Psycho-Oncology as a Component for the Comprehensive Management of Pediatric Oncology

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A. Introduction: Purpose of the Chapter

The main objective of this chapter is to offer an introduction to the many issues that constitute the field of psycho-oncology and to use that introductory information to build on specific themes within this topic. It is important to mention that the inclusion of this chapter promotes the multidisciplinary spirit of oncology and provides a useful tool for all members of multidisciplinary teams.

B. Historical Overview

Psycho-oncology, known as a core stream of oncology practice, emerged only 4 decades ago. However, the extent of clinical influence and research produced during this short period is impressive. The discipline of pediatric psycho-oncology and its development are closely tied to the progress and
advances in the medical practice of oncology. It was only in the late 1960s that
the use of combined chemotherapy drugs in association with surgery and
radiotherapy started to improve therapy outcomes, and psychologists working
with children with cancer became actively involved in attending and researching
childhood cancer. Before that time, cancer was synonymous with fatality in
medical settings, and psychologists working in the field addressed only death
and the dying.\textsuperscript{1,2,3} As intensive and modern treatment changed this view, the
common practice of hiding information from patients about their own illness
started to change; this enabled mental health interventions and research
focusing on the new needs of patients and families during the treatment
process while facing the prospect of survival.\textsuperscript{4} The wide set of psychosocial
issues involved in patients’ and families’ adaptations to both cancer and
treatment are within the scope of psycho-oncology.

This field involves all disciplines related to and in cooperation with
medical specialists: this is how psycho-oncology engages contributions from
members of diverse occupations, such as nurses, social workers, and child-life
specialists, in addition to psychologists, encompassing the wide scope of
psychosocial aspects affected by and affecting the experience of cancer.

\textbf{B. References}

\textsuperscript{1}Holland JC. Societal views of cancer and the emergence of Psycho-oncology. In: Holland JC. ed. 

\textsuperscript{2}Patenaude AF, Kupst MJ. Psychosocial functioning in pediatric cancer. \textit{Journal of Pediatric 


\textsuperscript{4}Holland JC. History of Psycho-Oncology: Overcoming attitudinal and conceptual barriers. 
C. Psychosocial Issues

Besides the general aspects of adaptation to diagnosis and treatment, some of the main topics included in the scope of psycho-oncology are the neurocognitive consequences of treatment, survivorship, school adaptation, siblings’ needs, and palliative care. Survivorship as the ultimate goal of oncology is not an exception anymore, but a common expected outcome and with this, psycho-oncology has also developed several related aspects of research, such as examining the long-term psychosocial effects of treatment, survival, quality of life, and adaptation to a life free of treatment and disease.

Although siblings are part of an important aspect for the families’ well-being and a current key target of study, they were an initially an unseen at risk population; the results of such research have provided guidance for useful interventions oriented toward helping and preventing complications in family dynamics. Such studies have improved the comprehensive management of the entire scope of consequences of cancer within the family.

School re-entry and adjustment as a resource for the academic and social adaptation of children with cancer has also been an important topic of research and has provided information regarding the effects of cancer and its treatment on the expected return to normal activities.

Apart from the aspects related to the family coping process, the psychological short- and long-term impact of treatment side effects and procedures as well as coping with treatment modalities (such as radiotherapy and bone marrow transplantation) have been studied, and these studies have provided specific recommendations for improvements in clinical settings as well as supportive measures.

On the other hand, the study of grief and dying, including the family’s process of coping with prognosis, palliative care, and death, as well as the understanding and awareness of death by children, has been explored
exhaustively. The improvement in our knowledge of children’s perceptions of their situation has led to the growth and specialization of palliative care and pain management as a specific field to enable better care for patients and their families. The aforementioned and several other issues constitute the basis of a growing body of knowledge; many years of quantitative studies have built the foundations of this field, and now, qualitative studies present a growing standpoint, adding strength to the scientifically based trajectory of psycho-oncology. This shift represents remarkable progress. The initial objectives of psycho-oncology research were the development of psychometric instruments to identify variables and specific responses to specific diseases and treatment-related situations. Such a strong scientific route, upon which the growing field has been based, has been strengthened with qualitative studies. The qualitative perspective collaborates with wider implications for applied clinical work and helps direct continuing research. In addition, psycho-oncology embodies a multidisciplinary perspective on the nature of clinical interventions and research targets, which can be almost completely addressed by qualitative research.

