European Journal of Oncology Nursing (2005) **9**, 218–238

ELSEVIER

European Journal of Oncology Nursing

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Quality of life of children following bone marrow transplantation: critical review of the research literature

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KEYWORDS
Bone marrow transplantation;
Child;
Quality of life;
Systematic review

Summary Children's quality of life (QOL) following bone marrow transplant (BMT) is an important but poorly understood concept. The aim of this paper is to critically review all research study designs to determine the QOL of childhood BMT recipients and to identify implications for research, practice and theory. The studies' methodological quality was evaluated separately by two investigators according to a set of formal criteria modified from Hoodin and Weber (Psychosomatics 44 (2003) 181). The review yielded one retrospective, one cross-sectional, six descriptive surveys and two prospective longitudinal study designs. The studies included 568 childhood BMT recipients ranging from 0.8 to 33 years. Only one study used a generic and disease-specific, psychometrically sound, QOL measure. Timing of assessments ranged from pre-BMT to 21 years following BMT. Due to the poor methodological quality, rendering conclusions across the studies was challenging. While the available evidence seems to suggest children experience good QOL following BMT, several studies found BMT to have a negative impact on various aspects of QOL. These results appear to be influenced by timing and type of measurements undertaken. Ultimately, there is a need for larger, more methodologically rigorous trials using prospective longitudinal study designs with pre- and post-measures to examine all QOL domains in children.

Zusammenfassung Die Frage nach der Lebensqualität von Kindern nach der Knochenmarktransplantation (KMT) ist ein wichtiges Thema, doch ist das Verständnis dieses Problems gering. Ziel dieser Studie ist eine kritische Überprüfung aller Arbeiten innerhalb der Forschungsliteratur zur Frage nach der Lebensqualität von Kindern nach der KMT, um Implikationen für die Forschung, die Theorie und die Praxis zu bestimmen. Zwei unabhängige Ermittler untersuchten die methodologische Qualität der Forschungsliteratur nach einer Reihe von formalen Kriterien, die in

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doi:10.1016/j.ejon.2004.08.006

modifizierter Weise den Methoden von Hoodin und Weber (Psychosomatics 44(2003) 181) folgen.

Die Überprüfung ergab einen retrospektiven und einen Querschnitt-Studienentwurf, sechs deskriptive Untersuchungsentwürfe und zwei prospektive Längsschnittsstudienentwürfe. Die Literatur umfasste 568 Kinder nach der KMT im Alter von 0,8 bis 33 Jahren. Nur in einer Studie wurde ein populations- und krankheitsspezifischer, psychometrisch solider Maßstab für die Bewertung der Lebensqualität angewandt. Die Untersuchungen fanden innerhalb einer Zeitspanne von vor der KMT bis 21 Jahre nach der KMT statt. Wegen der niedrigen methodologischen Qualität waren studienübergreifende Schlussfolgerungen schwer zu ziehen. Während vorhandenes Beweismaterial darauf hindeutet, dass die Lebensqualität von Kindern nach der KMT hoch ist, bewiesen einigen Studien negative Auswirkungen der KMT auf verschiedene Aspekte der Lebensqualität. Diese Ergebnisse scheinen durch den Zeitpunkt und die Art der Messungen beeinflusst zu sein. Abschließend besteht ein Bedarf an größer angelegten und methodologisch rigoroseren Untersuchungen unter Anwendung prospektiver Längsschnittentwürfe mit Messungen vor und nach der KMT, um alle Bereiche der Lebensqualität von Kindern zu untersuchen.

Introduction

Bone marrow transplantation (BMT) is an aggressive, life threatening medical procedure offered to chronically ill children who have haematological, oncological, or metabolical diseases. Children are also offered BMT if they have failed conventional treatment protocols due to disease relapse. Although the therapeutic success of paediatric BMT is improving, there has been little research on children's quality of life (QOL) after BMT. Historically, QOL was omitted as an outcome from most BMT clinical trials. Now, QOL is recognized as an important, if not the most important, outcome in BMT outcomes research (Andrykowski, 1994; Sanders et al., 1989). According to Andrykowski (1994), QOL for survivors following BMT is an important outcome along with the mortality and morbidity research outcomes that have been traditionally measured. Other BMT outcomes research include short-term adaptation and coping, compliance with medical recommendations, acute symptom development, and psychosocial factors (Andrykowski, 1994).

Although QOL is an important outcome measure in BMT research, it is poorly understood. The definition of QOL has been a matter of considerable debate (Eiser and Morse, 2001). Although consensus has yet to be reached on a QOL definition, the most common definition used is one by the World Health Organization (WHO). The WHO defines QOL as the individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1993). Moreover, QOL is conceptualized as a multidimensional construct encompassing several domains (Aaronson et al., 1991) and can include both objective and subjective perspectives (Testa and Simonson, 1996). The most common domains include physical, psychological, social, and role functioning as well as spiritual. In addition, others argue that, for children, assessment of QOL include measures of cognitive functioning, autonomy, body image and family relationships (Eiser and Morse, 2001) along with children's expectations and experiences (Carr et al., 2001) should be included. Meanwhile, in the health care context, several treatments may not affect overall life but focus narrowly on medical complaints (Feeny et al., 1999). Therefore, the notion of health-related quality of life (HRQOL) refers to the subjective and objective impact of dysfunction on the physical, psychological, and social aspects of QOL that are influenced by an individual's disease and its treatment (Strand and Russell, 1997).

Several reasons have been proposed for the inclusion of standardized assessments of QOL throughout the BMT process. First, QOL assessments might help clinicians, children and their families decide more easily between different treatment options. This would allow for more realistic informed consent where all the decision makers have greater cognizance of the broad range of potential and actual outcomes (Andrykowski, 1994; Hjermstad and Kaasa, 1995). Furthermore, to enhance QOL after BMT, there is a need to understand the long-term adjustment and rehabilitation difficulties experienced by BMT recipients (Andrykowski, 1994). A systematic assessment of QOL may enable health professionals to identify and target treatments for children and families who are at