Psychosocial Impact of Pediatric Cancer on Parents: A Literature Review

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Abstract: A diagnosis of childhood cancer represents challenges for patients, family members, and health workers. The parents of a child or adolescent have to play an expanded role because they need to reconcile parental tasks and treatment demands. This study presents an integrative literature review concerning difficulties experienced by pediatric caregivers during onco-hematological treatment. The CAPES periodicals portal and the Scientific Library Online (SciELO) were searched for papers published between 1999 and 2009. Relevant themes are highlighted in Brazilian and international studies published in the field, such as psychological disorders experienced by caregivers, the professional and financial impact associated with treatment, changes in educative practices and family dynamics, and the influence of cultural practices on the experience of treatment. Suggestions for further research are presented to support efficient psychosocial interventions and minimize the psychosocial costs experienced by pediatric caregivers over the course of onco-hematological treatments.

Keywords: Childhood Cancer, Caregivers, Children, Psycho-oncology.

Impacto Psicosocial do Câncer Pediátrico para Pais: Revisão da Literatura

Resumo: O diagnóstico de câncer infantil representa desafios para pacientes, familiares e profissionais de saúde. Os pais de uma criança ou adolescente em tratamento têm seu papel estendido, pois precisam administrar práticas parentais e exigências do tratamento. Este artigo objetiva realizar revisão integrativa da literatura relacionada a dificuldades vivenciadas pelos cuidadores pediátricos durante tratamento onco-hematológico. Foi realizada revisão da literatura publicada entre 1999 e 2009, a partir da busca em bases de dados Portal de Periódicos CAPES e Scientific Library Online (SciELO). Com base na literatura nacional e internacional recentemente publicada na área destacam-se temas importantes, como perturbações psicológicas vivenciadas pelos cuidadores, impacto profissional e financeiro associado ao tratamento, mudanças em práticas educativas, alterações na dinâmica familiar e influência de práticas culturais na vivência do tratamento. São apresentadas sugestões para pesquisas que possam subsidiar intervenções psicossociais eficientes para diminuir custos psicossociais vivenciados por cuidadores pediátricos ao longo do tratamento onco-hematológico.

Palavras-chave: Câncer em Crianças, Cuidadores, Crianças, Psico-oncologia.

Impacto Psicosocial del Cáncer en la Infancia para Padres: Revisión de la Literatura

Resumen: El diagnóstico del cáncer en la infancia es desafío para enfermos, familia y profesionales Hoekstra de salud. Los padres del niño o adolescente en tratamiento tienen su papel extendido y necesitan asociar prácticas de paternidad a exigencias del tratamiento. Constituye objetivo de este artículo realizar revisión integrativa de literatura, con atención para dificultades vivenciadas por cuidadores pediátricos en tratamiento onco-hematológico. Fue realizada busca en la literatura publicada entre 1999 y 2009, Portal de Periódicos CAPES e Scientific Library Online (SciELO). La reciente literatura nacional e internacional ofrece temas importantes, como perturbaciones psicológicas experimentadas por los cuidadores, impacto profesional y financiero asociado al tratamiento, cambios en prácticas educativas, el compromiso en la dinámica familiar y el influencia de prácticas culturales en la vivencia del tratamiento. Se presentan sugerencias para investigaciones, con fines de subsidiar intervenciones psicosociales eficaces para minar los costos psicosociales experimentados por los cuidadores pediátricos a lo largo del tratamiento onco-hematológico.

Palabras clave: Cáncer Infantil, Cuidadores, Niños, Psiconcología.

Even with advancements achieved to prolong life, childhood cancer is still associated with death, incurability, loss, and suffering (Malta, Schall, & Modena, 2008; Rodrigues, Rosa, Moura, & Baptista, 2000; Shiota, Santos, & Miyazaki, 2004). The family is required to adapt to a new situation that involves long hospitalizations, aggressive therapy, many losses, and changes in family relationships and routines that may hinder the child and the family in performing tasks inherent to the developmental process (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; McGrath, Paton, & Huff, 2005; Nascimento, Rocha, Hayes, & Lima, 2005; Young, Dixon-Woods, Findlay & Heney, 2002).

