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Experiences of Brazilian children and family caregivers facing the recurrence of cancer

M.N.F. Arruda-Colli ^{a,*}, E.M. Perina ^b, M.A. Santos ^a

^a Faculty of Philosophy, Sciences and Letters of Ribeirão Preto, Department of Psychology, University of São Paulo, Av. Bandeirantes, 3900 – Monte Alegre, CEP: 14049-901, Ribeirão Preto, SP, Brazil

^b School of Medical Sciences, University of Campinas, Rua Tessália Vieira de Camargo, 126 – Cidade Universitária “Zeferino Vaz”, CEP: 13083-887, Campinas, SP, Brazil

A B S T R A C T

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Purpose: The aim of the study was to examine the different perspectives of the children and their family caregivers' experiences in the treatment of relapsed cancer.

Methods: We conducted 16 sessions of the Drawing-and-Story Procedure (D-S) with 5 to 12-year-old children who were in treatment due to recurrence of cancer, and 8 in-depth interviews among their family caregivers. The D-S and the interviews were audio-recorded with the participants' consent; the transcripts were analyzed using the thematic content analysis.

Results: The children evidenced that they perceived the threatening and uncertainty, independently of their age or kind of communication established about the disease and prognosis. Caregivers expressed feelings of frustration, threat and loss of control in view of the relapsed cancer diagnosis and prognosis, which enhanced the fear of losing their children and hampered the process of attributing meaning to their existence. Dyads showed similar experiences related to the recurrent cancer issues, and the first treatment experience seemed to help them to give new meanings to the current situation.

Conclusion: Understanding the experiences of the children and their family caregivers can support the planning of psychological interventions that favor coping with the peculiarities of the disease situation resulting from the relapse diagnosis of childhood cancers.

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Introduction

Childhood cancers are rare and have been described as permeated by stress, pain, and uncertainties, which imply important psychosocial issues (Bruce et al., 2011; Gibbins et al., 2012; Menezes et al., 2007). It represents the second cause of death in Brazilian children and adolescents, and the first one due to health issues, which strengthens the relevance of studies and care improvement (Instituto Nacional do Câncer, 2008, 2014).

Efforts have been made in Latin America to establish cancer registries for the sake of a better understanding and treatment of the disease (Curado et al., 2009). Despite of the lack of infrastructure and its implications for the quality of cancer data available, the Global Initiative for Cancer Registry Development in Low- and

Middle-income Countries estimates 900,000 new cases and 542,000 deaths annually in Latin America. Twinning programs with specialized cancer centers in high-income countries have been implemented and shown improvement for childhood cancer outcomes (Howard et al., 2007).

Brazilian Population-Based Cancer Registries were established in all regions of the country to systematize the incidence, mortality, and survival data, considering the population density, regional peculiarities, and socioeconomic disparities (Camargo et al., 2010). In Brazil, leukemia (29%), lymphomas (15.5%), and central nervous system tumors (13.4%) are the most common cancer types in children. Prognoses have been improving as a result of more accurate diagnosis and treatment strategies (Instituto Nacional do Câncer, 2008). Average mortality rates have slightly decreased for all types of cancer in Brazil between 1979 and 2005. The average mortality rate of acute lymphoid leukemia dropped by 1% per year, Hodgkin lymphoma showed a cutback of 2.4% per year for girls and 4.3% for boys, and non-Hodgkin lymphoma had 2.4% and 2.5% lower average mortality rates for girls and boys per year. Average

* Corresponding author. Tel.: +55 (16)3602 3645; fax: +55 16 3602 4835.
E-mail addresses: arruda.colli@gmail.com (M.N.F. Arruda-Colli), elisaperina@uol.com.br (E.M. Perina), masantos@ffclrp.usp.br (M.A. Santos).

mortality rates for nervous system tumors increased by 2.4% for girls and 2.3% for boys per year between 1996 and 2005, probably related to a criterion change for death classification in case of nervous system tumors (Instituto Nacional do Câncer, 2008). It is important to highlight that the South and Southeast regions showed a significant reduction, which reveals the gains resulting from the establishment of specialized centers for cancer treatment, but also draws attention to the health access disparities between the different regions of the country (Silva et al., 2013).

Oncology treatment begins after the definition of the diagnosis, determined by clinical, laboratory, and imaging exams. The Brazilian Unified Health System offers universal cancer treatment free of charge to the entire population, following the international protocols for each type of tumor. Specialized centers for cancer care offer chemotherapy, surgery, and radiotherapy, considering patients' specific needs and treatment responses (Instituto Nacional do Câncer, 2008). Prognoses may vary, considering individual (e.g. sex, age, race, social and economic factors), tumor (e.g. extension, primary site, morphology), and healthcare system aspects (e.g. screening, diagnosis, treatment), but advances in early diagnosis methods and childhood cancer treatment have turned cure into a reality in Brazil (Instituto Nacional do Câncer, 2008).

