

How to Accompany Children and Parents During the Different Phases of a Severe Chronic Disease

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1. Introduction

Our experience is related to the treatment of a lifethreatening disease (leukaemia) and from it should be applicable the same concepts or strategies to any other severe chronic disease.

Since the early 1970s, a cure for childhood cancer has become a reality: over 80% of cases are now cured. Yet, despite the relatively high cure rate, the diagnosis of leukemia continues to place a heavy burden on family functioning. The parents must walk the narrow line between focusing too much on the child's disease and treatment and maintaining a normal family life. Because cure is such a real possibility, the children must be prepared for a full and active participation in adult life, just like their peers. Proper discipline must be maintained within as normal a family life as possible. The child's continued attendance at school and participation in normal childhood activities is imperative in the child's preparation for adulthood.

For all these reasons, psychosocial intervention has become a necessity in the treatment of the child, even for those children who eventually will die from the disease.

Although there is little disagreement that the ultimate goal of treatment for childhood cancer is the total cure of the child-medical, educational, psychological, and social-the issue is how best to achieve this end. The literature is filled with research-based conclusions on which type of psychosocial intervention is best, including when and how one should communicate with the child about the diagnosis, how to help the parents maintain some sense of normality in their family life, how to help the child return to school, how to keep the siblings informed, how to start parent groups, how to involve parents in medical decision-making, how to prepare for the terminal phase when it occurs for some children, and how to continue to monitor long-term survivors. Problems occur whenever the approach must be modified to meet the needs and cultural preparation and expectations of the children and their families. This is especially true when one tries to apply conclusions that are appropriate in one culture to other centers and to other cultures.

What works in one cultural setting may not work as well in others. How might a center apply programs from one country or setting to another? Not all hospitals can afford a psychosocial team.

Not all cultures appreciate intervention by a psychologist or psychiatrist. What can pediatric hematologists do to modify their approach to the children and their families with maximal success, in a manner most appropriate to and respectful of the needs of the families within their own cultural setting? And above all, how can a center best monitor its intervention programs, to ensure that the needs of the children and their families are being met appropriately, in their best interests, and with greatest effectiveness and use of resources?

How do we help a family whose child has been diagnosed with a life-threatening illness? How do we help the children and their families cope with the illness and its treatment? As the medical treatment of childhood cancer has moved from an inevitable death sentence to an approximately 80% cure rate, the importance of including the psychosocial in the treatment of the children has now been so integrated that the majority of the pediatric cancer centers throughout the world now view treatment as a biopsychosocial process.

From the very beginning, with the shock of the diagnosis itself, the children and their families undergo a critical change in their lives. The illness has a high social and economic cost, even if the treatment itself is done free of charge to the families. Whether the child is treated in countries with limited resources or in the wealthier countries, personal, family, and cultural circumstances can block access to a full cure, a cure that treats the child at all levels: medical, psychological and social. As the families face the task of adjustment to this new reality, with the support of the hospital health care team the families can find a source of renewed energy and the inner strength to cope with the disease and the treatment process.

Each phase of treatment has its own characteristic that contribute to the reaction of parents and children. The phases are the following: acute phase, during treatment, after treatment, long-term follow-up, end-of-life.

2. A Multidisciplinary effort: Type of strategy in all the phases of the disease

From the earliest years, the effort to care for the child with cancer has been multidisciplinary, multi-institutional, and international, involving a highly cooperative and collaborative effort of physicians, nurses, psychologists, social workers, and allied health care professionals all working together across national borders. When, thirty years ago, physicians treating the children found themselves struggling with the psychological and social repercussions of the cancer on their young dying patients and their families issues that ranged far beyond their medical expertise and training, psychosocial practitioners helped in dealing with these broader human concerns. The pediatric oncologists and hematologists from countries throughout the world began working cooperatively with psychiatrists, social workers, nursing care specialists, and psychologists. To the credit of all involved, this cooperative multidisciplinary, multi-institutional and international effort has been from the very earliest years and continues to be the hallmark of the treatment of childhood cancer. It is important that all members of the health care team engage in psychosocial support, and not just the psychosocial personnel.