The child or adolescent undergoing treatment needs to deal with invasive procedures, side effects, the interruption of school and social routines, the suspension of leisure activities, changes in diet, in self-image and self-conception,
uncertainty of how the treatment will progress, doubts, periodical hospitalization, physical pain, separation from family members and familiar places, losses that harm socialization and interfere in personal relationships (Gomes et al., 2004; McGrath et al., 2005; Shiota et al., 2004; G. M. Silva, Teles, & Valle, 2005). For the patient’s siblings, changes in family relationships may interfere with school performance, cause suffering due to separation during hospitalization, lead to psychosocial maladjustment, somatic symptoms, feelings of rejection, isolation, jealousy, preoccupation, anxiety, sorrow and uncertainty. On the other hand, siblings may be involved in care, helping with household chores and providing emotional support to family members (Costa & Lima, 2002; McGrath et al., 2005).

Difficulties for the patient’s parents include fear of relapse, anxiety, the need to assimilate information received, care provided to healthy children, attempts to adapt to the new health condition, provide care in the event of side effects, and care provided for intercurrences, among other situations, which harm the family’s quality of life (Beck & Lopes, 2007a, 2007b; Björk, Wiebe, & Hallström, 2005; Clarke, Fletcher, & Schneider, 2005; Eiser & Eiser, 2007; Klassen et al., 2007; McGrath, 2001).

Considering the dreadful context to which the patient’s parents are exposed, it is important to identify the psychosocial impact imposed on caregivers in order to understand their experiences and devise efficient psychosocial interventions. This paper presents an integrative review of studies published between 1996 and 2009 concerning the psychosocial aspects involved in the treatment of childhood cancer, emphasizing psychosocial difficulties experienced by parents.

**Method**

Studies published from 1996 to 2009 addressing psychosocial processes associated with treatment were searched online in the following databases: CAPES Periodicals Portal and *Scientific Library Online* (SciELO). The key words used included *childhood cancer, pediatric cancer, pediatric onco-hematology, neoplasia, childhood* and their equivalent in Portuguese.

Criteria to select studies included: (1) being published between 1996 and 2009, (2) being written either in Portuguese or English, (3) addressing psychosocial aspects (treatment’s psychological impact, psychological disturbances, coping strategies, changes in marital and/or family dynamics, changes in financial/professional/personal spheres), (4) specifically focusing on parents or caregivers (studies exclusively addressing the lives of patients, siblings, or health workers were not selected).

Studies were organized according to year of publication, country of author affiliation, and main topic. Content was analyzed in an integrative manner in order to identify the main psychosocial elements and difficulties experienced, as well as factors associated with adaptation to treatment.

**Results and Discussion**

We note the increased number of papers published beginning in 2002, especially of studies addressing psychosocial variables associated with treatment. Figure 1 presents the distribution of 90 papers selected by year of publication.
Figure 2 indicates the country of author affiliation (the country of the main author was considered in the case of multi-author studies).

Figure 2 indicates the prevalence of studies with an affiliation in the United States. The category ‘others’ totals studies originating in Sweden, Japan, Turkey, Italy and Israel. Figure 3 shows the prevalence of topics related to difficulties and demands, including treatment demands, mobilization of financial resources and the need for social support. The process of psychosocial adjustment and psychological disturbances (distress, depression, anxiety, post traumatic stress) were extensively studied, as were changes in family dynamics. Cultural and gender differences were also highlighted themes, while few studies focused on marital dynamics, changes in educational practices, or the quality of life of caregivers during treatment.
The Psychosocial Impact of Childhood Cancer on Parents

In addition to accompanying the painful process of a child undergoing treatment, parents also have to deal with increased parental responsibilities and administer the treatment requirements. Parents have their role extended in the context of pediatric care: they need to provide the emotional responses of the patient and siblings, moderate their own emotions, establish satisfactory communication within the medical-hospital context, adapt to family routines, deal with potential relapses, deal with expectations, care for the child’s wellbeing, and pay attention to medication, handle intercurrences and side effects, establish protective care, and accompany the child on medical consultations, hospitalizations and for invasive exams (Clarke & Fletcher, 2003; Holmbeck, Bruno & Jandasek, 2006; Kars, Dujnoscie, Pool, Delden, & Grypdonck, 2008; Keegan-Wells et al., 2002; McGrath et al., 2005; Shiota et al., 2004; S. Silva, Pires, Gonçalves, & Moura, 2002).

