



ORIGINAL ARTICLE

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



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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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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

& Trondman, 2000) using two data-gathering methods: a direct participation with observation in the hospital setting and in-depth interviews, together with constant comparison with data triangulation to ensure trustworthiness. This research approach enabled us to describe the participants' points of view through the analysis and interpretation of their discourse and explore the meanings given to their reality in a hospital environment. Using an inductive analysis of the participants' narratives, the researchers were able to identify a series of themes revealing the needs of adolescents with cancer and their performance of meaningful activities in a hospital environment. Each theme relates to a specific need for adolescents. Once these themes were identified, the research focused on the analysis of possible cases of occupational deprivation. For data-collection purposes, in-depth interviews were the preferred method used to take into account the subjective perspective of the informants relating their experiences or life situations, expressed in their own words (Taylor, Macdonald, Bezjak, & DePetrillo, 1996). These interviews were carried out by one researcher (S.A.V.) when the adolescents were available and healthy enough to do it. These interviews were supplemented by direct observation of the participants in doctors' offices and waiting rooms from November 5, 2012 to May 26, 2013. The observations were performed independently by two researchers (N.C.R. and S.A.V.), to increase the accuracy and trustworthiness of gathered data (Appendix 1). The researchers also interviewed indirect informants (medical staff members and relatives) and designed the scripts for individual interviews *ad hoc*, based on different sources of information including a bibliographical review in the following electronic databases: MEDLINE (via PubMed), Dialnet, Cochrane, Trip Database, and OTseeker, using the MeSH terms described; as well as based on primary caregivers' opinions. A pilot test of the interview was conducted, which adjusted and enriched the process with new questions (Appendix 2). Overall, eight different adolescents were interviewed. Five of them went through the process two times and the other three adolescents were unable to repeat their interviews due to their medical condition. Thus, a total of 13 interviews were carried out. The interviews took place in a room equipped for this purpose, making sure privacy was preserved and without the presence of others who were not to be interviewed except in the case of minors under the age of 18 years. The average duration of the interview was 20 minutes. To increase the trustworthiness of data gathered, the following three strategies were used: triangulation of consulted sources of information (direct and indirect informants, bibliography, and digital documents); triangulation of data-gathering documents (interviews and observation), and triangulation of data gatherers (observation and data recording performed independently by 2 researchers). In addition, to ensure credibility of data, once the interviews were finalized, a meeting with all adolescents took place and the analyzed results were discussed with all the participants. This allowed the researchers not only to obtain the patients'

agreement with the authors' interpretation of the data but also gave the patients, parents, and legal guardians a chance to make sure that no content had been omitted. The interviews were conducted by S.A.V., as a member of the team who is exclusively devoted to research. Participant observation was also carried out as noted earlier. The research procedures were performed in accordance with bioethical principles established in the Belmont Report, in compliance with good practice guidelines of the Declaration of Helsinki and the Convention on Human Rights and Biomedicine of the Council of Europe. The research protocol was supervised by an independent body not involved in the investigation (consisting of staff members of the Virgen de la Salud Hospital, Toledo, Spain). The aforementioned team supervised and evaluated practices before, during, and after fieldwork, thus ensuring ethical principles are followed. This item complies with 30 of the 32 items of Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007).

Participants

The selection of participants in the field study was conducted in the offices of the Paediatric Oncology and Paediatrics ward of the Virgen de Toledo Hospital, Toledo, Spain.

The study sample was selected following a purposive theoretical sampling and by applying the following inclusion criteria: adolescents diagnosed with cancer aged between 15 to 19 years who were admitted at least to the hospital and who had signed a consent form. Exclusion criteria were as follows: adolescents suffering from other added or associated pathology. A total of eight adolescents (5 male and 3 female participants) were finally included in the study, and they were from either Toledo or Madrid in Spain (Table 1).

Fieldwork

The first study contact was established with the members of staff responsible for the paediatric oncology ward of the Virgen de la Salud Hospital, to locate and involve the possible participants in the study. Following this, the researchers met the chosen adolescents and their families with whom no previous relationship existed before the study. For the final selection of participants, medical and psychological reports of patients receiving treatment in the Virgen de la Salud Hospital were consulted. In addition, the researchers also met with the oncologists responsible for each individual participant. A total number of eight adolescents met the study's conditions and later signed the informed consent. Four declined participation in the study due to their parents' refusal who alleged time-related problems to participate. Finally, the fieldwork was conducted. The informants' subjective perspective on their experiences and life situations, expressed in their narratives, was obtained by observing the patients and spending time with them.

Table 1 Profile of Participants.

