some experts<sup>(28,29)</sup> have highlighted the necessity for the staff to be trained in the detection and addressing of the patient's needs. According to these authors, one of the factors that makes the situation more difficult to bear for them is the fact that they do not interpret their needs and they do not know how to help the patient. As we will state later, the Family Partnership Model emphasizes the early detection of the patient's needs and those of their families. Since this model provides us with a theoretical framework of the helping process, we find it suitable to train medical staff (nurses, oncologists...) who works in Pediatric Haematology/Oncology Units.

## CURRENT APPROACHES TO MEET THESE NEEDS

In order to respond to these needs, some psychological interventions for children with cancer and their families have been developed. Some interventions such as social skills training<sup>(30)</sup>, problem solving skills training to reduce negative affectivity in mothers of these children<sup>(31)</sup> or the intervention program developed by Kazak to address posttraumatic effect symptoms in adolescents<sup>(22)</sup> have proven to be promising. Nonetheless, findings regarding intervention effects on specific psychological outcomes across intervention studies are mixed<sup>(32)</sup>.

In order to shed light on this issue, Pai et al<sup>(32)</sup> conducted a meta-analysis to estimate the effectiveness of psychological interventions in pediatric oncology. As we stated earlier, most of the times the psychological symptoms these children are suffering from are subclinical, thus the psychological outcomes reviewed in the meta-analysis were psychological distress (upsetting or aversive feelings which may include symptoms of anxiety or depression but may or may not meet the criteria for a mental disorder) and psychological adjustment (skills and abilities that are related to social, occupational and educational functioning).

The findings of the review provide modest support for the effectiveness of the available interventions. The most notable findings were for parents (a reduction in their distress and an improvement in their adjustment) but the effects in children were relatively small. Among the explanations which might account for these facts, the authors pointed out that the interventions were relatively unfocused and that they were eclectic in nature, employing a variety of modalities within the same intervention (cognitive-behavioral techniques, education, support...)

Kazak<sup>(1)</sup> also conducted a study to examine the state of the art of psychological interventions for children with cancer and their families. Regarding the management of pain, the review carried out by Kazak found that the integration of cognitive-behavioural therapy with pharmacological approaches has proven highly effective<sup>(33, 34)</sup>.

With regard to the interventions to reduce PTSD symptoms, the Surviving Cancer Competently Intervention Program (SCCIP)<sup>(35)</sup> is noteworthy. The program integrates cognitive-behavioral and family therapy in a four-session, one-day program involving groups of adolescent cancer survivors and their mothers, fathers and siblings. In a randomized clinical trial carried out by the authors, they found that families randomized to the SCCIP arm showed significant reductions in PTSS, particularly for survivors and fathers<sup>(22)</sup>.

In order to address families' needs, a manualized intervention was developed for the parents and other immediate caregivers of newly diagnosed pediatric oncology patients<sup>(36)</sup>. The SSCIP helps caregivers link their cancer-related beliefs to their actions and emotions by identifying strategies to maximize adaptation in an interpersonal, family context. The goal of the intervention is to prevent PTSS and enhance family adjustment over the course of treatment<sup>(35)</sup>.

### **DIRECTIONS FOR FUTURE INTERVENTIONS IN PEDIATRIC ONCOLOGY**

In an article published by Kazak in 2005<sup>(1)</sup>, the author, after an extensive review of the interventions available for survivors of childhood cancer and their families, proposed some directions to improve evidence-based psychological interventions in pediatric oncology. From our point of view, the recommendations

made in the article are useful not only for researchers but also for practitioners.

First of all, Kazak suggested that, in order to develop interventions useful for this population, we need to move outside of deficit-oriented treatment models. According to this author, such interventions should build on competency-based models (children and families' strengths) rather than on psychopathology.