3. Research: Psychosocial research is essential to build up different clinical approaches

The primary psychosocial concern in child cancer care is to help the children and their families cope with the diagnosis of cancer and its aftermath. The children and their families, the great majority of whom are struggling with the new diagnosis but who do not show signs of falling apart, need our support. How can we most effectively help mentally healthy children whose lives have been suddenly turned upside down with the diagnosis of a life-threatening illness? We can't expect the families to wait for intervention until we can fully determine which intervention works most effectively and validly. We must try to help the child and family who have an immediate here-and-now need for support, while pursuing scientifically valid controlled research designed to sort out effective from ineffective interventions. The optimal clinical service is the application of the best available evidence-based findings applied locally in cultural context. Well done research is costly and difficult to accomplish in centers with limited resources. However, the health care team even a center with limited resources can listen carefully to the children and their families to find out how they are functioning and how they are responding to the service that is offered. It is recommended that parents be asked formally how well they view the center's functioning and this satisfaction within a simple nonrandomized like study. Modifying one's approach based on a reflection on the families' level of satisfaction with the service can help make the service better. Even in countries with limited resources, it is possible and critically essential to give full attention to the psychosocial needs of the children and their families.

4. Alliance between parents and physicians: The basis in all the phases of the disease

It is clear that a hospital health care team can not do it all. Parents should be invited increasingly to participate actively in their child's medical, psychological and social care, brought in as part of the decision-making process and support system. There should be a healthy, cooperative, and open alliance between the parents and the members of the health care team, including the establishment of parent groups for self-help and for raising supplementary and critical funding.

Wasteful expenditure of negative energy by anyone involved might be more profitably used, and in turn mobilize new and even more powerful positive energies, by cooperating toward fighting the disease in a therapeutic alliance. This alliance may take one or both of two forms: (a) an alliance between individual family members parents and children and individual medical staff members; and (b) an alliance between families as a group and health care team members as a group. These therapeutic alliances are formed when both parties work together with a common purpose pooling resources toward a common goal: curing the cancer and minimizing its medical and psychosocial side-effects, and mobilizing the energies of all members of society to this end.

The role of physicians and health care team members working together in cooperation with parents as equal partners is to:

1. Dedicate time, energy and creativity to collaborate with parent associations by suggesting and arranging joint meetings and acting in advisory capacities.

2. Encourage all parents, especially shy or cautious parents, to join a parent association and help activate parents to organize such associations where they do not already exist.
3. Have parent association members, together with members of the health care team, cooperate in deciding upon a global medical, psychosocial and social-cultural intervention program, toward which they all can converge their united energies.
4. Do all in their power to ensure that cured children and young adults are successfully reintegrated into society, without being penalized in school, work, social relations or insurability for having had cancer as a child.

5. Open communication: At diagnosis, during treatment, at the end of life

Communicating the diagnosis and how best to do is the first step in a communicative process and relationship that involves the medical team and the family, and that allows for growth and change over time. As the evidence mounts that the children, siblings, and parents would be best served by being encouraged to bring into the open their anxieties about the illness and its possible consequences, studies have been paying more attention to how parents and medical personnel communicate with the child. The initial diagnosis is a model for all future interchanges of information between the medical professionals and families and between the family members themselves, especially between parent and child. As the families of the children diagnosed with cancer struggle to face the new emotional crisis which is challenging the relationships among the family members and the very balance of family life, we need to help the families strengthen their coping skills, alleviate their anxiety and offer the type of support the children and families are seeking, in specific ways that are most important to the children and families at a given moment. Basic to effective family coping is the belief that communication of both happy and painful thoughts and feelings, by the parents and by the children, is a healthier state of mental well being than retaining those thoughts in silence. This belief is a prerequisite to mutual support among family members. The families which allow open discussion of the illness and its prognosis are able to cope more effectively with the illness within their own family, and are also able to give and receive the support of other parents in the clinic.

Management of this communicative process has an important influence on how all involved child, parents, other family members, and medical staff work and care for the child together.

At diagnosis the child and family's level of anxiety is very high, and their level of prior information and understanding varies greatly. Most parents want to know as much as possible about the disease, treatment procedures, prognosis, practical coping details, and emotional impacts. The staff's communication of the diagnosis and treatment plan should be done in a way that is responsive to these needs, and that develops confidence and trust among the pediatric cancer staff, patient and family.

Our general view is that full and open communication between the medical care team and the family (including the child), and within the entire family, is the ideal situation. However, this is not always possible or preferable. It also must be done in a way that is sensitive to different cultural styles and preferences.