Subject	Diagnosis (type of cancer)	Age (y)	Sex	Time since diagnosis/hospitalization	Active treatment	Studies (last course for which they had been registered)	Environment of habitual residence
I1	Ewing's sarcoma	14	Male	12 / 10 mo	Yes / bone-marrow transplant	Year 10: secondary education	Urban
I2	Medulloblastoma	16	Female	10 / 2 mo	Yes / chemotherapy	Year 12: secondary education	Rural
I3	Ewing's sarcoma	18	Female	18 / 19 mo	No	Year 13: secondary education	Urban
I4	Hodgkin's lymphoma	14	Male	1 / 1 mo	Yes / chemotherapy	Year 9: secondary education	Urban
I5	Leukaemia	17	Female	16 / 10 mo	No	Year 12: secondary education	Rural
I6	Leukaemia	12	Male	4 / 8 mo	Yes / bone-marrow transplant	Year 7: primary education	Rural
I7	Bone tumour	19	Male	72 / 3 mo	No	Year 13: secondary education	Rural
I8	Hodgkin's lymphoma	14	Female	2 / 1 mo	Yes / chemotherapy	Year 9: secondary education	Urban

Data collection

Recording equipment was used during interviews with the consent of parents or legal guardians and the informants' narratives were later transcribed word for word for analysis. To collect the participants' data and the information regarding direct observation, a fieldwork diary was used with notes that were processed afterwards in ATLAS.ti software (Version 6.2.28, Thomas Muhr, Berlin, Germany). Field notes were also taken after the interviews.

Data analysis

After the verbatim transcription of the interviews, each researcher carried out an independent analysis of the data using the ATLAS.ti software (Version 6.0). The three researchers organized data coders to compare the notes and interpretations of individual analyses, while discussing how to reach consensus (peer debriefing).

Following the interviews with the study participants, 20 different data coders were identified and a series of semantic connectors, subcategories, and top-level categories were defined. These categories were then organized by themes, with each theme corresponding to a specific need of adolescents with cancer. The themes were all extracted from the analysis of the participants' discourses. Finally, five themes were extracted from the analysis of the participants' discourses (Table 2). Once the themes were defined, the researchers analyzed other possible relations between the data coders. This analysis enabled us to create a content tree, in which the diverse relations between each data coder and the defined themes were fixed (Figure 1).

Results

The authors identified five themes in relation to the needs of adolescents with cancer within a hospital environment: (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. These themes were later used to analyze their influence on the participants' occupational performance. Interviewees' quotes, originally in Spanish, have been translated into English. Each informant was labelled in a fieldwork diary with the letter "I" (which stands for informant) and a number.

Table 2 Identified Themes.

1. Educational needs: The participants' views regarding changes in the performance of their academic activities.
2. Leisure needs: The participants' views regarding the leisure activities they performed in the hospital.
3. Physical space of the rooms: The participants' views regarding basic activities of daily living while in the hospital.
4. Interaction with medical personnel: The participants' views regarding interactions with the medical personnel in the Paediatric Oncology unit.
5. Lack of specific care units for teenagers: The participants' views regarding the Paediatric Oncology unit.