Secondly, it has been recognised the necessity of cost-effective psychosocial interventions within the health care system. In order to ensure the cost-effectiveness and feasibility of psychosocial interventions, this author proposed interventions that are tailored to patients and their families' needs. By matching level of intervention with level of need, those who are most distressed will received the most intensive treatments, without negating the needs of all families for effective psychosocial care. The overall competence of most families facing childhood cancer indicates that many of them may not need traditional or intensive intervention. However, a small subset of families would clearly benefit from specific interventions. The challenge is to identify level of need and to provide interventions that are tailored to those needs. The ideal thing would be to deliver the most intensive treatments to those who are most distressed, without negating the needs of all families for effective psychosocial care. In another paper, a tiered model of psychosocial need and care using the concepts of universal, selected and targeted interventions was proposed<sup>(37)</sup>. Most families would receive universal care (psychosocial support) and those with more severe difficulties would require targeted care. If those families at highest risk for psychosocial distress during treatment can be identified reliably and if interventions can be developed to match these levels of risk, psychosocial care would be cost-efficient<sup>(17, 38)</sup>.

Thirdly, alternate models of intervention delivery should be considered. Taking into account the needs of ethnic minority and lower income families, practitioners need to consider the use of innovative formats and the delivery of care in the community and in schools<sup>(39)</sup>. Besides, interventions that combine treatment modalities (e.g. pharmacologic and psychological, cognitive-behavioral and family systems) and those that can be delivered by health care professionals outside of mental health settings (e.g. physicians, nurses, teachers...) are of particular interest.

Furthermore, it has been suggested that the amount and quality of support available to patients with cancer and their families is an important area of work<sup>(1)</sup>. Empirical studies of pediatric cancer show that parental social support is associated with adjustment to cancer and that lack of social support for parents is related to greater risk for distress and psychopathology<sup>(40-42)</sup>.

Finally, it is noteworthy the lack of psychological interventions targeted at the subset of patients who are likely to die (or have died) and their families. According to Kazak<sup>(1)</sup>, perhaps this is the most obvious area of neglect. In spite of the growing data on cancer survivorship, it is important to remember that not all patients survive. Although it is well established that the occurrence of a relapse is an extremely stressful time for patients and families<sup>(43)</sup>, there is no much data to support this idea. Researchers have given little attention to this aspect.

On the other hand, the empirical literature on interventions related to end of life and bereavement is extremely limited<sup>(44)</sup>. Palliative care programs tend to focus on medical care (e.g. symptom management). Social workers and chaplains take care of social issues and spiritual needs, nonetheless psychological interventions to address the psychological needs of patients

facing these specific circumstances have not been developed.

### **THE FAMILY PARTNERSHIP MODEL AS A METHOD TO ENHANCE CARE AND MEET CHILDREN'S NEEDS**

All these problems encountered by the specialists demonstrate the necessity of creation of a whole system of psychological monitoring of oncological children and members of their families, in order to make their life's quality as good as possible.

The Family Partnership approach is a holistic, family-centered and strengths-based model intending to provide effective help specifically tailored to family needs. This model puts special emphasis on the importance of establishing a partnership relationship (based on mutual trust and honesty) with parents and on the development of the interpersonal skills involved in the helping process.

In the United Kingdom, several services have been set up using the Family Partnership Model. These services have been mainly developed in educational and health settings. The first one was a service to provide psychosocial support for families with children with severe and multiple disabilities. Health visitors, social workers, nurses, physiotherapists, teachers... were trained in the model and then worked with these children and their families by home visiting. A detailed description can be found in Buchan, Clemerson and Davis<sup>(45)</sup> and Davis and Meltzer<sup>(46)</sup>.

More specific services were set up to help families of pre-school children with emotional and behavioural problems; families with one parent –or both– suffering from a mental illness; families of young offenders, etcetera. These programs have been carried out together with the Pediatrics services<sup>(47,48)</sup>. The Avon Premature Infant Project is also noteworthy<sup>(49)</sup>. In this project, a team of nurses were trained in

order to home visit families once the child had been discharged from hospital.

