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Description and adequacy of parental coping behaviours in childhood leukaemia

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Abstract

This investigation explored how parents perceived the child's leukaemia and how well coped with it. Forty-one mothers and 30 fathers recruited from the largest Hellenic paediatric hospital were asked to answer closed and open-ended questions and to complete the Coping Health Inventory for Parents [CHIP]. Most of the participants perceived the child's disease as a serious and threatening situation. The strategies aimed at maintaining family strength and an optimistic outlook were ranked as being the most helpful. Using specific criteria, it became evident that, overall, the subjects coped well. Neither gender nor spousal differences were found in the variables examined. Implications for health-related research, theory and practitioners are addressed.

Keywords: Childhood cancer; Parents; Appraisal; Coping

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1. Introduction

As a result of medical and technological advances, the prognosis for many childhood cancers has improved considerably over the last 30 years (Eiser et al., 1995; Stiller, 1994). Today, approximately 60% of children with malignancy in many developed countries such as Greece, Britain and the US achieve cure or long-term survival (Granowetter, 1994; Matsaniotis, 1998; Stiller, 1994). In accordance with international protocols of medical practice (Eiser, 1993; Miller, 2000), current medical treatment of childhood cancer in Greece aims at controlling the severity of symptoms, decreasing complications, reducing the incidence of relapses and helping the child to have as normal a life as possible (Matsaniotis, 1998).

Because childhood cancer is now viewed as a chronic life-threatening illness (Thompson and Gustafson, 1996; Woodgate and Degner, 2003), parents are increasingly becoming the primary caregivers and thus are challenged to cope with multiple and complex problems and tasks (Eiser, 1994). Although coping of family members with chronic childhood illness has been given a high priority in the health care field, the knowledge of the degree of versatility of parental coping strategies is limited, and there is a need for data-gathering research designed specifically to further assess them (Grootenhius and Last, 1997; Murray, 1998).

In Greece, little focus has been placed on identifying the ability of parents to maintain and/or adopt functional behavioural patterns to meet both the present and the anticipated needs of their family resulting from the child's cancer. This is so because, traditionally, Hellenic health care education and training are based on a strong medical philosophy centring on the physiology of the body and the pathophysiology and treatment of

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the disease. As a result, much of the clinical work is still patient-focused and concentrated primarily on the illness itself. In addition, a shift has occurred during the last decade in Hellenic health care policy. Due to the remarkable expansion of the private health care sector and the deinstitutionalisation of much of health care, the state has reduced its responsibilities for health and social welfare, expecting families to increase their participation in the care of patients. Despite this shift, however, the provision of services at the individual level still remains the predominant mode of health care practice and family oriented care is seldom incorporated even in the most orthodox intervention designs. Furthermore, in paediatric oncology, supportive programmes aimed at improving parents' coping or decreasing emotional distress are still rare and their effectiveness has not been evaluated.

The philosophy that guided the present study was based on the current emphasis on "coping" as opposed to traditional approaches that focus on "maladjustment" and "maladaptation" (Swallow and Jacoby 2001a; Trask et al., 2003). Its implementation was also dictated by the need for nurses and other health care professionals to look beyond the care of the chronically ill child to the needs of parents (Hodgkinson and Lester, 2002). Thus it is the objective of this investigation to describe Greek mothers' and fathers' appraisals and behaviours when coping with a child's leukaemia in the remission phase. This study also assesses how well these parents cope with the child's disease. Such knowledge will enable health caregivers to offer both individualised and holistic care (Eiser, 1993), and to reveal areas in which there is a deficiency in coping (McCubbin, 1987). In addition, because the literature is contradictory in terms of the degree to which specific personal, familial, and illness-related factors influence parental appraisal and coping (Eapen and Revesz, 2003; McGrath, 2001; Sterken, 1996), this study was designed to elicit information about the role that some of these variables play in parents' experience with the child's cancer. Finally, it attempts to identify gender and/or intra-couple differences and/or similarities in the reported appraisals and coping behaviours. Professional awareness of spousal similarities and differences is essential to the provision of family-centred care (Eiser and Havermans, 1992; Goldbeck, 2001).

2. Theoretical premises of the study

Although it has been noted that coping is not a linear process but a series of "ups" and "downs" which are often exacerbated by unpredictable events (Swallow and Jacoby, 2001a), two major approaches have been suggested to explain familial coping with a child's cancer. The first approach, called the "stages" framework, has a developmental perspective and depicts four phases that parents go through as they adapt: disbelief, anger, demystification, and conditional acceptance (Austin, 1990). Fortier and Wanlass (1984) describe five similar stages and label them as the following: impact, denial, grief, focusing attention, and closure. In this view, the diagnosis causes feelings of shock, anxiety and depression whereas parental adaptation occurs over a period of time through the use of active behaviours that are employed, especially, during the last two stages.

Yeh et al. (2000) also enumerate five components of the coping process in childhood cancer: confronting treatment, maintaining family integrity, establishing support, maintaining emotional well-being, and searching for spiritual meaning. Qualitative nursing research has indicated that the coping of parents of children with cancer is a dynamic process whose ultimate goal is to help them "come to terms" with the disease and the problems it causes (Yeh, 2003). In Yeh's study, the identified components of parental coping included the following: confrontation of reality, management of treatment issues, cognitive and affective shifting, recognition of the situation, and adjusting properly. The nurse researcher has concluded that these stages have a sequential pattern when the medical condition of the child is relatively steady. In contrast, they are less obvious when complications and relapses frequently occur in an unpredictable manner.

The second approach includes the "Double ABCX Model of Family Adaptation" developed by McCubbin and Patterson (1982), and the "Stress, Appraisal and Coping" theory developed by Lazarus and Folkman (1984). This view directs attention to parents' perceptions of the situation and provides a comprehensive framework for psychosocial research in cancer care and a useful tool for assessment and intervention in the clinical setting. Literature suggests that nurses and other health caregivers should incorporate aspects of both the "stages" and the "coping-adaptation" approaches in their practice and research (Miller, 2000).

The present study was guided by the theoretical framework of Lazarus and Folkman (1984) in which coping is a process that mobilises effort and utilises resources to resolve a stressful situation, rather than a static event that implies success. The theorists have defined coping as "…the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate" (p.19). In this theory, the subjective perception of the stressful event is a major component of the coping process. A stressful encounter may be evaluated as a source of harm, loss, threat, or challenge. Appraisal and coping patterns change as the stressful situation changes. Coping consists of cognitive and behavioural efforts and may be problem-focused,