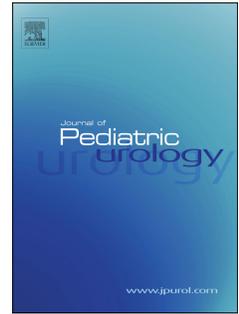


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Parental experiences of their child's vulvovaginitis: a qualitative interview study

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Title: Parental experiences of their child's vulvovaginitis: a qualitative interview study.

Summary

Introduction: Vulvovaginitis is described as a common self-limiting paediatric gynaecological condition. Parents' experiences of their child being diagnosed with this condition and subsequent treatment have not previously been described.

Aim: The aim of this study was to explore parents' experiences of their child's diagnosis and management of vulvovaginitis.

Study design: The study was conducted in the North West of England over a two-year period. Qualitative data were generated by semi structured in-depth interviews. Mothers of nine children with vulvovaginitis consented to participate. Data were analysed using thematic analysis.

Results: The analysis of the data resulted in four themes; Trauma and uncertainty of initial symptoms, seeking a diagnosis; an uncertain journey, managing the symptoms; a process of trial and error and managing the impact; keeping it private. Parents experienced a difficult and protracted journey to their child's diagnosis and were involved in a process of trial and error to try and monitor and manage what can be a difficult ongoing condition.

Discussion: Clinical reports suggest that vulvovaginitis is a minor childhood condition; this is not necessarily the perceptions and experiences of parents, who can experience uncertainty and ongoing difficulty following their child's diagnosis.

Conclusion: The diagnosis of vulvovaginitis can have a major and ongoing impact on children's and their family's lives.

Summary Figure: Themes arising from parental interviews.

Keywords: Parental Experiences; Vulvovaginitis; Diagnosis; Management.

Introduction

Vulvovaginitis is defined as a condition involving inflammation of the vulva and vagina, with symptoms including vulvar irritation that can include burning and itching with or without vaginal discharge [1]. Vulvovaginitis is the most common gynaecological complaint in pre-pubertal girls [2], with evidence suggesting that 4 young girls out of every 10 demonstrate symptoms of vulvovaginitis [3]. The condition is predominantly seen in girls between the ages of two and eleven and it is a self-limiting condition that improves at the time of puberty [4].

A child often presents with complaints of vaginal discharge, pruritus, vaginal soreness, dysuria and an offensive odour [2,5]. A diagnosis of vulvovaginitis is made through a detailed history and clinical examination, and if vaginal discharge is evident then vaginal swabs can be taken. There is some debate regarding the value of taking swabs, as the majority of cases no specific pathogen is identified and the procedure of gaining a swab can cause distress to the child and parents/carers [6,7]. However, obtaining a swab can be beneficial if this results in the condition being treated with an appropriate antibiotic [8].

Young girls are vulnerable to this condition due to a variety of reasons including; the vaginal mucosa being very thin, the vagina having an alkaline Ph, the lack of labial fat and the small minora offering little protection from infection [9-11] and the close proximity of the vagina to the rectum [9-11]. Girls of this age also have increasing responsibility for their own perineal hygiene which can mean that if they do not follow good handwashing practices then bacteria can be easily spread by their hands from one part of the body (usually from the rectum, nose and mouth) to their vagina [4,12].

Vulvovaginitis is a long-term condition which involves vaginal pain, discharge, offensive odour and a burning sensation when passing urine [1,5,12,]. Recurrent non-specific

infections can be difficult to manage and symptoms can reoccur frequently. The lack of effective treatment for this condition results in the main emphasis being on the prevention of future infections through regular and rigorous handwashing, perineal hygiene and good dietary habits [11,13,14]. If the recommended hygiene advice is not followed then evidence suggests that there is a higher incidence of re-occurrence and the need for antibiotic administration [5].

There is no evidence regarding how parents experience and manage this difficult condition. The aim of this study was to explore parents' experiences of their child's diagnosis and management of vulvovaginitis.

Materials and Methods

Qualitative data were generated using face to face semi structured interviews undertaken in the parent's home or at a location chosen by the parent. Interviews were guided by a topic sheet, but were flexible to encourage parents to talk about issues of importance to them. The content and framing of the questions on the topic sheet was informed by consultation with three non-participating parents. Written consent was gained and the interviews were audio recorded and then transcribed verbatim. The researchers who conducted the interviews (JM, LB) had no prior clinical relationship to the parents. Thematic analysis [15] was inductive and undertaken following data collection. To ensure rigour during analysis, initial coding of the data was undertaken independently by all members of the research team and then the resultant codes and themes were discussed and agreed [16].