With respect to the effectiveness of the Family Partnership Model, there are some studies which provide direct support for its effectiveness. There is evidence of benefits for families who have been supported by people trained in the model in different contexts: in families of children with severe intellectual disabilities<sup>(50)</sup> and in families of preschool children with emotional and behavioural problems<sup>(51)</sup>. The model proved effective in terms of decreased levels of stress, increased self-esteem of the mothers, improvements in the behaviour of the referred children, adherence to the treatment and improvement in the relationship among all the people involved in the child's treatment.

On the other hand, there are also a lot of studies which provide indirect support for its effectiveness. Davis and Fallowfield<sup>(52)</sup> reviewed the available research concerned with the effects of improving professional communication. They found evidence that improved communication is associated with: decreased stress and increased job satisfaction in professionals, increased patient satisfaction, increased accuracy of diagnosis, improved patient adherence to treatment, better outcomes (both physically and psychologically) and increased prevention. There is also an extensive body of research on psychotherapy and counselling showing consistent positive benefits<sup>(53)</sup> including the effectiveness of paraprofessionals in providing social support<sup>(54,55)</sup>.

Although this model has been mainly implemented in the context of primary care, schools and home visiting, we consider that training medical and nursing staff who work in Pediatric Hematology/Oncology Units in the Family Partnership approach can be promising. There are very strong arguments for the need for the approach based upon evidence of high psychosocial

needs in these children, high psychosocial needs of parents and medical and nursing staff, poor communication in health care professionals and parents' dissatisfaction with professionals and professional dissatisfaction with their own training.

Davis and Fallowfield<sup>(52)</sup> summarized the deficiencies in health care professionals communication including: avoidance of information of a psychosocial nature; failing to elicit feelings about the illness; a directive style; failing to provide adequate information regarding diagnosis or treatment etcetera. The need for the Family Partnership Model is clear, given the fact that these are the skills that are explicitly covered in the model and are specifically trained.

Regarding the professional dissatisfaction with their own training, we can state that there is evidence that many professionals (health visitors, pediatricians, nurses...) have not been specifically trained in psychosocial issues, such as the identification, assessment and treatment of emotional and behavioural problems. It is common for non-specialists in mental health professionals to be overwhelmed by such psychosocial issues because they do not know how to deal with them. This aspect was previously described when the needs of the staff were analyzed. People who are trained in the model are taught to identify the specific emotional and behavioural problems that these children and their families may have.

The Family Partnership Model fits perfectly with the previously detailed recommendations for best practices. In South-East London, where several services have been established following this model, a four-tiered system has been developed. The general tiered model for the organisation of helping services is an overall system of care for children and families, indicating a clear psychosocial role for all people working with them. It is

here that the Family Partnership Model has its place in providing support for all families preferably before problems develop. On the other hand, as we stated earlier there are no interventions targeted at subclinical cases. Thus, these services are mostly preventive and aimed at subclinical cases. People trained in this model are taught to early identify children and families' needs and facilitate the referral to more specialised resources for those who have more complex needs.

What is more, as we stated before, one of the most distressing problems that medical personnel working in Pediatric Hematology/Oncology Units face is the lack of training in the identification of these patients' needs and hence, they do not usually know how to help them. Given this situation, it is relatively common for the staff to feel frustrated. However, among the benefits of the Family Partnership Model for the helper, one might expect helpers to find the process less stressful as a result of understanding parents better and working together with them in finding solutions as opposed to be solely responsible for them.

