



Effect of parental depression level on children's quality of life after haematopoietic stem cell transplantation



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ARTICLE INFO

Article history:

Received 18 April 2016

Received in revised form

20 July 2017

Accepted 11 August 2017

Keywords:

Child

Stem cell transplantation

Quality of life

Parent

Depression

ABSTRACT

Purpose: This descriptive cross-sectional study aimed to determine the impact of parental depression level on children's quality of life after haematopoietic stem cell transplantation (HSCT).

Method: This study was conducted in a bone marrow transplantation unit of a children's hospital in Ankara, Turkey. The research sample consisted of 82 parents. Children aged 2–18 years and monitored in polyclinics 100 days after HSCT were included in the study. A sociodemographic data form, parent forms of the Pediatric Quality of Life Inventory, and the Beck Depression Inventory (BDI) were used.

Results: Forty (48%) mothers and 42 (51.2%) fathers participated in the study. Of the children, 30 (36.6%) were female and 52 (63.4%) were male, and their mean age was 10.68 [standard deviation (SD) 4.80] years. Twenty-six children (31.7%) had been diagnosed with thalassaemia, and 29 children (35.4%) had undergone HSCT in the previous 25–36 months. The mean total scale score on the Pediatric Quality of Life Inventory was 61.37 (SD 21.85), and the mean parental BDI Score was 14.57 (SD 11.03). Fourteen (17.1%) parents had severe depression and 10 (12.2%) parents had moderate depression. Low statistical correlation was found between the parental BDI score and the total scale score on the Pediatric Quality of Life ($r = -0.281$; $P = 0.011$).

Conclusion: Parental depression level affects children's quality of life after HSCT. Following transplantation, it is important to evaluate parental depression level and provide support.

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1. Introduction

Application of haematopoietic stem cell transplantation (HSCT) has increased over the years to treat diseases such as leukaemia, lymphoma, solid tumour, thalassaemia, bone marrow deficiency, and immune deficiencies that are malignant or non-malignant (Passweg et al., 2012). Some deaths result due to complications that occur after HSCT (Arat, 2011).

After HSCT, severe mucositis (Raber-Durlacher et al., 2010), hepatic complications (Lee et al., 2010), infections, septicaemia (Neofytos et al., 2009) and acute graft-vs-host disease (GVHD) (Paczesny et al., 2010) can be witnessed during the acute period. Chronic issues following transplantation include organ damage, pulmonary diseases, oral complications, secondary malignancy,

relapse of disease and chronic GVHD (Faraci et al., 2008).

In addition to physical effects, children and adolescents exposed to HSCT are known to be at risk of emotional, social and behavioural problems in the long term (Clarke et al., 2010). These children face problems with school, friend and family relationships, and experience anxiety about their future (Forinder et al., 2008). Cognitively, they have memory and concentration problems (Shah et al., 2008). As a result of physical changes after HSCT, such as short stature, atrichia and skin breakdown, a high level of anxiety has been reported in children whose body image was affected (Forinder and Posse, 2008). As children who undergo HSCT experience physical, emotional and social problems, their quality of life can be affected (Clarke et al., 2010; Forinder and Posse, 2008). Therefore, it is crucial that their physical, emotional and social problems are examined and dealt with in order to increase their quality of life.

Forinder (2004) found that child survivors of HSCT face problems due to physical and psychological impacts in the long term, which influence family functions. Post-transplantation complications (Manne et al., 2004), fear of losing their children, fear of relapse (Forinder, 2004) and financial problems are sources of

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stress for families (Phipps et al., 2005). In addition, families experience problems meeting the children's care needs (Gemmill et al., 2011; Phipps et al., 2005).

Research shows that some families face high levels of anxiety, depressive symptoms and stress before and during the acute period of HSCT (Phipps et al., 2005), and most families go through such conditions during the chronic period following transplantation (Manne et al., 2004; Vrijmoet-Wiersma et al., 2009). Barrera et al. (2012) examined depression levels of parents whose children underwent HSCT, 1 and 2 years after transplantation, and determined that maternal depression levels were higher than paternal depression levels. After HSCT discharge, children are cared for at home by their parents (Phipps et al., 2005). The psychosocial condition of parents during this period can affect the children's quality of life (Vrijmoet-Wiersma et al., 2009). As such, it is vital to take measures against parental problems in order to increase children's quality of life during this period when psychosocial problems occur.

1.1. Research questions

1. What are the depression levels of parents of children undergoing HSCT?
2. What are parental perceptions of children's quality of life among children after HSCT?
3. Is there a relationship between parental depression level and children's quality of life?