Participants

Parents were approached to take part from the gynaecology and urology departments within two children's hospitals from the North West of England. Clinical staff diagnosing

vulvovaginitis in a child aged seven years and under provided written information to the parents regarding the study, the parents then contacted the researchers if they wanted to take part.

Results

100 parents were provided with information about the study. Ten parents agreed to be interviewed, one parent was uncontactable and was not interviewed. All nine parents who participated were mothers and their children had developed symptoms of vulvovaginitis between the ages of 18 months and 4 years and diagnosis occurred between the ages of 3 to 5 years of age (Table 1).

Table 1: Child characteristics of the mothers interviewed

The findings will be presented under the four themes developed from the analysis; the trauma and uncertainty of initial symptoms, the uncertain journey of seeking a diagnosis, the process of trial and error involved in managing the symptoms and managing the impact of the condition by keeping it private (Figure 1).

Trauma and uncertainty of initial symptoms

There were a range of symptoms described by parents at the time the condition started. These symptoms ranged from redness, itching, discharge and dysuria to extreme episodes of night time pain and bleeding. The following mothers described their daughter's "*bloodcurdling screams in the middle of the night*" (P4) and how "*stabbing pains woke the house*" (P9). Some mothers described how the pain at night was "*the hardest bit to deal with*" (P8) and so extreme that "*your child is screaming to*

the point where she can't breathe properly at night" (P2). Some children were experiencing pain on a nightly basis.

Many mothers recalled the stress, worry and *"heart break"* (P2) caused by seeing their child experience such extreme pain and how they had to *"hide our tears...just thinking about it now makes me upset"* (P9).

The extreme nature of some symptoms left mothers feeling lost, uncertain, guilty and frustrated that there was *'very little they could do to help'* (P2) and at times felt as though they were *'tearing their hair out'* (P4).

Seeking a diagnosis; an uncertain journey

Many mothers described feeling *'fobbed off'* (P1) when they initially took their child to see a health professional. They described a protracted journey of multiple appointments, various diagnoses and the prescription of a range of ineffective treatments. *"The doctor wasn't sure what it was it was only when I took her back five times they said okay we will refer you"* (P1). Parents felt reassured when a referral resulted in a diagnosis finally being made and clear guidance being provided *"It was such a relief when we were referred as it had been such a nightmare"* (P5). The following mother discussed how she was relieved to have:

"got an answer as to what is wrong with her and there is a reason why. I knew it was more, we were being fobbed off. I told the doctor and he said it was normal, I thought 'no' this isn't normal for a four year old to be scratching herself and making herself bleed" (P3).

One mother described how she felt so desperate to receive specialist help for her daughter's symptoms that she agreed for a referral to social services and internal swabs. This resulted in the mother describing how she was happy in the end that *'it*

wasn't sexual abuse or anything' (P5). There was also relief expressed by other mothers when a diagnosis confirmed that they had not been doing *'anything wrong'* (P2).

Managing symptoms; a process of trial and error

Many of the mothers described the difficulties and uncertainties associated with the ongoing management of their child's vulvovaginitis. They described the vigilance required to ensure the condition was kept *'under control'* and that *'flare ups'* were promptly treated. Some mothers talked about *'constantly keeping track'* and some described recording their child's activities and symptoms in *'diaries'* to ensure the condition was *"kept on top of"* (P4). Many mothers described that they were constantly *'nagging their child'* to ensure good levels of hygiene were maintained.

"I am constantly – get your hands out of your mouth.... stop picking your nose and wash your hands...take your hands off it" (P1).

Management involved daily thought and planning to make sure that toilet roll, baths, wipes, underwear, drinks, food, temperature and activities such as swimming were controlled. This level of work remained *"a mammoth task"* (P3) for many mothers.

The management of symptoms required some mothers to accept that they were not able to make it better for their child *"I don't know a solution, I don't know what would stop her hurting as much"* (P2) and they engaged in a constant process of *"trial and error"* (P9); trying new products such as detergents and searching for treatment tips from the internet. One mother had insisted her child was *"tested for diabetes"* (P7) as they were so many comments online regarding vaginal infections and diabetes.

Managing the impact; keeping it private

In most of the families it was the mother who adopted the role of managing their child's condition. Mothers talked about how many of their husbands felt *"really uncomfortable applying creams and cleaning it"* (P7). Some mothers felt that it was their role to *"keep it private between me and her....a girlie thing"* (P7) and *"it is a mum thing not a dad thing"* (P8).