Regarding the provision of support, as explained above, the amount and quality of support available to children with cancer and their families is an important field of work<sup>(1)</sup>. Social support for parents is related to a better adjustment to the illness and the lack of it is related to a higher risk for psychological symptoms<sup>(40-42)</sup>. In this respect, one of the aims of the Family Partnership Model is to promote social support. A major aim should always be to enable parents to build, strengthen or use existing social support networks more effectively. Besides, the Family Partnership Model was developed to enable all potential helpers to understand the processes and skills of helping, so that they can use their own technical expertise more effectively by taking into account the interpersonal

issues involved in the helping process. Establishing a working relationship with parents may go a little way to meeting this need, but this will not make up for the lack of relationships or problems in their social networks, nor meet all the needs that are potentially fulfilled from social sources. So, one of the tasks of the helping process is to promote social support networks.

Finally, with regard to the needs of the terminally-ill patients and their families, one of the points made by the Family Partnership Model is that there are situations in which parents do not need to be assessed or diagnosed but to be listened to. In situations of bereavement or terminal illness, acceptance is the only effective help and simply listening actively to the patient in spite of one's own helplessness may give a very powerful message of support. Listening to the patient with the intention of deriving a clear view of the parents' picture of the situation is an aim of the helping process in itself. It may reduce parental anxiety and can be a relief, even when little else can be done to change the situation. For instance, it might eliminate unnecessary and inappropriate shame or guilt and reduce the likelihood of developing a complicated bereavement in a long term in the case of the parents.

### **IMPLEMENTATION OF THE FAMILY PARTNERSHIP MODEL IN THE CONTEXT OF PEDIATRIC HEMATOLOGY/ONCOLOGY UNITS**

The theoretical bases of the Family Partnership Model, developed in the Centre for Parent and Child Support (Guy's Hospital- South London and Maudsley NHS Trust) are psychotherapy, counselling and cognitive-behavioural therapy. It is particularly influenced by George Kelly (Personal Construct psychology), Carl Rogers (Humanistic psychology) and

Gerard Egan (author of the "Skilled Helper" model of problem managing).

According to the Personal Construct theory we all develop constructs in order to make sense of our own experience. In the case of a child who has been diagnosed with cancer, suddenly both the child and his/her parents are forced to inhabit in a threatening world. This radical change in their view of the world and life in general can manifest itself in the form of anger or frustration. Afterwards, the sadness stage that patients and their families undergo can be seen as the result of the collapse of a great part of their construct system. Previous constructs are not useful to understand this "new" world and the patients and their parents lack tools to manage in it. The task of the care provider is to facilitate the change of the construction system to enable them to cope with this new situation. Care providers may fulfil these tasks by providing them with new information and by encouraging them to get involved in the treatment of their child. For instance, if parents strongly think that they cannot do anything to help their child, it is unlikely that parents be actively involved in their child's treatment.

On the other hand, the medical and nursing staff who are trained in this model are taught to identify the constructs that may interfere with the adherence to the treatment. Notions of "illness" and "death" change over a child's emotional and cognitive development. Therefore, it is vital to take into account the age of the children when talking about the disease with them. The constructs that the child develops determine his/her hypothesis of what is going on and why it is happening to them. It is also important to explore the fantasies they use to understand the disease they are suffering from. Most of the times, these fantasies are self-blaming and anxiety-provoking. In order to prevent these guilt and anxiety from arising sometimes it may

be helpful to explain to them how cancer works by using metaphors or stories.

The way the child and his/her parents construct the disease is going to determine how they are going to cope with it. For instance, if they interpret the disease as a punishment, the child may think that he/she deserves it and, subsequently, he/she is not likely to fight against it.

On the other hand, along the course of the disease, physical symptoms are usually prominent. The bodily changes these patients usually undergo threaten the child's self-image and the image that the others have of them. The way in which the child understands these changes is going to determine their emotional reaction to the situation<sup>(56)</sup>. According to these authors when the most prominent factor is the fact of being threatened, the child is likely to be anxious; when the disease is regarded as an unjustified attack against him/her, the child is likely to be angry; when the disease is seen as a fair punishment for something he/she did, the child will probably feel guilty and, finally, when the disease is mostly interpreted as a loss, the child will probably feel sad.