2. Methods

2.1. Design, population and sample

This descriptive cross-sectional study aimed to determine the impact of parental depression level on children's quality of life following HSCT, from the parent's perspective. The study was undertaken in a bone marrow transplantation unit of a children's hospital in Ankara, Turkey. The study population consisted of 90 children who had undergone HSCT and their parents; of these, 82 children aged 2–18 years who attended the outpatient follow-up clinic between 10 December 2013 and 30 April 2014, and whose parents spoke Turkish and had not been diagnosed with depression before their child's diagnosis were included in the study. Two of the 90 children were aged >18 years and four children were at an acute stage; these children were not included in the study. In addition, two parents who were unable to speak Turkish were excluded from the study.

2.2. Data collection

This study used a sociodemographic data form, parent forms of the Pediatric Quality of Life Inventory (PedsQL), and the Beck Depression Inventory (BDI).

2.3. Sociodemographic data form

A sociodemographic data form was prepared in order to evaluate children's and parent's sociodemographic information and problems that affected children's quality of life. The form consisted of three parts. The first part included 17 questions related to the child's age, sex and his/her parent's ages and educational status; the second part contained nine questions about the child's disease; and the third part covered the complications that children experienced (Clarke et al., 2008). Information regarding complications and medical diagnosis of parental depression were obtained from patients' files by the researcher.

2.4. Pediatric Quality of Life Inventory

The PedsQL was developed by Varni et al. (1999) in order to measure the quality of life of children and teenagers aged between 2 and 18 years. The PedsQL consists of a parental report of the child's health-related quality of life. In addition to physical health, emotional, social and school functionalities are included in the scale. Three scores are calculated – the total scale score (TSS), the physical health summary score (PHSS) and the psychosocial health summary score (PSHSS) – to evaluate emotional, social and school functionality (Varni et al., 2001). The scale is made up of 23 items. The higher the TSS, the greater the perceived health-related quality of life. In the original scale, Cronbach's alpha coefficient was found to be 0.90 for the parent forms (Varni et al., 2001). The validity and reliability of the Turkish version of the PedsQL were investigated by Uneri et al. (2008) for children aged 2–7 years, and by Cakin Memik et al. for children aged 8–12 years (Cakin Memik et al., 2008) and 13–18 years (Cakin Memik et al., 2007). Cronbach's alpha coefficient ranged between 0.85 and 0.88 in parent proxy reports (Cakin Memik et al., 2007; 2008; Uneri et al., 2008).

2.5. Beck Depression Inventory

The BDI was developed by Beck and his colleagues in 1961 to objectively determine the degree of depressive symptoms (Beck and Beamesderfer, 1974). The BDI assesses 21 depressive symptoms using 'never', 'sometimes', 'often' or 'always', and is graded from 0 to 3. Scores vary between 0 and 63; a total score ≤ 9 indicates no depression, a score of 10–16 indicates slight depression, a score of 17–23 indicates moderate depression, and a score ≥ 24 indicates severe depression (Hisli, 1989). Hisli (1989) undertook a validity and reliability study of the Turkish version of the BDI, and reported a Cronbach's alpha coefficient of 0.80.

2.6. Application of the research

Information from the data forms was applied to parents who attended the outpatient follow-up clinic at the bone marrow transplantation unit between 10 December 2013 and 30 April 2014. Each family was evaluated at a single time point at the outpatient follow-up clinic, while they waited (1–2 h period) for laboratory/radiology examination results. The child and their parent were taken to a quiet, empty room, and informed about the study; parents who agreed to take part in the study were given the data collection forms. The PedsQL forms were completed by parents, and children were not asked to comment. Parents also answered the questions on the BDI on their own.

The answers were marked on the data collection forms by the parents themselves if they knew how to read and write; parents who asked for help filling out the forms had an interview with the first researcher. Completing the questionnaires took approximately 15 min. Children's diagnoses and details of complications were obtained from the patients' files by the researcher.

2.7. Data analysis

The data obtained in this study were evaluated by the researcher using SPSS 17, and values are given as numbers or percentages. The significance level was taken as $P < 0.05$. The normal distributions of the PedsQL and BDI scores were tested using visual (histogram) and analytic [Kolmogorov–Smirnov (K–S)] methods. The TSS (K–S = 0.123; $P = 0.004$) and BDI score (K–S = 0.156; $P = 0.001$) did not show a normal distribution, so correlation coefficients and statistical significance were computed using Spearman's correlation test. In this test, $r = 0.05–0.30$ was taken to indicate low or

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