Mothers described how the private nature of the condition meant that it was difficult to talk about to teachers in school and with friends *"it is not the sort of thing you want to be talking to people about at the school"* (P8). The treatment involved was seen by some mothers as a private matter, one mother described how she had told her child *"not to tell her friends that I put cream on her bum as that can be a bit embarrassing for her"* (P1).

The decision of the mothers to keep the condition 'private' led to some children being excluded from activities such as sleep overs and days out, *"for a while it was awful, it got to the point that we didn't go out"* (P6). One mother (P4) described how her daughter was not invited on a camping trip with school friends because: *"with her having the condition that she's got we were not quite sure if (friends' mother) would be able to look after her"* (P4).

Discussion

The current clinical perception is that vulvovaginitis is a relatively minor self-limiting condition [4] which is best managed through behavioural interventions such as hand hygiene, perineal hygiene, general dietary advice and avoiding constipation

[11,12,13,14]. The difficult and ongoing nature of some children's symptoms is often perceived by health professionals to be due to parental/child non-adherence to the behavioural interventions [5]. However, the findings of this study suggest that parents are vigilant in the monitoring and management of their child's condition. This vigilance and the ongoing work associated with keeping on top of the condition and any symptoms impacts not only on the mother and their child, but the whole family. Although it has been acknowledged within the literature [10] that this condition can be difficult to manage, the extent to which it can be disruptive to the daily life of the parents and child has not been discussed previously. The daily and ongoing nature of managing vulvovaginitis has similarities to how other chronic and long-term conditions can impact on children's, parents' and families' lives [17,18].

Particular to vulvovaginitis is the perceived private nature of the condition, which caused mothers in this study to assume the responsibility as sole carer and feel unable to share their child's diagnosis with others. Mothers also encouraged their child to keep the condition secret, which could result in children missing out on social activities with their friends. This study has shown that vulvovaginitis is often considered by families to be an embarrassing and taboo subject; reflecting the social stigma often associated with conditions such as incontinence [19-21].

The small sample recruited to the study is a limitation with the potential that those interviewed could have experienced more difficulty than those who chose not to participate. The parents were also those whose child had been referred to a specialist centre with persistent symptoms and therefore their experiences may not be representative of all parents. This study which explored parents' experiences of their child's vulvovaginitis provides insight and a useful starting point for gaining further understanding of a broader sample of parental experiences.

Conclusion and implications for healthcare

Vulvovaginitis is often considered to be a relatively minor self-limiting childhood condition. This study highlights that some children can experience severe symptoms and a protracted journey to diagnosis. Parents are involved in a process of trial and error to try and monitor and manage what can be a difficult ongoing condition. Health professionals should acknowledge that a diagnosis of vulvovaginitis can have a major impact on children's and their family's lives. There is further work to be done to gain an understanding of parents' ongoing guidance and support in the management of their child's condition.

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Conflict of Interest

None

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Ethical approval

Ethical approval for this study was granted by the National Research Ethics Service (NRES) (reference number 15/LO/0516) and the research department of each participating hospital trust.

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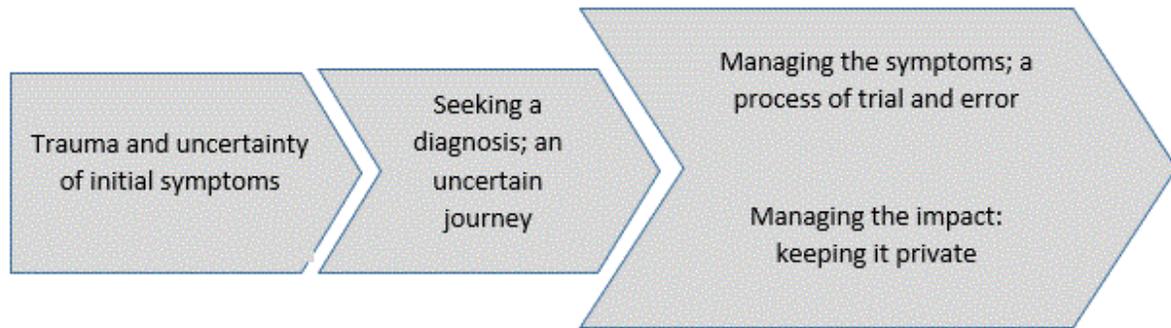
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Table 1: Child characteristics of the mothers interviewed

Child	Onset of symptoms	Age at diagnosis	Age at interview
1	2	4	7
2	4	4	6
3	4	5	7
4	18/12	4	5
5	2	3	6
6	2	3	4
7	2	3	5
8	4	5	6
9	18/12	4	7

Figure 1: Parents' experiences of the process of diagnosis and management of their child's vulvovaginitis.



ACCEPTED MANUSCRIPT