The responsibilities falling on parents may increase the probability of responses such as anxiety, depression, guilt, sleep disorders, somatic symptoms, risk behavior (smoking and alcoholism), changes in diet, perception of physical and emotional overload, events that put one’s health at risk, harm to professional and social life, and worsening of one’s quality of life, consequences that remain after the diagnosis (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; James et al., 2002; Kazak et al., 2004; Moreira & Angelo, 2008; S. Silva et al., 2002; Young et al., 2002). On the other hand, it is possible for parents to satisfactorily adapt to the new condition, with somatic symptoms and psychological disturbances not very different from those experienced by parents of children not exposed to treatment contexts (Clarke & Fletcher, 2004; Greening & Stoppelbein, 2007).

In general, the treatment of childhood cancer negatively impacts the social and professional routines of parents, often requiring them to leave their jobs and give priority to treatment (Björk et al., 2005; Earle, Clarke, Eiser, & Sheppard, 2006; Kerr, Harrison, Medves, & Tramner, 2004; Ljungman et al., 2003; McGrath, 2001; Steffen & Castoldi, 2006; Young et al., 2002). Attention totally focused on a child may lead to marital conflict, impair communication and/or the self-care of parents (Costa & Lima, 2002; James et al., 2002; Steffen & Castoldi, 2006).

Suffering arising from the treatment and care demands often represent secondary gains to patients as the parental care system changes due to the parents’ difficulties dealing with feelings of powerlessness to protect their child from painful and invasive procedures. As a consequence, limits are changed, responsibilities are reduced, and parents become more permissive (Santos & Gonçalves, 2008; Herman, Santos, & Miyazaki, 2007; Palmer et al., 2000; Woodgate, 2004; Young et al., 2002).

The parents’ quality of life during the event of childhood cancer is directly related to the patient’s quality of life during treatment (Vance, Morse, Jenney, & Eiser, 2001; Wegner & Pedro, 2009). As the experience cancer influences the emotional response of parents in relation to their child’s needs, the ability of the child or adolescent to deal with adverse situations is related to the parents’ ability to manage situations of crises. This relationship reinforces the importance of understanding the psychosocial impact of childhood cancer on parents (Hoekstra-Weebers et al., 2001; Robinson, Gerhardt, Vannatta, & Noll, 2007; Santacroce, 2002; Streisand, Kazak, & Tercyak, 2003).

It is worth noting that fathers and mothers face distinct demands and tend to deal differently with challenges. Mothers usually assume the role of primary caregiver and become emotionally involved while the fathers act as providers and tend to distance themselves emotionally from the situation (F. A. C. Silva, Andrade, Barbosa, Hoffmann, & Macedo, 2009; Svavarsdottir, 2005a). The challenges for the mothers are mainly related to decision-making, administration of medication, promotion of comfort and support, planning of family activities, handling the children’s behavioral problems, paying attention to intercurrences, and supervising routine responsibilities (McGrath, 2001; Svavarsdottir, 2005a; Yeh, 2002). Fathers face conflict between working and staying in the hospital, in addition to the demand to provide emotional support to the wife and children (McGrath, 2001; Svavarsdottir, 2005a). Cultural gender roles may influence the manifestation of feelings, fears, and expectations between parents (Brody & Simmons, 2007).

Psychosocial Distress

Recent literature shows that the study of the psychosocial impact of treatment of childhood cancer on parents includes: (1) negative impact of treatment (financial costs, changes in routine, changes in marital relationships) concomitantly with behavioral disorders (depression, anxiety, posttraumatic stress symptoms, distress); (2) that factors that moderate the impact influence the vulnerability of caregivers, depending on the availability of resources (social support, gender, information supply). In general, aspects such as educational level, socioeconomic status, and socio-demographic variables are not associated with better or worse psychological conditions of parents (Greening & Stoppelbein, 2007; Hoekstra-Weebers et al., 2001; Klassen et al., 2007; Steele, Dreyer, & Phipps, 2004).

The parents may respond to the diagnosis with behavior indicative of depression, such as persistent sadness, pessimism, hopelessness, guilt, helplessness, decreased energy, difficulty concentrating or making decisions, fatigue, insomnia or sleepiness, which may last for several months, especially with initial levels of moderate or severe depression (Bayat, Erdem, & Kuzucu, 2008; Vrijmoet-Wiersma et al.,...
Studies addressing anxiety indicate that manifestations frequently occur at the time when a diagnosis is disclosed and usually decline to normal levels, though remain higher than levels experienced by parents of healthy children (Bayat et al., 2008; Gerhardt et al., 2007; Lähteenmäki, Sjöblom, Korhonen, & Salmi, 2004; Piersol, Johnson, Wetsel, Holtzter, & Walker, 2008; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000; Vrijmoet-Wiersma et al., 2008).