The communicative session should be conducted in a private space, with comfortable seating and an environment conducive to discussion of painful issues, as a conversation

between equals. Both parents and the chairman or a senior medical staff member should be present, as well as the head nurse or another staff member. The attendance of the family's local physician should be encouraged unless parents do not agree. If requested the child with cancer (according to age), other family members (e.g. grandparents: they are significant sufferers that often receive little attention!) or close friends also may attend this session.

When communicating with the child, the physician should explain the disease at the level of development of the child, using pictures and analogies such as the flower garden to help the child's understanding. The physician should make sure that the dialogue is truly a two-way interaction, with the child invited to ask questions and having the answers explained as clearly as possible. Depending on age and level of development, the physician should talk to the siblings as well, explaining to them the basic elements of the disease and its treatment, and having them as well communicate back to the parents what they understand about the illness. In this way, an open system of communication is set up within the family.

6. The siblings: At diagnosis, during treatment, over the time

From the earliest intervention periods, the health care team members have all they can do, first to focus on the needs of the children with cancer, and then on the needs of the parents. The parents are overwhelmed by their concerns for the sick child, giving their immediate and full attention to the medical treatment of their sick child. Without any ill intention on the part of already overburdened parents, siblings are often inadvertently ignored. We should try to give attention to the needs of the siblings as well, and not let them be forgotten. During this time of crisis, when the parents are already giving their almost undivided attention to the sick child, how does one bring the needs of the siblings to parents' attention? How does one encourage and help the family to return to as normal a family life as possible as soon as possible? There are general principles for helping take care of the needs of siblings that apply throughout the treatment process, and there are principles specific to each phase of treatment: what to expect both for themselves and for their brother or sister now versus after physical changes occur, or changes in their relationships with their brother, sister, and parents, and what they can do to help during these transitions; and what adverse effects the siblings might have on the patient (for example, "spreading germs," e.g., a cold, or picking fights). Members of the health care team can speak with parents about the need to support the siblings, despite all of the other burdens that go into caring for the ill child. They can encourage the parents to share and generate suggestions regarding how to involve the siblings from the very beginning. Parents need to communicate with and listen to siblings. As an instinctively human reaction, in the absence of factual information, siblings tend to fear the worst, even for their own health. When parents and members of the health care team attempt in good faith to shield the siblings from knowledge about the illness, such well-intentioned hiding of the truth often drives the siblings to fear even worse possibilities, and can lead to feelings of isolation, guilt, and resentment.

At the time of diagnosis, health care team members and other parents when feasible should share with the parents of a newly diagnosed child the need to keep siblings informed from the very beginning, demystifying the illness and the treatments; parents should be

encouraged to bring the siblings to the hospital if the siblings wish to go, let them visit with their brother or sister, and let them see how the hospital looks; parents should be encouraged to explore the benefits of immediately telling the siblings, and should help choose which person will be the one to inform the siblings, using simple and age-appropriate language and phrasing when delivering the news of the diagnosis; and siblings should have explained to them that they were in no way responsible for causing the cancer.

7. Living a normal life/back to school: During treatment

Improvements in the ability of medical care made it possible for children diagnosed with cancer to live longer and, in increasing frequency, to be cured. The children are able, while in remission, to live a relatively normal life, somewhat free of their concerns about their illness. We need to help the children to engage in the educational and social activities that accompany normal growth and development. It is not enough for young people simply to survive what was once a life-threatening illness. Survival means that the children have to continue to be educated toward one day becoming fully functioning adult members of society. Thus, parents and professionals have the increasing responsibility of promoting sound academic and social development as the children go through the treatment process.

Going back to school has a very normalizing influence on the child. Integration into school is a critical and essential part of the normal psychological and social development of any child. Children with cancer are not only entitled to attend school, but they must be stimulated to do so. Even while in the hospital, children should continue their schooling, as an indication to them of hope for cure, that their life will continue as normal, despite the illness. Programs should be developed to help the children continue their schooling while in the hospital, and to help them return to their normal life as school children as soon as possible, and their teachers trained to treat the children as normally as possible. We should pay special early attention to patterns and difficulties of socially adaptive behavior in the children and most importantly be aware of the strong link between the use of cranial radiation and subsequent learning deficits. As a group, children with cancer function at less socially adapted levels in school than peers, have a tendency not to reach out to others, not to initiate activities, not to try new things, and not to express feelings freely. The children retain a self-protective attitude. And so, in addition to already being devastated by the emotional stresses associated with a child having cancer and undergoing what to them were extraordinary medical treatments, we know that the cognitive side effects of the therapy place a group of the children at a higher risk not only for learning difficulties, but also for subsequent adaptive behavioral problems.