What is more, we are used to using all kind of devices so as not to talk about death. Expressions such as "He left us" or "She is gone" are common in our vocabulary. However, children use the word "Death" in their games. "I killed you", "You are dead" are common when they play. Children, as any other person, need to talk about what is happening to them. More than being talked to, they also need to talk and to be listened to. Our model puts special emphasis on allowing them to express their emotions: anger, guilt, hopelessness, etc.

Taking all this into account, it seems essential to explore the constructs that lie behind some of the attitudes of the patients and their families. The way they are going to cope with the disease and their emotional reactions to it are determined by such

constructs. An important task of the care provider is the identification of constructs that may interfere with the adherence to the treatment.

The way parents make sense of the disease and their treatment (their constructs of the situation) are going to determine the decisions they make along the treatment. For instance, the decision of informing the child depends upon the constructs that families and staff have in this regard.

Concerning this issue, we find two attitudes. The most traditional one claims that parents and medical staff should protect the child against any kind of painful information. The other approach advocates an open communication with the child because they have the right of knowing everything concerning them. Although most of the works that have studied this issue show the benefits of an open communication with the child, eventually the decision has to be made by parents. Of course medical staff must respect whatever decision parents may make. But, sometimes the members of the staff are asked about the suitability of sharing some of the information with the child. Medical staff should let parents know that research shows that an open communication contributes to a better prognosis of the disease.

Sometimes, children make medical and nursing staff be an active part of the process. Although, parents are usually the ones who inform the child, sometimes parents ask for the collaboration of the oncologist or a nurse. Medical and nursing staff must be qualified to answer the questions children make. It is also important that parents be present in the moment of the diagnosis. In this way they can support the child and know exactly which information has been given to them. A warm and flexible communication between the staff and the members of the family contributes to strengthen the emotional bonds and

to create an atmosphere of mutual trust, characteristic of the partnership relationship that Family Partnership Model encourages.

The constructs that parents and staff may have not only are going to influence the decision they have to make on whether the child needs to be informed about the disease or not, but also other decisions they will have to make all over the process. Some parents think that is better for the child not to know anything of what is happening. This construct stops the child from expressing their fears, contributing to their feeling of being alone. The need for pretending normality increases when the physical state of the child gets worse. In this situation, parents are afraid of saying something inconvenient, so the relationship is more and more difficult and child feels more and more isolated. This construct leads to a relationship based on mistrust. What is more, this attitude can make the child fantasise about the situation. These fantasies can lead the child to think that the situation is more severe than it really is.

It has been proved that sharing the information regarding the disease with the child contributes to a better adaptation to it. In a study carried out with survivors of leukaemia<sup>(57)</sup> found that those children who had been early informed (at the age of six or within the year following the diagnostic) were more adjusted than the ones who were informed later or were not informed.

On the other hand, constructs that patients and their families have to make sense of the disease vary all over the course of the treatment. According to Elisabeth Kübler Ross<sup>(59)</sup>, the patient and the members of the family go through several stages of adaptation to the disease. Although each stage implies specific emotions, the phases can alternate or overlap and can vary in terms of intensity or duration. Medical and nursing staff must be aware that stages do

not always occur in sequence. Shifts from one stage to another may occur.

These stages also illustrate how human constructs are resistant to change. We tend to “see” things that confirm our beliefs and ways of seeing the world and tend not to see the things that do not, in this way we can get trapped in familiar habits and set ways of seeing ourselves, others and the world around us. This fact explains the first stage of adjustment to the illness (Denial). It is better for parents to believe that their child is healthy and nothing wrong could happen to them. So, firstly, they pay selective attention to the signs of health in the child and only, gradually, when the illness fully manifests itself, start to notice that their child is suffering from a serious disease.

