



## ‘A worse nightmare than expected’ - a Swedish qualitative study of women's experiences two months after obstetric anal sphincter muscle injury



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### ARTICLE INFO

#### Keywords:

Experiences  
Perineal laceration  
OASIS  
Qualitative approach  
Qualitative content analysis

### ABSTRACT

**Objective:** this study explores women's experiences of the first two months after obstetric anal sphincter injury (OASIS) during childbirth with a focus on problematic recovery.

**Methods:** this qualitative study used inductive qualitative content analysis to investigate open-ended responses from 1248 women. The data consists of short and comprehensive written responses to open-ended questions focusing on recovery in the national quality register, the Perineal Laceration Register, two months after OASIS at childbirth.

**Results:** the theme ‘A worse nightmare than expected’ illustrated women's experiences of their life situation. Pain was a constant reminder of the trauma, and the women had to face physical and psychological limitations as well as crushed expectations of family life. Furthermore, navigating healthcare services for help added further stress to an already stressful situation.

**Conclusions:** we found that women with problematic recovery two months after OASIS experienced their situation as a worse nightmare than expected. Extensive pain resulted in physical and psychological limitations, and crushed expectations of family life. Improved patient information for women with OASIS regarding pain, psychological and personal aspects, sexual function, and subsequent pregnancy delivery is needed. Also, there is a need for clear organizational structures and information to guide help-seeking women to needed care.

### Background

Perineal damage after childbirth has increased (Ekeus et al., 2008; Laine et al., 2009) and Sweden has the highest prevalence of obstetric anal sphincter injuries (OASIS) among the Nordic countries (Laine et al., 2009). An observational study shows that 78% of Swedish women giving vaginal birth have perineal tears of any degree (Samuelsson et al., 2002). The Swedish medical birth register (MBR) records the most severe perineal damage (OASIS grade 3 and 4 lacerations of the anal sphincter muscle). In 2014, 3.4% of all women (6.0% primiparas and 1.6% multiparas) with vaginal birth were diagnosed with OASIS (Socialstyrelsen, 2015). International figures indicate that 0.5 to 2.5% of vaginal births are complicated by OASIS (Byrd et al., 2005); however, the prevalence may be affected by the population studied and the accuracy of the used diagnostic tools (Byrd et al., 2005; Poulsen et al., 2015).

Perineal damage may cause complications and suffering such as pain (Andrews et al., 2008), urinary and faecal incontinence (LaCross et al., 2015), difficulties emptying the bowel, prolapses of vaginal walls, and sexual dysfunction (Samarasekera et al., 2008). Furthermore, negative effects on daily life and quality of life are reported (Uustal Fornell et al., 2004; Cornelisse et al., 2016) as well as anxiety and depression (Desseauve et al., 2016). These problems may lead to social isolation and changes in sexual intimacy (Priddis et al., 2013) and poorer quality of life even 10 years postpartum (Samarasekera et al., 2008). In addition, feelings of guilt, shame, and frustration are reported (Tucker et al., 2014). The many negative aspects related to OASIS have been summarised as ‘OASIS syndrome’, a hidden condition consisting of emotional, social, and psychological consequences. This syndrome also covers a compromised role as a mother (Keighley et al., 2016a). Incontinence, dyspareunia, and perineal pain are more common among women with OASIS, but similar persisting problems are frequent among women without OASIS as well

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<https://doi.org/10.1016/j.midw.2018.02.015>

Received 10 October 2017; Received in revised form 14 February 2018; Accepted 17 February 2018

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(Sundquist, 2012). Swedish follow-up studies have found that anal function deteriorates over time (Wagenius and Laurin, 2003; Pollack et al., 2004; Fornell et al., 2005) and after several vaginal deliveries (Pollack et al., 2004; Fornell et al., 2005). Even 20 years postpartum, women show increased problems as a result of the OASIS (Haadem and Gudmundsson, 1997). Anal incontinence at nine months after childbirth appears to predict persistent problems (Pollack et al., 2004).

### The rational of the study

In 2014, a national quality register for medical and self-reported aspects of perineal lacerations (The Perineal Laceration Register, PLR) was introduced to systematically identify women in need of treatment and compare hospitals according to patient related outcomes. The overabundance of substantial comments and consequently, subsequent need for systematic analysis of them was identified by EU (register holder) when the first years' register database was set up. So far, the research has predominantly focused on quantitative studies of bodily functions and on quality of life after OASIS. Because the voices of affected women are seldom heard, there is a lack of knowledge about important aspects of life after such an injury. By focusing on the experiences of women with OASIS the first two months after childbirth, this study adds new and important knowledge to the field as well as for clinical practice. This study explores women's experiences of the first two months after OASIS with a focus on problematic recovery.

