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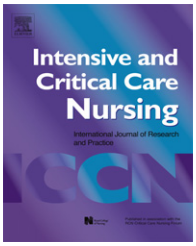

ORIGINAL ARTICLE

Recovery in parents of children and adolescents who survived septic shock caused by *Neisseria meningitidis*: A cross-sectional study

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KEYWORDS
Disease-specific psychosocial limitations;
Long-term;
Psychological distress;
Parents;
Septic Shock;
Coping;
Recovery

Summary

Objectives: To assess psychological distress, styles of coping and disease-related psychosocial limitations in parents of children and adolescents who survived meningococcal septic shock (MSS) 4—16 years ago.

Research methodology: An exploratory design using standardised questionnaires and interviews.

Setting: The psychological investigation took place in the department of Child and Adolescent Psychiatry of the ErasmusMC-Sophia Children's Hospital.

Main outcome measures: 87 mothers and 77 fathers participated in this study. The General Health Questionnaire was used to assess parents' psychological distress; the Utrecht Coping List to assess styles of coping. A semi-structured disease-specific interview served to explore long-term disease-related psychosocial limitations for parents.

Results: MSS parents reported similar psychiatric symptoms and styles of coping in comparison to reference groups. Severity of illness and the child's age at time of illness were not significant predictors of parental psychological distress and styles of coping. The presence of somatic sequelae, cognitive or behavioural and emotional problems was not associated with the levels of parental psychiatric symptoms or styles of coping. The vast majority of parents reported no current disease-related psychosocial limitations due to the MSS.

Conclusion: Parents of children who survived MSS show recovery. Nevertheless a minority still experiences emotional burden and disease-related limitations.

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Introduction

Septic shock caused by *Neisseria meningitidis*, also called meningococcal septic shock (MSS), is a life-threatening illness that has an abrupt onset and a fulminant course. It occurs predominantly in young children and adolescents. Despite better knowledge about its pathophysiology and treatment, it is still associated with high case mortality rate (15.7%; Maat et al., 2007). Children with MSS are one of the most severely ill and unstable groups of children admitted to a Paediatric Intensive Care Unit (PICU). MSS may result in somatic sequelae like amputation(s) of digits(s) as a result of skin necrosis, limited motor functioning because of orthopaedic sequelae (amputation and limb-length discrepancy), and neurological impairment.

The clinical presentation of MSS is often dramatic and death may follow in a matter of hours. Typically, a previously 'normal, healthy' child suddenly becomes very ill and has to be rushed to a PICU. Here, the child and its parents may suffer an overwhelming amount of emotional distress. Haines (2005) evaluated the experiences of parents of children who suffered meningococcal disease, and concluded that living through this experience is perceived as a major stressor. Major determinants of stress were the transition from the role of 'parent of a healthy child' to 'parent of a critically ill child', as well as feelings of helplessness and guilt. Parents are stated to be extremely emotional, to feel vulnerable, or to disbelieve what is happening. Fear that the child will die and anxiety about physical and mental outcome after survival will raise the stress and anxiety levels. Parents tend to be shocked by the invasive treatment measures and the changed appearance of their child. Thus, MSS does place an immense burden not only on the child but also on his/her parents (Haines, 2005). For the parents, the MSS period of their child can be considered a traumatic event.

The short- and long-term consequences for parents of children who survived septic shock have received little attention until now. Three studies have focused on parental short-term outcome, albeit in heterogeneous patient samples, encompassing children with meningitis, septicaemia or both (Ehrlich et al., 2005; Judge et al., 2002; Shears et al., 2005). In these studies the follow-up ranged from 3 to 12 months after admission to the PICU. Psychiatric symptoms were found in 42—69% of mothers and in 24—58% of fathers (Ehrlich et al., 2005; Judge et al., 2002; Shears et al., 2005). At risk for Post-Traumatic Stress Disorder (PTSD) were 38—48% of mothers and 19% of fathers (Judge et al., 2002; Shears et al., 2005). Regrettably, these studies did not differentiate between severities of disease.

Only one study investigated long-term consequences of meningococcal disease in parents (Ehrlich et al., 2005). The authors assessed parents of five small cross-sectional subgroups of patients at different time intervals (3—36 months or longer after discharge from the PICU). The prevalence's of psychiatric symptoms in mothers and fathers 3 years or more after discharge were comparable to those in the general population. Here, too, severity of disease was not taken into account. Furthermore, data were not gathered in a standardised manner (parents completed questionnaires at home).

Our study is the first to investigate coping styles, psychiatric symptoms and disease-related psychosocial limitations in parents of children who suffered from MSS, the most severe form of meningococcal disease. The present study was undertaken to address these issues. It is nested in a larger multidisciplinary study into the long-term psychosocial and medical outcomes of MSS survivors and their parents (Vermunt et al., 2008a,b, 2009).

Parents of children who survived MSS between 1988 and 2001 participated in the present study. We distinguished between outcomes of mothers and outcomes of fathers, since previous studies into short-term outcomes in meningococcal diseases indicated gender differences (Ehrlich et al., 2005; Shears et al., 2005). Furthermore, the role of severity and age at time of illness, presence of somatic sequelae (amputations and orthopaedic sequelae), cognitive and behavioural and emotional problems in the children on psychiatric symptoms and styles of coping of the parents was investigated. A previous study had shown higher disease severity at time of admission was associated with higher maternal PTSD symptom levels at 3—12 months follow-up (Judge et al., 2002). Finally, long-term disease-related psychosocial limitations for parents (such as limited possibilities to go out or going on holiday) were explored. The aims of the present study were:

1. To compare the levels of psychiatric symptoms and styles of coping of mothers and fathers of children and adolescents who survived MSS with those of men and women in reference groups.
2. To identify the role of severity and age at time of illness, presence of somatic sequelae (amputations, orthopaedic sequelae), cognitive and behavioural and emotional problems in the children on psychiatric symptoms and styles of coping in the parents.
3. To explore disease-related psychosocial limitations for parents of MSS survivors.

Methods

Design

This study concerned a psychological follow-up of a cross-sectional cohort of parents of all consecutive surviving patients with meningococcal septic shock (MSS) and purpura at least 4 years ago. Two primary outcome measures were used, the General Health Questionnaire and the Utrecht Coping List.

Recruitment and procedure

The Medical Ethics Committee of the Erasmus Medical Centre approved the study protocol before the start of the study. All parents (and their children) who could be traced were approached uniformly and provided written consent to participate in the study. The psychologist interviewed the parents after a psychological investigation of their child in the department of Child and Adolescent Psychiatry of ErasmusMC-Sophia Children's Hospital, which was performed in combination with a medical examination by a