The other stages through which both parents and children go may be seen as the modifications that take part in their system of constructions to adjust to the change of the situation. As the situation implies a radical change in their lives, these modifications have to be done rapidly. Suddenly, parents are forced to inhabit in a threatening world. This radical change in their view of the world and life in general can manifest itself in the form of anger, frustration. Afterwards, the sadness stage can be seen as the result of the collapse of a great part of their construct system. Previous constructs are not useful to understand this “new” world and parents lack tools to manage in it. The task of the care provider is to facilitate the change of the construction system to enable parents to cope with this new situation. Care providers may fulfil these tasks by providing them with new information and by encouraging them to get involved in the treatment of their child. All these stages must be respected and accompanied by medical and nursing staff.

First of all, these children go through a stage of shock and denial: patient’s initial

reaction is shock, followed by denial that anything is wrong. It is common for the child to behave as if nothing was happening. From our point of view, both parents and staff have to allow time and give information at the child’s pace. Information about the illness should be provided only when they ask. After that, patients become frustrated, irritable and angry that they are ill. Younger children feel frustrated because they cannot play with their friends or go to school, adolescents, on the other hand, may wonder “Why me?”. Both parents and personnel have to be ready to answer this kind of questions. It is important to provide them with an explanation of the causes of the illness adjusted to their age; on the contrary, some children may think that they are to blame for the illness. Patients in this stage are difficult to manage because their anger is displaced onto doctors and nurses. It is necessary to let parents and staff know that this difficult behaviour is their way of expressing their inner feelings, so it is important to let children express themselves, contain their desperation and let them know that they will be taken care of regardless of their behaviour. Sometimes, anger is directed at themselves in the belief that illness has occurred as punishment for wrongdoing. In such a case, it is important to clarify to a certain extent the reasons for the illness.

In this point, some children may attempt to negotiate with physicians, friends or even God, that in return for a cure, he or she will fulfil one or many promises (e.g. attend church regularly). In this “Bargaining stage”, children can promise to behave themselves in order to be healthy again. It is common for children to display rituals, magical thinking... It is a desperate attempt to delay or postpone the unavoidable. It is important to respect this kind of defence mechanism.

After the “bargaining stage” some children show clinical signs of depression:

withdrawal, sleep disturbances, hopelessness, and etcetera. Adolescents may present with suicidal ideation. Medical and nursing staff should be specifically trained in the identification of these thoughts. It also should be noted that these depressive feelings can manifest themselves as conduct disorders. In this stage, regressive behaviours typical of previous stages of the development can be observed. Sometimes, children are excessively submissive to treatment. When the patient is a teenager, there might be a rebellion against the dependence imposed by the disease. This anger manifests itself as defiant behaviours difficult to manage. On other occasions, teenagers prefer to be left alone. This attitude can be related to wrong beliefs regarding the idea of being contagious or because they do not want to be rejected by others. It is important to facilitate the expression of the feelings and to explore the wrong beliefs that lie behind some of these attitudes. Finally, some patients come to terms to the disease they are suffering from (the so-called "Acceptance stage" according to the model of Kubler-Ross).

Families, for their part, go through similar stages. The initial response to the diagnostic, both in parents and in children, is usually of shock and inability to believe what they have been told. One of the main problems is the uncertainty about future which causes a strong anguish. Paradoxically some children that have felt badly before being diagnosed feel relief because consider that if the disease has been detected it can be treated. It is common for parents to say: "It must be a mistake". At first, some families consult several specialists hoping that the diagnosis is wrong. The longer parents deny the disease, the more the expression of their fears (and their elaboration) is going to be delayed. The sooner parents admit the diagnosis, the sooner they will be able to

acquire some control over the situation and they will look for support.

It is important to let the family be the guide. Many parents will want to know all the details of the diagnosis (concerning treatments, course and prognosis), whereas others will not. The staff has to determine what the parents already know and understand about the prognosis. When the diagnostic is recognised in some degree, parents will look for an explanation. Parents can live their child's disease as a personal aggression, they can blame themselves (e.g. because of genetic reasons) or others (doctors, fate, God). Children also look for a reason, according to the concept of the disease they have. Their explanation will determine their attitude towards parents. Thus, it is essential to explore these constructions (both in parents and in children) because strongly held beliefs may interfere with the adherence to the treatment and the relationship between family and medical staff.