The recurrent disease, defined as the reappearance of the cancer after a period of remission (DeVita et al., 2011), entails a lesser possibility of cure, the return to the hospital routine and treatment situation (Hinds et al., 1996; Vivar et al., 2009). Treating recurrent cancer remains a challenge. Considering acute lymphoid leukemia, for example, relapse rates correspond to approximately 20% in children and adolescents. The site of relapse and time from diagnosis are the two most important prognostic risk factors, and current protocols point out cure rates after relapse between 30 and 50% (Einsiedel et al., 2005; Locatelli et al., 2012; Cancela et al., 2012). Along with the specific protocol for the relapsed cancer treatment, interdisciplinary support and symptom management are usually offered (Lopes et al., 1999). Treatment options, clinical trials, and palliative care support must be discussed with the family to offer a better care for the patient and, also, facilitate the decision making process in this treatment phase.

The presence of anxiety and post-traumatic symptoms in family members is well described in the literature, related to the uncertainty and lack of control experienced with their children's relapsed cancer (Hinds et al., 1996; Mu et al., 2001; Espíndola & Valle, 2002; De Graves and Aranda, 2008; Dunn et al., 2012). The psychological impact when experiencing the recurrence of the cancer diagnosis and the need to make decisions related to the child's treatment were highlighted. Authors suggested the role of the health team as mediators, offering them support when dealing with such a crisis situation. In the last decade, attention to the psychosocial aspects of recurrent cancer has increased, particularly focusing on adult patients' experiences (Andersen et al., 2007; Shim et al., 2010; Vivar et al., 2010).

The recurrence diagnosis and treatment in adulthood were accompanied by feelings of frustration, uncertain, hopelessness, and threat, demanding reorganization in different life aspects (Vivar et al., 2009; Vivar et al., 2010). Despite the contribution about emotional stress, interpersonal relations, and the impact on daily activities when experiencing a recurrent cancer in adults, studies with child populations are required to better understand and address their specific needs (Hinds et al., 2002).

Studies about young patients' perception when facing treatment and relapse are less frequent. In a Swiss population of adolescents, Essig et al. (2012) investigated acute lymphoid leukemia survivors' health-related quality of life. Survivors had similar or better scores in all dimensions evaluated by means of the Short Form-36 when

compared with the general population. Those with relapse experience showed lower scores in general health perception, probably associated to the late effects of treatment, which highlights the importance of addressing these aspects. In children, Grootenhuis and Last (2001) analyzed the psychological adjustment in 84 children with cancer, in terms of control strategies (Cognitive Control Strategy Scale for Children), defenses (Defense Scale for Children), anxiety (Trait Anxiety Inventory), and depression (Depression Questionnaire for Children). There was no significant difference related to the relapse experience. Psychological adjustment showed a relation to capacity of defense and positive expectation regarding the disease process. Hockenberry-Eaton et al. (1995) investigated children between 6 and 14 years old about the role of illness longevity and relapse in self-perception (Harter Self Perception Profile), cancer stressors (About my Illness Inventory), anxiety (Spielberger State Trait Anxiety Scale), and coping strategies (Children's Coping Strategies Inventory). Data indicated higher trait anxiety and lower self-worth in patients with longer cancer treatment and in those who experienced recurrence. There was no difference between those who had relapsed or not in terms of stressors or use of coping strategies. Authors suggested that early assessment of children's emotional and self-worth perceptions may be helpful as a screening method when planning nurse support. Being aware of emotional aspects of relapsed cancer can help in the planning of care, in order to offer a better nurse care to both the patient and family.

In order to comprehend the experiences of facing the recurrent cancer treatment, a qualitative study was conducted with children and their family caregivers in southeast Brazil. The aim of the study was to describe the phenomenon of living with relapsed cancer by children's and their family caregivers' perspectives.

Methods

Recognizing the possible range of health issues and care process research, a qualitative study was carried out, focused on the meanings of the family unit and the perceptions about the lived experience of recurrent cancer treatment (Crossley, 2007).

Case study research can lead to an understanding of a complex issue or object and can enhance experiences or add strength to what is already known based on previous research (Stake, 2000; Yin, 1984). Case studies emphasize a detailed contextual analysis of a limited number of events or conditions and their relationships. Researchers have made wide use of this qualitative research method to examine contemporary real-life situations and provide the basis for the application of ideas and methods (Stake, 2009). Yin (1984) defines the case study research method as an empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used.

Setting and selection of participants

The child participants were between five and 12 years old incomplete, undergoing cancer relapse treatment at Boldrini Children's Center, a Brazilian referral center for childhood cancer and hematological treatment. Having motor, comprehension and/or communication difficulties that could interfere in the response to the instrument, and having no curative possibilities were defined as exclusion criteria, aiming for major homogeneity of emotional patterns. The caregivers included were mothers, fathers or legal guardians who were considered the children's primary caregivers and who accepted to participate and authorized the children's

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