We cannot freeze children for years during treatment while their peers continue to grow and develop, leaving the children with cancer developmentally far behind and in a catch-up mode. We must prepare children for their future. Not only should we give priority to the children continuing to live a normal life during the course of treatment, we have in fact come to view childhood cancer as a golden opportunity for the children to learn skills in coping that can give them a running start on their preparation for engaging in a fully functioning adulthood.

8. Long-Term survivors or better “cured” subjects: After treatment, long-term follow-up

How well are the children responding to the increasingly successful treatments? Programs oriented to the needs of the long-term survivor should begin when the child goes off therapy, with centers focusing on the sequelae specific to each form of illness, treatment, toxicity, and future problems specific to each child’s needs. Centers should offer counseling programs for the more serious medical and psychosocial problems, adapted to the need of each individual and local culture. Centers should develop specialty clinics, managed by the pediatric oncologist who treated the children, and having available a full range of adult and young adult specialists as consulting physicians. Each long-term survivor should be monitored for special conditions related to their unique history as well as their age-specific developmental concerns. Programs should include psychological counseling for the survivors experiencing adjustment difficulties and significant side effects.

As medicine continues to achieve an increasingly higher success rate in long-term survival, we should follow survivors to determine further potential long-term sequelae. The long-term role of each pediatric hematology/oncology center is to follow the survivors until there is assurance that the child will have no further long-term sequelae. It is important and critically necessary to follow the child until the disease is considered “cured” (at about five years). After that time, one should not over-medicalize the survivor, but help the child to make the transition to normal health-care status. When specific sequelae (such as heart problems) are known for a particular child, that child should be followed for the issue of concern specific to that child.

The clinic should keep a careful computerized record of essential data particular to each survivor so that in the future, when the now-adult survivor is seen by an adult physician, the data on the survivor’s previous cancer experience will be available upon request.

Psychological research studies that have followed the survivors of childhood cancer for many years after successful treatment have found, not only that the now-adult-survivors are doing well, but that in many way having learned from the challenges of their childhood cancer experience they are better prepared for the more pressing challenges of adulthood than are their peers. The so-defined resilience is not an utopia but a always more visible reality.

9. Impending death: At the end of life

Despite the remarkable growth in the percentage of cures and the increasing sense of hope being given to newly diagnosed children and their families, many of the children are not able to be cured. Death for some remains a reality. There are three periods of time surrounding this final phase of life that have become the subjects of research. The first is the period when treatment is judged to be no longer effective and the difficult decision is made to move from curative intent to the palliative phase of care. The second is the period from the beginning of palliative care to the death of the child. The third is after the child dies, with the staff counseling the parents in their grief following the death of their child.

A child with cancer is considered by his/her physician to be moving from curative to palliative care when the child cannot be successfully treated by presently available therapies, and the child needs specific treatments, identified to be palliative and not

curative, for physical or mental distress. There can be a long delay between the moment when the physician determines that the child will not be cured and the moment when everyone involved agrees that the child has entered the last or final phase of life.

In managing this transition from the curative to the palliative phase of the child's treatment, it is critical to protect the child. The expectations of the family must be considered to help them avoid feelings of guilt for not having done everything possible. However, a real dilemma is created for everyone if aggressive therapy is continued when the possibilities of cure are virtually not existent.

The decision to move from the intent to cure to palliative care should be made with the parents and the full health-care team, certainly including the nurses. Depending on age and level of development, the child should also be involved in the decision, with older children especially participating more actively. The child should know as much as possible and developmentally appropriate about the seriousness of his/her situation. However, if the child wishes to remain less informed, this wish should be respected, and whatever information is given should allow the child to retain a margin of hope.

The continuation of curative treatment beyond the point when cure is no longer possible should be avoided (the so-called "ruthless obstinacy" treatment).

After a child dies, that individual child's medical history should be evaluated. This evaluation should be made by the health-care team as a group. It is very important to reflect on all events, even minor ones, that occurred during the course of the child's treatment. It is critical to reflect on the choices that were made and why, in order to help the staff come to terms with their own grieving and to learn from the experience in order to help future families.

The center's health-care team should be prepared to modify its overall philosophical goals and reset directions and guidelines when appropriate, based on such review of individual cases and parental comments.

