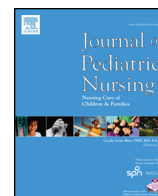




Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Impact of Low Anorectal Malformation on Parenting Stress: A Mixed-Method Study

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ARTICLE INFO

Article history:

Received 5 December 2017

Revised 30 April 2018

Accepted 5 May 2018

Available online xxxxx

Keywords:

Low anorectal malformations

Parenting stress

Mixed-methods study

Communication

ABSTRACT

The purpose of this study was to investigate parenting stress among parents of children with low ARM. Study aims: 1) Compare parenting stress among parents of children with low ARM, with parents of healthy children using questionnaires. 2) Identify subscales within the questionnaire which needed to be further explored. 3) Use semi-structured interviews with parents of children with low ARM, to explore parenting stress and to explain, expand and or support the quantitative findings.

Design and Methods: An explanatory sequential mixed methods design was used in this follow up study. The parents completed the Swedish Parenthood Stress Questionnaire (SPSQ), semi-structured interviews were conducted.

Results: Fifteen mothers and 13 fathers of children with low ARM age 8–18, returned completed questionnaires. A control group of 17 mothers and 6 fathers of healthy children age 8–18 that had visited the hospital for a minor procedure was recruited for comparison purposes. There were no significant differences found between index group and controls except in the subscale Incompetence, where parents of children with low ARM reported lower levels of stress compared to controls. Nine semi-structured interviews were conducted with parents of children with low ARM. Qualitative content analysis was used and revealed three themes – *Communication between parents, Expectations of parenthood, and Challenges concerning parenthood.*

Conclusions: Parents of children with low ARM did not report high levels of stress. When interviewed, they told about earlier experiences of emotional stress, feelings of guilt, and chaos at the time the child was born and during infancy.

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Introduction

Anorectal malformations (ARM) are congenital anomalies involving the anus and the rectum. The incidence of ARM is 1 in 4–5000 live births, and it affects both males and females (Bischoff, Levitt, & Peña, 2013; Levitt & Peña, 2007). The malformations vary from minor to more complex, and can be divided into low, intermediate and high form (Holschneider et al., 2005). In this study low ARM refer to perineal fistula and imperforate anus without fistula (Pakarinen & Rintala, 2010). Children who have been operated on and treated for ARM often have varying degrees of functional problems such as constipation or incontinence (Levitt & Peña, 2005). The functional bowel problems often continue into adulthood (Rintala & Pakarinen, 2010). Anal dilatation is

necessary to prevent stenosis of the neoanus. Dilatations are performed according to an anal dilation program by the parents twice a day until a desired size is reached (Levitt & Peña, 2007). The child might also require interventions such as regular enemas and washouts for managing constipation and fecal incontinence (Peña et al., 1998). Traditionally, long-term results in low ARM have been considered to be good by most of the patients (Iwai et al., 2007; Karkowski, Pollock, & Landon, 1973; Nixon & Puri, 1977). However, studies have shown that children with low ARM often have problems with constipation (Pakarinen & Rintala, 2010; Rintala, Lindahl, & Rasanen, 1997).

Parenting stress is defined as the psychological distress that parents experience while they are trying to meet the demands as a parent, and such stress can have a variety of effects on the parents and their children (Abidin & Wilfong, 1989). It is normal for parents to experience parenting stress to some degree, but in the presence of a pediatric illness the level of parenting stress tends to increase (Deater-Deckard, 2004).

Seen from the chronically ill child's perspective, the parent's psychological well-being is important because of the high correlation between

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the child's long-term outcome and the parents' mental health (Barlow & Ellard, 2006). The parents' mental health can affect the child's health-related outcomes and can interfere with the management of the child's chronic condition (Streisand, Braniecki, Tercyak, & Kazak, 2001), and it can also have negative effects on the entire family (Farrace, Tommasi, Casadio, & Verrotti, 2013). There are only a few studies conducted on parenting stress in parents of children with ARM, and especially children with low ARM. Results from previous studies are ambiguous. One group reported that parents of children with ARM had elevated levels of stress (John, Chacko, Mathai, Karl, & Sen, 2010). Another group did not find any differences in stress levels when parents of children with ARM were compared with parents of healthy primary school children (Hassink et al., 1998). Therefore, it is important to further explore what impact a low ARM might have on the parents.

Purpose

The purpose of this study was to investigate parenting stress among parents of children born with low ARM. The study aims were to: 1) Compare parenting stress among parents of children born with low ARM, with parents of healthy children using questionnaires. 2) Identify subscales within the questionnaire which needed to be further explored. 3) Use semi-structured interviews with parents of children with low ARM, in order to explore parenting stress and to explain, expand and or support the quantitative findings.