C. References


Psycho-oncology aims to provide professional guidance to patients and doctors, regarding the ability of children and families to cope with a cancer diagnosis, treatment, and survival. Oncology treatment involves much more than administering chemotherapy. While doctors and nurses improved and refined their skills and knowledge for comprehensive treatment, psycho-oncology emerged in multidisciplinary teams working in research, educational, and clinical specialties at major pediatric cancer centers.¹ ᵃ²

Scientific research on the psychosocial aspects of childhood cancer is vital and essential in the field of psycho-oncology. Since psycho-oncology developed as an objective and science-based field, it mainly involved the testing of hypotheses with appropriate reliable instruments and scientific methodology, which led to the development of a science-based body of knowledge to support clinical practices.³ ᵃ⁴

However, the speed at which medical advances have occurred during the last 4 decades posed challenge to the field of psycho-oncology to keep pace and offer timely contributions. Despite this, the detailed and variable aspects of research and clinical attention in psycho-oncology as a whole have directly influenced child and family management; furthermore, a considerable amount of psychosocial research has impacted clinical treatment in most major pediatric cancer centers.⁶

One important challenge for research in the psychosocial field is the fact that comparisons and generalizations are very difficult because of the variety of
settings, operational definitions, and variability in study designs. Because of this, research can provide coincidental results that are contradictory to previous conclusions when studies are performed in novel settings. This is a limitation for designing evidence-based interventions for psychosocial practices worldwide. However, at the same time, this limitation provides motivation for devoting greater effort toward multicenter and larger collaborative studies. Although such academic and scientific enterprises are not exempt from complexities or difficulties, they represent a useful step for increasing the science-based level of psycho-oncology and provide the best science-based care possible.  

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**E. Primary Areas of Focus**

The scope of psychosocial interventions is very extensive, but the topic of the family as the domestic unit that is directly impacted by the diagnosis represents the first focus of interventions and research once death was not the only possible outcome associated with the illness.

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**F. Family Functioning**

How do families deal with the devastating reality of having a child with cancer? What are their needs regarding the management of emotions, information, and help? How do they manage to focus on hope and return to the other aspects of daily life while dealing with the reality of cancer? As families confront their daily life with an endless number of painful questions, psycho-oncology builds its fundamentals on the attempts to answer these questions in
addition to seeking information on a long list of other issues. Adjustment and coping in the family have been the focus of numerous studies.

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**G. Adjustment**

As a consequence of the aforementioned improvement of curative possibilities in pediatric cancer through intensive multimodal treatment, psychosocial research and clinical care was initially focused on how families and children manage to adapt to cancer and its treatment.

For a family, the magnitude of the crisis of cancer in a child is exemplified by the following aspects: disruption in relationships and dynamics within the family and community; threats to the parents’ jobs and the family economy; a sense of a meaningless future; impacts on beliefs and spiritual life; a test of coping abilities and demands to learn a variety of adaptive skills; and unbearable emotional pain, fear, and uncertainty for the family. Hence, with every aspect of family life suddenly disrupted, the most important task from the time of diagnosis is adaptation. Consequently, it is not surprising that parents of children with cancer are reported to exhibit above-average emotional distress.¹

Studies show mixed outcomes with regard to adjustments to problems faced by families of children with cancer. Some establish that most families cope well and are capable of adapting to the cancer without major psychological problems, while others argue that families have considerable difficulty in adjusting to the disease and that these difficulties may persist with long-term psychological sequelae associated with the traumatic experience of cancer in their child.¹⁻⁴ Studies with more positive results regarding the adaptive capacities of families found that they are capable of adapting to cancer and tend to improve their level of adjustment over time. The characteristics of families that showed better adjustment are not related to the status or length of
the illness but to psychosocial issues such as open family communication and support, a good marital relationship, and lack of concurrent stresses.\textsuperscript{5–7} Among several demographic factors that represent risks for maladjustment, are lower levels of educational attainment, occupational status, and income.\textsuperscript{3}

A less optimistic set of findings, showed that families face high levels of distress over time after the diagnosis. Those parents exhibit higher distress levels than the comparable groups without significant differences for illness and treatment status; this indicates that the results are the same irrespective of whether the child is on treatment, in relapse, or off treatment.\textsuperscript{8} High levels of disease-related distress are also reported; these levels decrease as time elapses after the diagnosis.\textsuperscript{9} In addition, significant post-traumatic stress symptoms among parents of children who complete the treatment for leukemia have been observed.\textsuperscript{10,11} In general, about one-fourth to one-third of children and adolescents with cancer and their families have considerable difficulties in adapting to the experience of the disease and treatment.\textsuperscript{2}

Despite the many psychosocial difficulties reported in the literature, either with or without lasting consequences, some studies showed that some families experience positive responses related to their child’s diagnosis. Such responses include new values and goals in life, better family and couple relationships, and a stronger social support system.\textsuperscript{1} All of the findings mentioned above demonstrate that the diversity for adaptation is as wide as the personal and situational characteristics of each family. How families manage to cope with this reality is another closely related aspect of psychosocial research.

