



Socially disadvantaged parents of children treated with allogeneic haematopoietic stem cell transplantation (HSCT): Report from a supportive intervention study, Denmark

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A B S T R A C T

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Purpose: This study was undertaken to test a daily Family Navigator Nurse (FNN) conducted intervention program, to support parents during the distressful experience of their child's Allogeneic Haematopoietic Stem Cell Transplantation (HSCT).

Methods: A qualitative analysis of the supportive intervention program for parents whose child is under HSCT treatment while hospitalized. Parents to 25 children were included in the intervention group. Twenty-five parents were included in a participant observational study and 21 of these completed a semi-structured interview 100 days following HSCT.

Results: Three main problems faced by all parents included 1) the emotional strain of the child's HSCT; 2) re-organizing of the family's daily life to include hospitalization with the child; and 3) the financial strain of manoeuvring within the Danish welfare system.

The FNN performed daily intervention rounds to ease each of these problems during the study period. Having the following pre-existing risk factors, negatively influenced the parents' ability to address these problems: 1) being a single parents; 2) low-level income; 3) low-level education; 4) low-level network support; 5) being a student or unemployed; 6) physical/psychiatric illness; and 7) ethnicity. Six families with 4 or more risk factors had complex emotional, social and financial problems that required extensive intervention by the FNN and that impacted their ability to provide care for the child.

Conclusion: The parents' pre-existing risk factors were further complicated by their children's HSCT. A recommendation for clinical practice is to identify families with multiple interrelated problems and allocate resources to support these families.

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Introduction

Health services in Denmark, including allogeneic Haematopoietic Stem Cell Transplantation (HSCT), are provided free-of-

charge (www.denmark.dk). HSCT is a well-established, potentially curative treatment for children with malignant and non-malignant diseases (Loberiza et al., 2003; Copelan, 2006). Although there is increased therapeutic success with HSCT, it is an intensive and potentially lethal medical treatment. To ensure sufficient immunosuppression and myeloaplasia, the child receives conditioning (high-dose chemotherapy/total body irradiation) one week prior to HSCT, followed by an infusion of stem cells from a donor. To avoid infection, the child is isolated in a laminar air filtered room from the time of conditioning to approximately 4 weeks post-HSCT. To care for the child, at least one parent remains in the room with the child

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around the clock. Since both parents work outside of the home in more than 95% of Danish families (www.denstoredanske.dk), they receive full income compensation from the social welfare authorities during their child's HSCT.

The child's HSCT and consequent increased dependency on the parents pose a substantial strain on emotional well-being and family function and at a time when both parties faces uncertain futures (Lesko, 1994; Clarke et al., 2008; Manne et al., 2002). How parents manage the challenge is important since it affects the child's adjustment to HSCT while the way in which the child manages the HSCT also impacts the parents' level of distress (Lesko, 1994; Phipps et al., 2002a, 2002b; Vrijmoet-Wiersma et al., 2009b). Thus, psychosocial adjustment to HSCT and recovery has become a growing concern and the literature indicates a need for supportive interventions for these families (Vrijmoet-Wiersma et al., 2009a; Tremolada et al., 2009; Jobe-Shields et al., 2009). Intervention programs supporting the parents' well-being include psychotherapeutic interventions (Lesko, 1994) and parents giving massage therapy to their child (Phipps, 2002). Phipps et al.'s (2010) randomised complementary (humour therapy/massage/relaxation/imagery) intervention study, that included 178 children undergoing HSCT and their parents is the most comprehensive study to date. However, no differences were found between the groups in this study. No single therapy to date has been proven to be most beneficial, however, these intervention studies call for further research within these families, and the most promising results included cognitive behavioural therapy (Sherman et al., 2004; Tremolada et al., 2009; Packman et al., 2010).

The current psychosocial intervention study was developed to allow a Family Navigator Nurse (FNN) to provide daily support to parents with a child undergoing HSCT. The study was designed to compare the intervention group with two control groups of parents, including three months follow-up after completion of the intervention. However, this paper only includes an analysis of the qualitative data from the intervention group. Theoretically, the Roy Adaptation Model inspired the intervention study design i.e. how the FNN interacted with the families. Furthermore, Roy's notion of a person/family is a bio-psycho-social being in constant interaction with a changing environment; and emphasis of the relationship between stimuli, coping mechanisms and adaptation served as inspiration (Roy and Roberts, 1981). Cognitive behavioural therapy inspired the FNN's daily emotional support targeting the parents (Beck, 1979; Beck and Emery, 1985; Beck, 2005) and the theory on social marginalization inspired the analysis of the parental risk factors (Walker and Walker, 1997; Backett-Milburn et al., 2003; Attree, 2006; Davies et al., 2008).

The current intervention study primarily included daily medical information relay, emotional and social support by the FNN and in addition, the parents were offered to participate in five one-hour educational sessions and weekly physical activity sessions.

The aim of the current paper is: to identify the predominant problems faced by parents of children treated with HSCT during hospitalization in isolation, to describe how these problems are interrelated with the families social situation, and to identify the required intervention by the FNN in assisting the parents address these problems.

Methods

Design

A qualitative analysis of 25 parents to hospitalised children treated with allogeneic HSCT included in a supportive intervention study.

Participants

Three groups of parents' children (aged 0–20 years) undergoing HSCT were included: an intervention group and two control groups receiving standard care. All resident parents of children undergoing HSCT in Denmark were eligible for inclusion in the study.

- The retrospective parental control group ($n = 57$) was recruited in June 2007. These parents had a child treated with HSCT during the period from January 1, 2004 to June 30, 2007.
- The prospective parental control group ($n = 8$) was recruited from July 1, 2007 to October 31, 2007.
- The parental intervention group ($n = 25$) was recruited from November 1, 2007 to October 31, 2009.

Exclusion criteria were: 1) parents to children with a medical prognosis of imminent death, 2) children without a resident parent as primary caregiver, and 3) a parents inability to speak Danish.

The intervention group sample

As illustrated in Fig. 1, a total of 31 children were approached for participation in the intervention group of the study, however, six (19%) were ineligible. 25 parents to children scheduled for HSCT consented to participate and these parents were included in a daily observational participant study during the child HSCT in isolation. Of the 25 parents included, 21 parents participated in a semi-structured interview 100-days following the child's HSCT. Four (19%) parents were excluded from the semi-structured interview due to one child being transferred to a referral hospital for terminal treatment, two children died and one parent did not complete the study.

The main characteristics of the parents to children treated with HSCT under study are shown in Table 1.

Data collection

Medical and socio-demographic questionnaire

Medical and treatment information for the children was obtained by reviewing the medical records, and all parents completed a questionnaire on socio-demographic factors including e.g. marital, financial, employment and medical status at the time of the child's admission to HSCT.

Participant observational study

A participant observational study was carried out daily by the FNN during the child's inpatient period of 4–6 weeks. The participant observational study provided insight in how parents, as primary caregivers, ascribed meaning to their behaviour and beliefs during action and interactions (Silverman, 2006; Teddlie and Tashakkori, 2009). To structure the data collection, the author (HBL) developed themes for the data collection process. These themes comprised a set of questions to systematically guide the observation process. The observations were systematically gathered in a logbook as field notes. The themes observed related to: the child's medical condition, side-effects and complications, care needs and emotional well-being. Furthermore the parents' performance of care tasks, interactions with the child and medical staff, concerns, emotional and practical coping with the child's care needs were noted. In addition the logbook-comprised information on the amount of time spent daily on observation, on the FNN intervention installed during the intervention program, and on the effect of the interventions.

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