Design and Methods

A sequential explanatory mixed method design was used in this study. This method provided us with a structure for the collection of initial cross-sectional quantitative data through questionnaires, which were followed, sequentially, by semi-structured interviews to add deeper understanding of the quantitative data. The interview questions (Fig. 1) within the qualitative inquiry, were based on the initial quantitative survey findings. To be able to answer complex research questions concerning parenting stress and rare congenital malformations such as low ARM. A mixed methods design is needed, to bring different perspectives and methodological expertise into the data analyses (Creswell & Plano Clark, 2011).

Participants

The participants were parents of all children with low ARM born in 1993–2007 who had been operated on as infants and cared for at Astrid Lindgren Children's Hospital in Stockholm, Sweden. Both mothers and fathers were asked to participate. The children were between 8 and 18 years old and attended the follow-up program at the hospital. Exclusion criteria for participating were: children cared for at the hospital but operated on elsewhere, children who have not been operated on, moved abroad, intellectual disability and language barriers. The families were identified through hospital case records (Fig. 2). A control group of 17 mothers and 6 fathers of healthy children between 8 and 18 years of

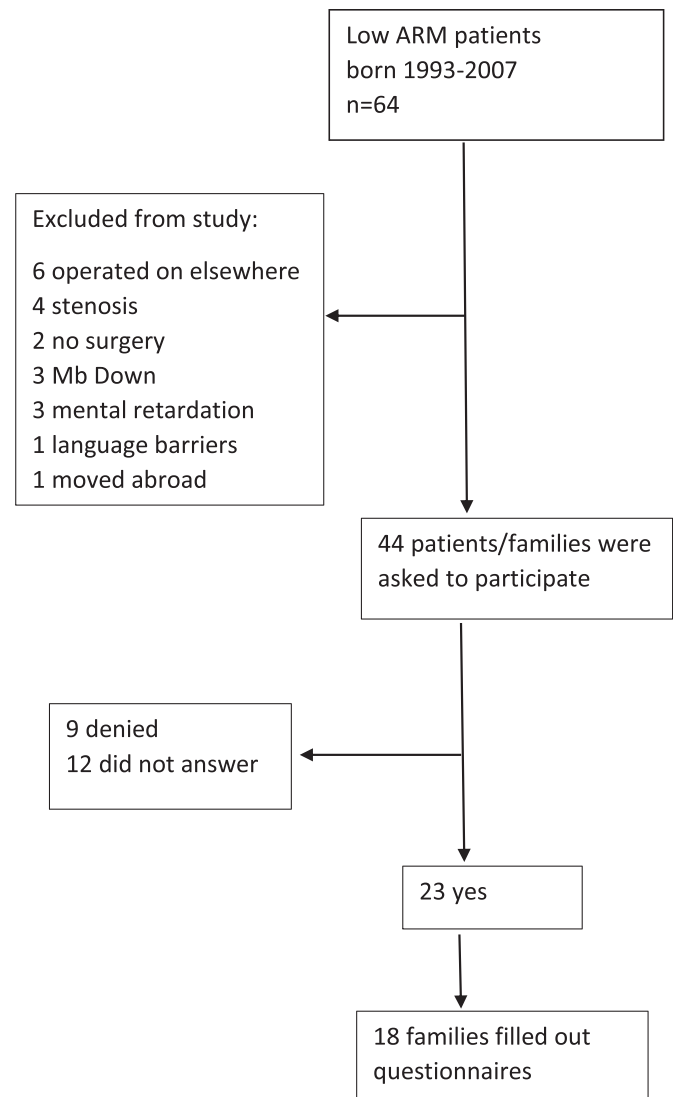


Fig. 2. Flowchart of participants.

age, that had visited Astrid Lindgren Children's hospital for a minor procedure was recruited for the quantitative part of the study for comparison purposes.

Measures and Data Collection

Parenting stress was measured using the Swedish Parenthood Stress Questionnaire (SPSQ), which is a psychometrically validated instrument that measures experienced parenting stress (Östberg, 1998; Östberg,

1. How did you and your partner share the responsibility at home? How did you cooperate?
2. Before becoming a parent; what expectations did you have on your parenthood? Did you have any thoughts on becoming a parent?
3. How do you look upon yourself as a parent? Have you been sufficient (good enough) as a parent? Compared to siblings?

Fig. 1. The interview guide.

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