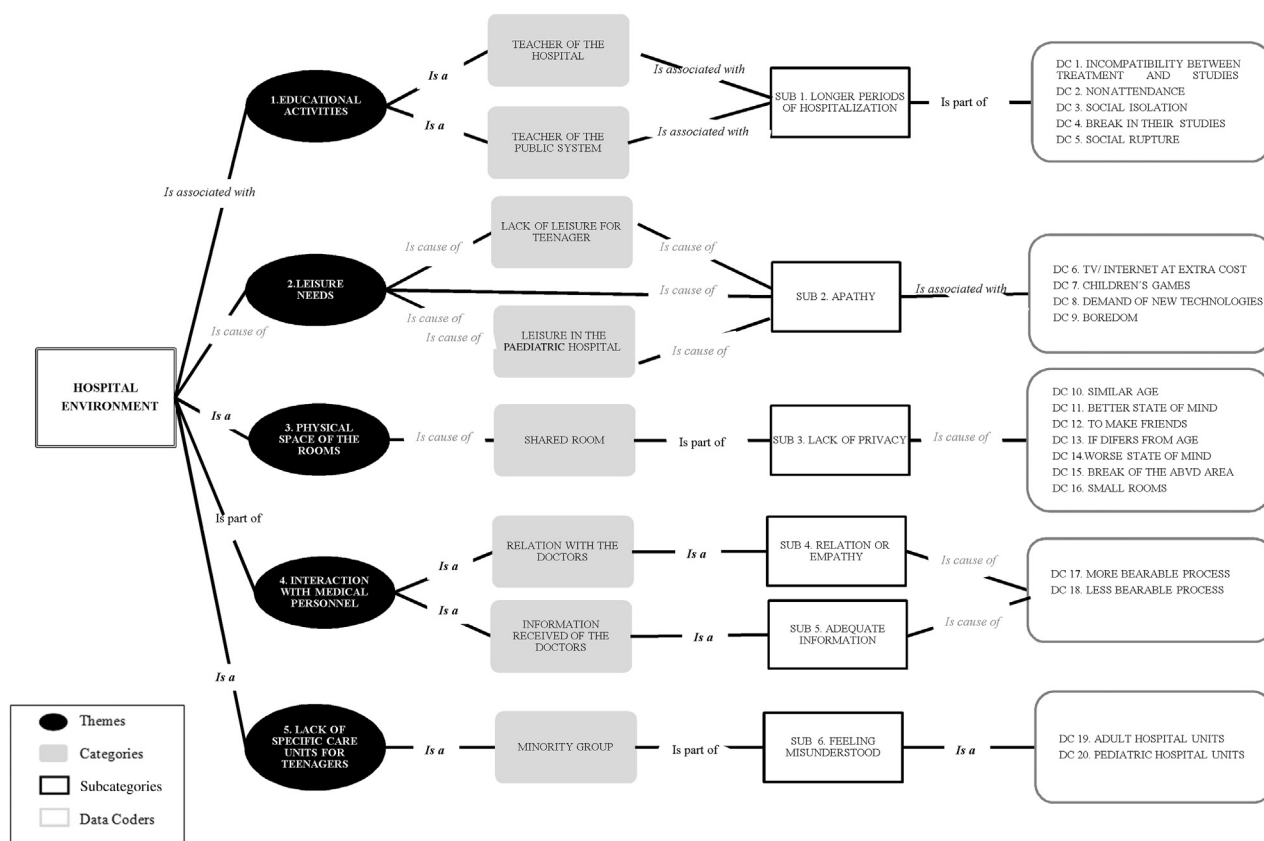


Figure 1 Thematic tree.

Educational needs

This theme describes the participants' views regarding the changes in the performance of their academic activities, highlighting some of the most significant difficulties encountered. One participant remarked:

During that time I did not go to class, I had help in the hospital and did not do bad. There were few hours, but I got on with it and then when I rejoined high school I did notice a change, because you feel it ... the ... you're at home, they go to your house when you want so you feel more comfortable. But, having to go to school at a certain time already forces you to catch the bus ... you notice the difference, but it wasn't bad. [15]

All the participants' narratives agreed in this matter. Educational activities available in the adult oncology wards only partially met the needs of adolescents. Most participants stressed the artificiality of educational activities and the absence of standardized routines and study habits (meeting schedules, travel to school, and relationships with peers). The data obtained corroborated the narratives; detachment from school and the difficulties associated with teacher support were the patients' most common complaints.

Leisure needs

All participants indicated that the lack of interesting leisure activities was one of the main reasons for not keeping themselves active. Two categories within this theme were especially significant in their narratives: one was the lack of leisure activities for adolescents and the other one was the existence of recreational activities only directed towards young children inside the paediatric hospital. These points are evidenced by the following narratives:

You watch TV, which is all you can do. [11]

No, well ... we also have Internet, that's what we do the most, because then ... there are board games, but the problems are that, or you play with your parents ... because the others are little children and nothing else ... you help in some activity, but, games for us, no. [13]

Physical space of the rooms

Shared rooms and the consequent lack of privacy were common categories in all interviews. These factors seemed

to interrupt or alter the performance of the basic activities of daily life. One of the informants mentioned:

Yes, I have had companions forever. Very bad, it's a bit annoying. [I2]

Another one noted,

If you are alone you have enough privacy, but if you are with someone there are many things you have to restrain yourself a bit from doing. [I7]

This situation was obvious when the age difference was greater. Most adolescents suggested that the problem lies not only in sharing a room, but also in sharing it with people of very different ages. If the age of the partner was similar, then their mood was improved. This was clearly evident in some narrations:

I've been with girls who were 8, 10, and even 3! There is a huge difference huge. [I2]

Interaction with medical staff

This was one of the most recurring themes in the narratives of the adolescents studied. For those patients who were treated in paediatrics wards, this was identified as a factor that facilitates the adaptation process during hospitalization and the recovery periods. It was no doubt that interaction with the medical staff in paediatric wards improved patients' experience during hospitalization. All participants in this study verbalized that:

The treatment provided by doctors is perfect, no doubt. [I6]

Yes, everything you ask, they explain, they clarify. [I4]

Yes, yes, the treatment is very good. [I2]

However, such experiences were different for those adolescents treated in adult wards.