Mothers tend to report higher levels of anxiety than fathers, whether at the time the diagnosis is disclosed or in other stages of the disease, though these manifestations can be a result of how gender roles are constructed or the way parental caregivers split responsibilities; the primary caregiver role is usually attributed to mothers (Beck & Lopes, 2007a; Dahlquist, Czyzewski, & Jones, 1996; Santos & Gonçalves, 2008; Vrijmoet-Wiersma et al., 2008). Parents reporting high levels of anxiety at the diagnosis usually continue to experience significant manifestations even after the treatment ends (Vrijmoet-Wiersma et al.). High levels of anxiety may be correlated with post traumatic stress, difficulties making decisions, loss of memory, difficulty concentrating, insomnia and treatment avoidance (Best, Streisand, Catania, & Kazak, 2001; Santacroce, 2002).

About half of parents report moderate to intense levels of posttraumatic stress, including intrusive thoughts, treatment avoidance, physiological responses, flashbacks and psychological agitation (Kazak, Boeving, Alderfer, Huang, & Reilly, 2005; Santacroce, 2002; Vrijmoet-Wiersma et al., 2008). On the other hand, the work of Jurbergs, Long, Ticona & Reilly, 2005; McGrath et al., 2005; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Webers, 2006). Variations in the duration and persistence of psychological disturbances have been reported in the literature and such levels are higher among mothers (Sahler et al., 2005; Svavarsdottir, 2005b).

In general, the treatment includes financial costs that result from the distance between home and hospital, leading to expenditures on transportation, accommodations, meals and phone calls. Losing one’s job or changes in one’s professional routine is a common occurrence (Cohn, Goodenough, Foreman, & Suneson, 2003; Dockerty, Skegg, & Williams, 2003; James et al., 2002; Lähteenmäki et al., 2004; McGrath et al., 2005; Rocha-Garcia et al., 2002).

Based on changes in parental roles required by treatment, parents may experience changes in their marital relationships, as well. Studies addressing satisfaction in marital relationships over the course of treatment have reported different results. Some couples do not report changes in their marital relationships (Dahlquist et al., 1996) while others report more positive attitudes toward the spouse, that their relationships were strengthened, they became more cohesive, and trust improved (Beltrão, Vasconcelos, Pontes, & Albuquerque, 2007; Kylmä & Juvakka, 2007; Lavee & Mey-Dan, 2003; Sloper, 2006). Reports that the parents’ relationship weakened and marital satisfaction decreased were also observed (Lavee & Mey-Dan, 2003; Pai et al., 2007).

Access to information concerning the disease, the child’s physical condition, procedures, benefits and side effects are stressed by the parents to be crucial over the course of the treatment (Ferreira, 2005; Kerr, Harrison, Medves, & Tranmer, 2004; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Mendonça, 2007). The availability of social support from family members, friends, co-workers, and neighborhoods is also extremely important (Bayat et al., 2008; James et al., 2002; Kerr, Harrison, Medves, & Tranmer, 2004; McGrath et al., 2005; Wijnberg-Williams et al., 2006). Higher levels of social support are generally available at the time the diagnosis is disclosed and decline over the treatment period, while mothers tend to receive more support than fathers (Hoekstra-Webers et al., 2001; Holm, Patterson, & Gurney, 2003; Iobst et al., 2009; Wijnberg-Williams et al., 2006).

Understanding cultural aspects that condition the experience of pediatric cancer is a challenge because such differences can be seen as elements that moderate the impact of treatment. Munet-Vilaró (2004) stresses that the experiences of groups culturally different are formed by a variety of
Many authors highlight the predominance of similarities in experiences with pediatric cancer among Western and Eastern families. Changes in the domestic routine, and also in the family and professional spheres, along with somatic symptoms are responses common to both groups (Leavitt et al., 1999; Lou, 2006; Wong & Chan, 2006; Yeh, 2002). The initial months of treatment demand more from parents regardless of culture; these have to adapt to the treatment requirements (Han, 2003; Leavitt et al., 1999; Ow, 2003). Some elements such as social support and seeking out information are commonly valued (Han, 2003; Ow, 2003; Wong & Chan, 2006). The care system also usually changes regardless of the cultural context, including overprotective behavior, changes in the imposition of limits, and in family relationships (Chao, Chen, Wang, Wu, & Yeh, 2003; Martinson et al., 1999).