\textbf{G. References}

\textsuperscript{1}Grootenhuis MA and Last BF. Adjustment and coping by parents of children with cancer: a review of the literature. \textit{Support Care Cancer.} 1997; 5:466–484.


H. Coping

After a period of shock following the diagnosis, parents can react in an attempt to regain control over their lives and needs. Most of them focus on participating and controlling the decisions regarding their sick child’s treatment and daily life as much as possible.

Kupst and Bingen (2006)\(^1\) remark that throughout the cancer experience, the general tasks of coping are focused toward “(a) developing a cognitive understanding of the disease and treatment demands; (b) managing emotional
reactions to the disease, treatment, and their implications; and (c) seeking and using available resources to meet specific situational tasks” (p. 36).

Coping represents the process by which parents adjust and adapt to the new order of life imposed by their child’s cancer and treatment. Studies seem to show that the success of a specific coping style aimed at adaptation depends mainly on the characteristics of the person, situation, and existing coping resources.

Each family employs coping strategies that best suit their capabilities and circumstances. Among many of his early studies on various topics in psycho-oncology, in one study, Spinetta (1981) reported that parents mainly rely on spousal support, religious beliefs, and honest communication with their children as more workable resources for coping with the illness. Although the aforementioned and other resources have been identified in many other studies, both the coping strategies and kinds of demands are known to vary during the process of the disease and its treatment.

Another description identifies 2 main coping styles depending on an orientation toward either practical or emotional concerns; active information seeking to gain a sense of control over the situation (problem-focused) or an emphasis on emotional strength and balancing feelings (emotion-focused).

Coping is mainly associated with control over a stressful situation. However, while control of the situation can alleviate some parents' anxiety, for others, releasing responsibility and control to the doctors or support teams is a less stressful way to manage their child’s diagnosis and treatment.

Relatively less research has been conducted to determine the specific adjustment outcomes of specific coping styles. Mixed results have been found in the existing studies; problem-focused strategies are helpful for certain controllable situations such as the secondary effects of treatment, whereas emotion-focused strategies are effective for uncontrollable stressors such as a bad prognosis. Accordingly, the various coping styles interact in a dynamic process of adjustment and not in opposition.
Regardless of the classification of the coping style as problem- or emotion-centered, Kupst (1994) summarizes helpful coping strategies from several key studies conducted during the 1980s, including open communication, denial, focusing on positive aspects, searching for information, seeking and maintaining social support, and living “one day at a time.” In various situations, communication has been reported to be a useful coping strategy. This can be referred to as maintaining open parent-children communication regarding the health situation, sharing feelings with relatives and others, and adequately communicating with the doctors with the intention of obtaining the best understanding of the medical condition of the child.

Closely associated with communication strategies, social support refers to the availability of positive relationships among family and friends to help maintain a positive attitude toward the experience of cancer. The medical team and other parents from the cancer unit constitute an important part of this socially supportive environment. Mothers are reported to be more eager to utilize social support and have more active family and social contacts. One important factor that can influence coping ability is the specific situation in which the child and his or her family are living, especially during the disease status and treatment phase. Clearly, all treatment phases and variations in the medical condition of the child require that parents constantly adjust their coping abilities, which represents an additional source of stress. Demands to achieve adaptation to situations such as the initial phase of treatment, the period of school re-entry, disease relapse, or the end of treatment require an emotional investment for maintaining control and addressing each situation while maintaining family stability.

Even with the considerable knowledge available presently, coping and adjustment to the childhood cancer experience will continue to be a key issue for psycho-oncology research with the aim of improving clinical interventions in psychosocial care to help children and their families overcome and go through this experience with the least amount of long-term psychological consequences.
H. References


I. Issues Unique to Developing Countries

In developing countries, psycho-oncology has followed the guiding path produced in resource-rich settings. However, 2 important issues should be when considering psycho-oncology in developing countries. The first is that some psychosocial issues in developing countries have specific and critical differences from those typically described in the scientific literature produced in developed countries; these not only affect the priority targets to be addressed in psychosocial care, but also the clinical outcomes of the treatment in those scenarios. Social and cultural characteristics greatly influence the way medical settings function as well as the efficacy of the treatments. These factors...
influence situations such as the emotional reactions to the diagnosis, relationship between the family and medical team, decision-making process, kind of family and community support available, concept of death, existing resources available to access and maintain therapy, and possibility of abandoning the treatment. Consequently, locally produced research is necessary and needs to be supported.