Regarding the tasks of the staff involved in their treatment, the care provider should start to build the relationship since the moment that they have been told the diagnosis. This relationship should be built gradually, following the parent's lead. It is not recommendable to stifle hope or break through parents' denial if that is their major defence, so long as they can accept and obtain necessary help. They will be encouraged to use their social networks for support. If parents refuse to obtain help as a result of denial, staff gently and gradually will help parents to understand that support is necessary and available.

After that stage, it is usual that families get angry with medical staff. Parents tend to wonder: "Why is this happening to us? It is not fair!" Staff should allow them to ventilate these feelings and take into account that they are a way of communicating the frustration they may be experiencing and should not take it as a personal offence.

Allowing parents to express whatever they may be feeling can contribute to building a working relationship. On the other hand, the care provider can gradually go on to the next tasks (Exploration and Understanding) through giving parents the confidence to talk openly and honestly about whatever might be worrying them.

Some parents tend to resort to religious beliefs or consult quacks in order to seek other possible alternatives to save their children. In this "Bargaining stage", parents start making questions about the treatment, the course or the prognosis. The members of the staff have to provide them with truthful answers.

Most parents reach the "Sadness stage", which implies some awareness of the severity of the situation. Depending on their previous experience with disease, anxiety, rage, guilt feelings or depression will appear in parents. Sometimes parents can interpret the child's sadness as a proof that the patient has surrendered. The ability of parents to cope with the child's sadness depends on their own ability to elaborate their own mourning for their healthy child. The medical and nursing staff should note that an anticipatory grief reaction may occur in advanced of loss and can mitigate acute grief reaction at the actual time of loss. This can be a useful process if it is recognized when occurring. Therefore, care providers should pay attention to this possibility. Grief reactions usually respond well to reassurance and social contacts, thus social and emotional support in this stage may be really helpful.

Ideally, children and their families reach the "Acceptance stage". Although, by this stage the diagnosis has usually been accepted, in this stage they are struggling with coming to terms with the prognosis<sup>(60)</sup>. It is in this stage when parents present with more psychopathological disorders. Anxiety, depression, insomnia and somatic complaints are present at least in 50% of

the parents<sup>(61)</sup>. Medical and nursing staff trained in the model will be trained to early identify this clinical symptomatology in order to refer them to the specialist in mental health.

In this stage, parents start to wonder what they can do to improve the situation. Sometimes, parents start to realise that other problems have arisen. For instance, they may have to face financial difficulties; other siblings may be having trouble in school or they may be experiencing trouble at work because of their irritability. It is the moment to explore extensively the whole situation of the family and to go on to the next tasks of the helping process. The helper will work together with the parents in order to enable them to manage problems. In order to do that, both the parents and care providers will set goals and priorities, plan strategies and implement them. Following with the same example, parents will have to decide on how to distribute their time in order to attend the other siblings. This decision can imply being off work for a while, establishing turns to be at hospital with the patient and etcetera. Both the goals and the strategies to achieve them should be negotiated by parents and the staff.

The constructs that children and their families have in order to make sense of death are highly important because they are going to determine some decisions such as whether to talk about religious or spiritual issues and concerns. It is necessary to take into account that children under 5 years of age do not appreciate death, they see it as a separation, similar to sleep; between 5 and 10 years of age, they become increasingly aware of death as something that happens to others, particularly parents and, after 10 years of age, children conceptualize death as something that can happen to them. The decision on whether to inform the child of his/her death will depend on the circumstances of each patient, nonetheless

the constructs that both patients and their families have in this regard will also have to be taken into account when making the decision.

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