Even though social and cultural factors play an important role in the perception of the disease and the impact of the treatment on the family, studies report that various responses are similar and refer to common demands (Leavitt et al., 1999; Martinson et al., 1999; Wills, 1999). Possibly, challenges are similar, but distinct cultural roots influence the way parents deal with such challenges (Yamazaki, Sokejima, Mizoue, Eboshida, & Fukushima, 2005). Currently, it is also important to consider to what extent, given the globalization of information and its continuous exchange, Western and Eastern cultures effectively remain distinct. Other factors should be considered, such as access on the health system, satisfaction with the service, government support, and the child’s age and family dynamics, which indicate the need for further studies to compare culturally distinct groups (Leavitt et al.).

Final Considerations

Considering that the experience with childhood cancer is related to several moderating environmental factors, we highlight the need for systematic and multicenter studies to support specific psychosocial interventions for each phase of treatment. Additionally, we emphasize the importance of longitudinal studies to understand the developmental dimension involved in pediatric cancer; it is a chronic condition that changes over time in individuals who are also developing.

Up to the end of the first year after diagnosis, the family routine tends to return to normal as the family resumes activities and reorganizes domestic life (Boman et al., 2003; Earle et al., 2006; Kazak et al., 2005). It may be difficult to resume activities that have changed, especially if psychological disturbances such as anxiety, depression, and posttraumatic stress were experienced (Clarke & Fletcher, 2004). Such a fact highlights the importance of the participation of multidisciplinary teams in health care delivery, as well as the importance of emphasizing preventive actions able to anticipate potential difficulties and needs.
Another aspect involves results that are marginally contradictory in relation to anxiety, depression and post traumatic stress. Some of the reasons such results are inconsistent include different and inaccurate operational definitions concerning the studied psychological processes, heterogeneous samples, methodological factors (reduced sample, inappropriate instruments to measure the proposed constructs, undifferentiated analysis of the responses of mothers and fathers), difficulties accessing specific problems and diverse evaluation methods. A great number of the studies in the field analyze the processes experienced by family members using an explicative model of the field of psychopathology, which requires careful observation to avoid unnecessarily attributing pathological parameters to the mobilization of family resources and natural responses to stress (Beltrão et al., 2007; Clarke & Fletcher, 2004).

We note the need to deepen understanding of factors that are potentially protective regarding the development of psychological disorders. Considering that many families efficiently deal with stressors, studies focusing not only on challenges that are disruptive to the family cycle but mainly on favorable factors used to satisfactorily adapt to the new condition, are needed. Sociocultural differences and also therapeutic differences may account for advantages in adapting to a stressor context. Much has been studied regarding family adaptation to treatment and psychopathological symptoms with control groups and normative samples, but little has been investigated concerning how fathers and mothers personally experience cancer treatment of a child. When the role of parents is identified as a central concern in pediatric treatment, it becomes essential to understand the implications of this function in the social construction of childhood.

The condition of being a caregiver of a pediatric patient is a process relationship related to the development experienced by the child, parents and family. Therefore, understanding the event of pediatric cancer should encompass changes of how one perceives and deals with challenges. Explanations based on the individual may restrict viewing the sources of difficulties as being inherent to the parents themselves, neglecting social, culture and micro-political forces that have a crucial impact on how one cares for cancer, thus ignoring the experiences of care as a process. Factors that need to be addressed in detail in studies involve access to the healthcare system, satisfaction with the health service, promoting healthful aspects, and the repertoire of self-care behavior. Such elements are essential to understanding how circumstantial differences may influence the impact of psychological disturbances or protect against them (Boman et al., 2003; Holmbeck et al., 2006; Vrijmoet-Wiersma et al., 2008).

Finally, we note the limitations of this study. Even though it offers an integrative proposition of the main psychosocial factors indicated in recent literature, the search for studies certainly did not include all the studies available, considering the large quantity of information available on the World Wide Web. Additionally, each category of analysis constitutes, in itself, a large body of information that should be further developed and deepened in subsequent research.

References


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