



ORIGINAL ARTICLE

# Adolescents with Cancer and Occupational Deprivation in Hospital Settings: A Qualitative Study



Pedro Moruno Miralles <sup>a,\*</sup>, Nieves Cedenilla Ramón <sup>b</sup>,  
Sandra Aranda Valero <sup>c</sup>

<sup>a</sup> Department of Nursing, Physiotherapy and Occupational Therapy, University of Castilla-La Mancha, Talavera de la Reina, Spain

<sup>b</sup> Department of Psychology, University of Castilla-La Mancha, Talavera de la Reina, Spain

<sup>c</sup> Association of Parents of Children with Intellectual Disabilities, Toledo, Spain

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**Summary** *Objective/Background:* The aim of this article was to analyze the needs of hospitalized adolescents with cancer in relation to the performance of meaningful activities as well as to explore the possible scenarios of occupational deprivation in hospital paediatric wards. *Methods:* The study follows an ethnographical research approach using two techniques: participant observation and in-depth interviews, with constant comparison by data triangulation. Eight adolescents diagnosed with cancer aged between 15 years and 19 years (5 males and 3 females) were recruited from Toledo and Madrid in Spain.

*Results:* Five themes revealing the needs of adolescents with cancer in hospital environments were identified: (a) educational needs, (b) leisure needs, (c) physical space of the rooms, (d) interaction with medical personnel, and (e) lack of specific wards for adolescents.

*Conclusion:* The lack of variety and availability of educational activities and leisure, and the subsequent changes of the individual physical, social, and cultural environments could cause situations of occupational deprivation, and also affect the health and quality of life of the individuals.

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\* Corresponding author. Facultad de Terapia Ocupacional, Logopedia y Enfermería (FACTOLE), Universidad de Castilla-La Mancha, Avenida Real Fábrica de Sedas S/N 45600, Toledo, Spain.

E-mail address: [Pedro.Moruno@uclm.es](mailto:Pedro.Moruno@uclm.es) (P. Moruno Miralles).

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## Introduction

Currently, cancer is one of the most significant diseases worldwide, not only for its incidence and prevalence but also for its mortality rates, as it is the leading cause of death by disease in children and adolescents (Buka, Koranteng, & Osornio, 2007; Cuevas-Urióstegui, Villasís-Keever, & Fajardo-Gutiérrez, 2003; Moro Gutiérrez, Domingos Videira, Fernández-Conde, & Villares Martín, 2010). According to the *International Association of Paediatric Oncology* (2015), around 25,000 cancer cases are diagnosed each year, with estimates suggesting 90,000 annual deaths due to cancer in children. However, advances in paediatric oncology with the emergence of international networks and their coordinated treatment protocols as well as high-quality clinical trials have increased the survival of the child population affected by cancer (Buka et al., 2007; Cañete et al., 2009). Survival rates in young cancer patients have increased remarkably from under 20% to approximately 80% in the last four decades. However, according to statistics provided by the National Registry of Childhood Tumours and the Spanish Society of Paediatric Haematology and Oncology (Peris Bonet, Felipe García, Martínez Ruiz, Pardo Romaguera, & Valero Poveda, 2014), 60% of survivors experience chronic health problems and such problems are severe in 27% of cases. The increase in life expectancy (Moro Gutiérrez et al., 2010) has revealed the serious physical and psychological consequences of cancer treatment, which is usually a direct result of its side effects and not caused by the disease itself (Cuevas-Urióstegui et al., 2003). Such effects limit the ability of the child and adolescent to lead a normal life, thus worsening their quality of life (Cañete et al., 2009). In many cases, the treatment of cancer is characterized by long and aggressive interventions, with frequent periods of hospitalization that often lead to abrupt changes in the patient's physical, social, and cultural environments. In such circumstances, the individual may lose the opportunity to perform meaningful activities associated with his/her age and stage of lifespan development. In particular, the interruption in the academic education that comes with periods of isolation is especially relevant (Cañete et al., 2009), and it affects not only the performance of meaningful activities but also the individuals' social integration (Arrecha et al., 2009; Berterö & Eriksson, 1997; Pérez de Heredia, Cuadrado, Rodríguez, López, & Miangolarra, 2001). These findings highlight the need for interventions that address the psychosocial impact before, during, and after chemotherapy treatment, to promote social integration and support to the families of the patients (Cañete et al., 2009; Moro Gutiérrez et al., 2010).

There are difficulties in creating an appropriate framework for the treatment of children and adolescents with cancer (Navajas, 2011). Adolescents are usually treated in adult wards and less frequently in paediatric oncology wards. Patients treated in paediatric oncology wards have a 30% higher cure rate than those who are treated in adult oncology wards (Barr, 2001; Carrión, 2005; Cuevas-Urióstegui et al., 2003; Lassaletta et al.,

2013; Navajas, 2011). Research shows that adolescents treated in specific areas for their age do better. The need to create wards for adolescents is based on this group's unique characteristics as both the evolution of the disease and the treatment are different from that of adults and children. As Erikson (2000) pointed out, adolescence is a critical period in which lots of new changes are experienced for the first time and these need to be considered when designing the treatment protocol. During this period, adolescents develop their self-image and identity, increase their independence, and adjust to their new-found sexuality. They also strengthen their social relationships and plan their future life. A diagnosis of cancer and its treatment and the subsequent breakdown in their activities, routines, habits, personal autonomy, and social relations interfere and seriously restrict this stage of social and personal development. If we add the burden of cancer to these physiological changes, adolescents also often experience a loss of self-esteem, control and independence, fear of rejection by their peers, and body image and sexual identity disturbance, all of which result in a reduced engagement in both physical and social activities (Cañete et al., 2009). The combination of these two issues—the lack of specific wards for the treatment of adolescents and the particular changes they undergo during this phase of life—can lead to situations of *occupational deprivation*. This concept describes a situation that limits certain activities of the individual's immediate context due to situational factors (Whiteford, 1995). Such a state of deprivation is not the product of the individual's inherent limitations, but the result of external factors that persist over time; among others, there are also limitations imposed by educational systems or health and social services (Whiteford, 2000). Townsend and Wilcock (2004) define it as a state of exclusion from participation in necessary and/or meaningful activities, due to factors beyond the individual's immediate control. In the case of adolescents staying in adult oncology wards, the lack of variety and availability of meaningful activities may cause situations of occupational deprivation.

This article follows those research studies that have analyzed sociological and physical aspects of specific situations to promote changes needed in the environment (Nilsson & Townsend, 2010). The goal of this study was to increase awareness of the psychosocial and contextual factors associated with alterations to occupational performance among adolescents with cancer.

The objectives of this research were as follows: (a) to analyze the needs of hospitalized adolescents with cancer and their relation with the performance of meaningful activities based on the subjective perception of the study participants (adolescents); (b) and to analyze possible scenarios of occupational deprivation in adolescents hospitalized with cancer based on the identified needs.

## Methods

This study was qualitative and descriptive in nature. It was based on an ethnographical research approach (Willis

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