After the child dies, hospitals should offer bereavement counseling on the part of physicians and nurses to help clarify past care and guide future grieving. Parents and siblings, when appropriate, can be invited to discuss with the physician both the level of care and the surviving family members' current needs. A first-step aid to bereavement is for the physician, about three to four months after the child dies, to call back the parents (and siblings, when age-appropriate) and to discuss with them the details of the terminal phase, to help them work through their understanding of what happened. If at this point, some families need further help in grieving, they can be referred to parent-self-help grieving groups or to one-on-one therapy. For the majority of the families, the one follow-up interview appears to be a sufficient step in helping them to move forward through the grieving process.

10. Final recommendations for application: Since diagnosis on

Psychosocial interventions have become so fully incorporated into the care of children with cancer that they are now considered, not just an appendage, but a critical component in the care of the child with cancer. Where do we go from here?

1. As we health care professionals become more experienced in dealing with the children with cancer and their families, we cannot forget that for each newly diagnosed family, it is truly all brand new. Each case is individual. We should continue to bring to the newly diagnosed children and their family a fresh sensitivity that acknowledges the newness of their experience.
2. Children, even the youngest, sense the seriousness of their illness. They pick up the fears and anxieties of the adults around them. They do their best to communicate with us, at all ages. Even the youngest try to talk to us, often without words, often just by their body language. How well do we listen? Do we truly listen? We need to develop more effective ways of attending to what the children are experiencing and their mode of communicating that awareness.
3. Many of our interventions have proceeded far ahead of our success in measuring their effectiveness. While many new instruments have been developed and older instruments have been creatively applied specific to the study of the children and their families, we need to continue this creative effort and plunge more deeply into the study of the effectiveness of our interventions.
4. Parent groups are critical to the continued success of each clinic's efforts, not only by forming support services for one another on mutual psychosocial needs, but as importantly in teaming with physicians in raising funds to keep the clinic up-to-date and growing both in research and in intervention. Health care professionals and parents should strengthen their alliance, making it a priority to continue sharing decision-making, not only in individual cases, but in parental support of the clinic's growth.
5. Among the newly diagnosed families, there will be a small percentage 15% or so who bring with them pre-diagnosis problems that can seriously interfere with the child's treatment. We should continue to develop ways to help identify these families at the very beginning, so that we can refer them for the extra psychosocial help that they will need in order to cope with the treatment. With our remaining resources, we will then be better able to help the families who bring with them a stronger history of coping abilities and who are less encumbered by long-standing behavioral, social, financial, or legal problems.
6. Burnout is a very serious possibility for those working with children with cancer and their families. Acknowledging this very real fact and talking about it openly within the health care team can help prevent serious burnout and alleviate the milder and more subtle forms of burnout.
7. While there is an ongoing need for professionals to publish their findings in refereed journals, it is equally important to translate these findings into readable, clear, and simple booklets or pamphlets for the children, for their parents, and for their teachers. We owe it to the children and their families to continue developing clear and simply written booklets that can help explain some of the complexities of the treatment in ways that they can understand.
8. Much of our psychosocial long-term follow-up study during these past years has focused on potential negative sequelae of the illness and how best to prevent and/or ameliorate them. The next step in helping the children as they grow into adulthood should be to focus on the potential for growth associated with their illness. The children-becoming-young-adults, by overcoming their illness, have a golden opportunity to develop their skills in coping and learning to deal with future life's problems as they enter adulthood.

9. Medicine advances most effectively by narrowing its scope. Psychology advances by broadening its scope and generalizing to theory. Both together are necessary in the treatment of the child with cancer. As we continue to develop the research and intervention efforts with the children with oncological and hematological illnesses, we have seen our biopsychosocial efforts become a model for the increasing integration of the psychosocial in the treatment of children with a variety of chronic illnesses (Roberts, 2003). We should continue to disseminate our research and intervention findings among pediatric practitioners who are dealing with similar issues in different settings and with different chronic childhood illnesses.

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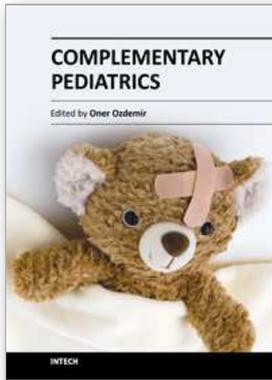
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