The other important issue is that the scarcity of personnel and difficult working conditions in developing countries prevent real possibilities for systematic research by on-site professionals. Since approximately 80% of the pediatric cancer population lives in developing countries, important knowledge can be obtained by studying in these populations, with proper support, and this will help to promote better understanding of the specific realities of children in those countries.

It should be noted that the tradition of scientific investigation in psycho-oncology was initially developed in major cancer centers with adequate resources. The availability of psycho-oncologists in minor centers has increased as resources have slowly reached these centers. This reflects the situation in low-income countries where cancer centers have to struggle with financial constraints. Despite these limitations, the number of countries with limited resources that at least can count 1 psychologist and 1 social worker as part of their multidisciplinary team are increasing. Unfortunately, these professionals have to manage a large daily clinical care load, and despite the amount of valuable empirical and practical knowledge they accumulate, research and scientific papers from these settings are hardly possible. Although a multidisciplinary approach to pediatric cancer in low-income countries is essential and can contribute to global research knowledge, both the proper management of the psychosocial issues and the support of the development of psycho-oncology remain pending priorities.
I. References


J. Future Directions

The rise of psycho-oncology has enhanced the notion of a multidisciplinary approach for cancer management. With the inclusion of psychosocial research, the dynamics between the reality of patients living with cancer treatment and the medical objectives of therapy have been explored; this provides necessary information for improving the quality of care while emphasizing the importance of quality of life beyond mere survival. Taken together, this indicates the progress of oncology. Advances in medical knowledge and technology will constantly provide new topics for psychosocial research according to the consequent situations that patients must deal with as a result of such advances. The use of each treatment modality leads to particular situations and needs for the patient and their family during therapy in addition to balancing its outcomes.

Besides the goal of refining and deepening knowledge and clinical interventions, the issue of access to psychosocial care is a main objective for the future. Twenty years ago, only a few centers had a proper psychosocial team as part of their oncology department; such deficits need to be addressed in order to utilize existing research, accumulated knowledge, and the real capacity of these centers to benefit patients through clinical practice.1 Making the benefits of psychosocial research accessible to the entire population that requires care after cancer diagnosis is the main and more ambitious goal of this discipline in the current century.2 One important barrier that must be overcome in order to facilitate the aforementioned is the lack of integrated
communication among medical and psychosocial teams, which impedes coordination and the existence of well-informed patients. Both material resources and well-trained medical and psychosocial personnel are the answer to this problem; this is even more evident in the developing world where psychosocial teams are still absent in many centers and institutional plans for the inclusion of cancer-specialized personnel such as psychologists, educational nurses, and social workers among others are not a priority. Because they are considered to be an expensive resource, the existing psychosocial teams are usually less favored.

In addition to the inclusion of well-trained professionals in psycho-oncology and the enrichment of multidisciplinary teams, other important goals to be addressed include physicians' and nurses' training on psychosocial issues as well as the improvement of access to psychosocial services by patients and professionals working in this field. The issue of financial constraints impedes the development of these teams; the many other objectives of psycho-oncology cannot be denied, and commitments to well-organized strategies to make resources available seem to be as important as the development and improvement of science-based knowledge. According to Koch (2008), ensuring the availability of resources is the key change needed to allow the inclusion of a well-organized level of psychosocial answers to the necessities in the treatment, research, and education aspects of cancer treatment.

In centers with better resources available, one important objective for the near future is to work on multicenter collaborative studies and focus their results toward practical outcomes in clinical settings to improve children’s and families’ treatment. More equitable access to knowledge, research opportunities for professionals, and good standards of care for patients continue to be ongoing goals. Considering the aforementioned factors, it is important to note that the same process has occurred before in various medical fields; there are a growing number of international partnerships showing positive outcomes, and establishing cooperative relationships among
centers in developed and developing countries could help provide technical collaboration and resources to psychosocial projects. Furthermore, enabling access to scientific knowledge and educational resources that are available through communications technologies is a useful tool for providing information to those in less well-funded academic and research settings. Thus, the future goals of psychoncology are strengthening research and clinical work as well as improving access to psychosocial knowledge and services worldwide.

J. References