## Methods

### Study design

This qualitative study analysed written open-ended responses to questions in a questionnaire responded by women with OASIS to two months after childbirth. The written responses were excerpted from the PLR. Inductive qualitative content analysis was applied, which is a suitable method when exploring a variety of experiences (Graneheim and Lundman, 2004; Krippendorff, 2004). This project was approved by the Ethical Board at Linköping University (No 2016/144-31).

### The Perineal Laceration Register, (PLR)

The PLR is a section register of the well-established Swedish National Quality Register of Gynecological Surgery (GynOp) and aims to identify women with complications, offer them follow-up and to allow national comparisons and research of factors that influence patient reported outcome measures (PROM) (GynOp registret). Data are available for research as well as clinical follow-ups. As of 2017, the PLR covered 85% of all births in Sweden. As a national quality register, the PLR adheres to Swedish legislation (Patientdatalagen 2008:355, 2008) and the inclusion of data is voluntary for affected women. The PLR consists of data extracted from medical records on obstetric data regarding childbirth including suturing and in the more severe cases surgery of the perineal laceration (GynOp registret). Furthermore, self-reported data are collected from affected women at three points by web or postal questionnaires; near delivery, at eight weeks, and one year after childbirth. The first questionnaire (Q1) comprises questions on continence, abdominal pain (irritable bowel syndrome), and experience of vaginal function before the pregnancy. The second questionnaire (Q2) covers suturing and its related complications, continence, and patient reported outcome measures (PROM). The third questionnaire (Q3) addresses function and further complications from two months up to one year and PROM. Whenever a woman wants to add further information to the pre-set questionnaire options, there is unlimited space to add written comments (GynOp registret).

For this study, written comments focusing on recovery were excerpted from Q2 and background characteristics of included women were assessed from Q1.

**Table 1**

Background characteristics of participants (n = 1248).

<b>Degree of perineal trauma n(%)</b>	
3rd degree	925 (74.1)
4th degree	323 (25.9)
<b>Body mass index (BMI) kg/m<sup>2</sup></b>	
Mean; SD	27.02; 5.2
<b>Maternal age in years, n(%)</b>	
≤ 25	170 (12.6)
26–30	502 (39.7)
31–35	437 (34.7)
≥ 36	139 (12.1)

### Participants and data collection procedure

This study included all respondents with an OASIS grade 3 or 4 who had added written comments of any length to their Q2 responses from 1 January 2014 through 31 December 2016. The comments comprised a variation of only a single word up to extensive comments. The respondents with a perineal laceration grade 1 or 2 were excluded (114 respondents), resulting in a sample of 1248 women out of 2955 responding women. Background characteristics of included women are presented in Table 1.

After the study approval by the Ethical Board, an application was made to the PLR for excerpting of data for this study. Background characteristics of participants were retrieved from Q1. The women's comments were excerpted from the following questions and directions in Q2: 'What caused the unexpected problems or complications?'; 'Please, describe further the problems you have indicated above.'; and 'Have your problems/complications been treated?'. Furthermore, comments made to the following questions: 'Do you still have problems related to the questions above (questions covering poor healing/complications)?' and 'Do you have any further problems related to your perineal laceration?' were included to the data. All data were distributed to the research team as a SPSS file, and the comments were converted to a word file for the analysis.

### Data analysis

Data were analysed using inductive qualitative content analysis as presented by Graneheim and Lundman (2004). This method is suitable for exploring variations within data as it highlights differences and similarities (Graneheim and Lundman, 2004). The analysis was performed in a stepwise manner. First, all extracted texts were read thoroughly by the first author (ML) and in most parts by IL. Next, meaning units relevant for the aim of this study were identified, condensed, and coded. The codes were then compared for differences and similarities. During this phase, categories and sub-categories emerged. Three of the authors (ML, MP, and IL) repeatedly discussed the analysis. All transcripts were re-read by ML to reassure that no significant data addressing the aim were neglected. As a final step of the analysis process, the theme was finalised; i.e. presenting the underlying meaning of women's experiences of the first two months after OASIS. All authors were included in the final discussions of the analysis. A member check was performed in the form of a focus group discussion with four women with OASIS, but not included in the present study. This discussion confirmed the findings.

## Findings

The theme 'A worse nightmare than expected' illustrated women's experiences with OASIS as a condition that not only interfered with normal life, but also crushed their dreams of motherhood and affected the relationships with the spouse and newborn. Both the physical and psychological effects of OASIS negatively affected participants' ability to function as a mother and partner. Furthermore, women strived to

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