Lack of specific care units for adolescents

Finally, the theme concerning the lack of specific wards for adolescents was identified. Participants perceived themselves as a minority group, a feeling that was accentuated when the participants shared their room with children whose age was drastically different from their own. The following narratives illustrate this point:

Unfortunately, most hospitalized people are children ... [I8]

Because everyone else is a young child, nothing else ... [I3]

You're surrounded by many children, there should be two sections, for the babies and for older kids, because, you know, there should ... be a ward in between, between young and old, and either they move you from a

room with a baby or they put you with an 80 year old man, and ... that shouldn't happen. [I5]

Discussion

The overall results of this study reveal specific characteristics about paediatric oncology wards and hospital settings. The study results also reveal the characteristics and settings that make it difficult for adolescents to carry out meaningful activities and those that not only affect the patients' quality of life during hospitalization but also their recovery. Since the mid-1990s, occupational therapy literature has shown a growing interest in investigating the influence of cultural, political, economic, and social features about human health in a population, and in particular the restrictions imposed by educational systems and social and health services when it comes to disease and disability. This interest has given way to a school of concepts—including occupational deprivation—proposed to serve as a theoretical foundation on which practical occupational therapy should be based (Braveman & Bass-Haugen, 2009; Molineux & Whiteford, 1999; Townsend & Wilcock, 2004; Whiteford, 1995, 2000, 2005). There are also many who call for the development of lines of research to develop and consolidate the methodology associated with these concepts, given the lack of tools and intervention strategies, as well as the lack of necessary competencies for the implementation of distinctive actions of proven effectiveness (Braveman & Bass-Haugen, 2009; Rappaport, 1981; Townsend & Wilcock, 2004; Wilcock & Townsend, 2000). One of the objectives of this article was to adopt a qualitative methodology to bridge the gap in this research area.

As previously stated, the concept of occupational deprivation describes situations that limit occupational performance, concerning the individual's immediate context. In particular, the lack of available opportunities in the environment may affect the time-use patterns and routines associated with the performance of meaningful activities. Such restrictions on the performance can have serious consequences for patient's health such as resulting in disorientation, loss of the sense of efficacy, high suicide rates, sleeping disorders, and difficulty acquiring adaptive skills to integrate themselves into the community (Whiteford, 1995). This concept emphasizes the fact that the mentioned state of deprivation is not due to limitations caused by the symptoms of the disease itself, but due to external factors beyond the control of the individual that extend over time. Its originality lies in changing the focus from the individual to a collective of events that, not only have individual consequences but also external social constraints, lead to occupational deprivation. The participants of this study emphasized the influence that the immediate physical environment had on their effective performance of meaningful activities, especially the importance of having roommates of similar age. When this happened, this scenario seemed to facilitate performance, as it provided privacy,

recreational opportunities, and shared leisure. However, when the adolescents shared the rooms with people of different ages, studies show that their performances were affected and were usually limited and inhibited; occasionally, certain performances were prevented from taking place. The paediatric ward's medical personnel were also considered to have a positive effect on the patients' health, which helped the adolescents' adaptation to the hospitalization and the disease. Similarly, the adolescents clearly and repeatedly stated their need for significant educational and leisure activities appropriate for their age. The peculiarities of childhood cancer wards hindered their performance opportunities in areas that are relevant during adolescence, because such settings are commonly not designed or organized to respond to the distinctive needs of adolescents, given that they are a minority group. The implications of these findings highlight the need to design a separate treatment environment in hospitals for adolescents with cancer or develop meaningful activities for them, addressing their unique necessities, which are different from those of children and adults.

In conclusion, this study has identified five basic needs related to the performance of meaningful activities among adolescents with cancer within a hospital environment. The findings of this research highlight that situations of occupational deprivation cannot only limit the performance of activities but also affect the health and quality of life of the individuals.

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Appendix 2. Script of the Interview.

ADOLESCENTS WITH CANCER AND OCCUPATIONAL DEPRIVATION IN HOSPITAL SETTINGS: A QUALITATIVE STUDY

1. Personal details:
2. Do you know why you are here? What do you know about your illness?
3. Have you received all the necessary information about your disease? And what about the treatments?
4. How long have you been hospitalized? What do you think about having to stay in hospital? Do you think there is anything you could do to make this easier or more bearable?
5. Do you usually share rooms with other patients? Do you share with people of similar age? And what do you think about that?
6. What do you think of the medical staff that is treating you? What is your relationship with them?
7. What do you think about the hospital premises? Are there any other hospital spaces you would like to see?
8. Are there hospital spaces appropriate to your age? Are there activities you can do according to your age?
9. Are there any activities that you would like to do in the hospital but that you don't? Why do you think that is?
10. What do you do during your spare time while in hospital?
11. What happens to your school education when you are going through treatment?
12. When you are back at home, do you go to school?
13. Is there anything else you would like to tell me about being in a hospital?

Annotations: