

Understanding Women's Differing Experiences of Distress after Colposcopy: A Qualitative Interview Study.

Item type	Article
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Citation	Understanding Women's Differing Experiences of Distress after Colposcopy: A Qualitative Interview Study., 25 (5):528-34 Womens Health Issues
DOI	10.1016/j.whi.2015.05.009
Publisher	Elsevier
Journal	Women's health issues : official publication of the Jacobs Institute of Women's Health
Rights	Archived with thanks to Women's health issues : official publication of the Jacobs Institute of Women's Health
Downloaded	7-Nov-2017 05:07:32
Link to item	http://hdl.handle.net/10147/620162

Abstract

Background: Women who have an abnormal cervical cytology test may be referred for a colposcopy. Accumulating evidence suggests some women may experience distress post-colposcopy. This exploratory study examined women's differing experiences of post-colposcopy distress with the aim of identifying factors that are predictive of, or protective against, distress.

Methods: We carried out semi-structured qualitative interviews with 23 women who had undergone colposcopies. Interviews were transcribed verbatim, coded and analysed thematically. The Framework Approach was used to summarise and organise the data and identify emerging higher-order themes.

Results: Two forms of post-colposcopy distress emerged: (1) short-term and (2) long-term. Short-term distress was experienced immediately following the colposcopy and in the days afterwards, and was usually related to the physical experience of the colposcopy. Long-term distress typically persisted over time and was related to concerns about fertility, cervical cancer and sexual intercourse. The drivers of short-term and long-term distress differed. Factors related to short-term distress were: feeling unprepared for the procedure; having a negative experience of the procedure; and attending the clinic alone. Factors related to long-term distress were: future intentions to have (more) children; having physical after-effects of the procedure that impacted on the woman's life; and being under on-going clinic surveillance. Absence of these factors (e.g. being accompanied to the clinic) was protective against short- and long-term distress.

Conclusions: Colposcopy can lead to short- and long-term post-procedural distress for some women. We identified a range of factors, some potentially modifiable, that appear to influence the chances of distress. These results may inform the development of strategies or

interventions aimed at preventing or minimising distress following colposcopy and related procedures.

Introduction

Colposcopy is used in many healthcare settings to follow up women with abnormal cervical cytology (Massad et al., 2013; National Health and Medical Research Council [NHMRC], Australian Government, 2005; Jordan et al., 2008; CervicalCheck, Ireland's National Cervical Screening Programme, 2012). In some settings, colposcopy examinations are office-based while in others they are hospital-based. The procedure is common and many women referred have low-grade abnormal cervical cytology. For instance, of a total of 167,394 women referred for colposcopy in England in 2012-2013, 52% had low-grade abnormalities (National Health Service [NHS], 2013). For some women, the colposcopy appointment will include taking biopsies for the histological confirmation of cervical disease, or treatment to remove cervical intraepithelial neoplasia (CIN) (CervicalCheck, 2012).

The psychological impact of undergoing colposcopy is well documented; studies report raised anxiety and distress prior to and during the examination (Galaal et al., 2011). Evidence is now accruing that colposcopy and related procedures are also associated with adverse psychological after-effects for some women. Studies from various healthcare settings show a range of adverse psychological outcomes including distress, anxiety and worries about cancer (Sharp et al., 2013; Bonevski et al., 1998; Bosgraaf et al., 2013). Of particular concern are suggestions that these adverse psychological after-effects may persist for some time. For instance, one study reported that 30% of women still had fears about cancer two years following their initial colposcopy (Hellsten et al., 2008). In another study, the prevalence of significant anxiety was higher among women who had undergone colposcopy 30-months previously than would be expected in the general population (Sharp et al., 2011).

A few quantitative studies have examined factors associated with psychological distress following colposcopy. Being diagnosed with CIN2/3 was associated with distress in one

study (Sharp et al., 2013), and in others psychological wellbeing was poorer in women who were of lower socio-economic status, had a partner, or had experienced more negative life-events (Orbell et al., 2004; Hellsten et al., 2008; Tiersma et al., 2005). In contrast, Sharp et al (2011) found no association between risk of anxiety and the type of management received by women with an abnormal transformation zone. . Beyond this, little is known about what leads some women and not others to experience post-colposcopy distress

In order to gain more in-depth understanding of women's experiences of post-colposcopy distress, we conducted exploratory semi-structured interviews among women with abnormal cervical cytology who had undergone colposcopy with or without related procedures. Our study aimed to: (1) examine women's differing experiences of psychological distress and (2) identify factors that are predictive of, or protective against distress following colposcopy.

Material and methods

Setting

The study was conducted in Ireland in 2013. In 2008, a national cervical screening programme, CervicalCheck, was implemented, offering free cervical cytology tests to women aged 25-60 years. Women with two or more low-grade abnormal cervical cytology test results, or one high-grade result, are referred for colposcopy (CervicalCheck, 2012).

Sampling, participants and recruitment

The sampling frame for the current study comprised women who had attended one of two CervicalCheck-affiliated colposcopy clinics and had previously participated in a quantitative study of psychological wellbeing, involving completion of questionnaires 4, 8 and 12 months post-colposcopy (O'Connor et al. 2013). Women were eligible for the current study if they had been referred for their initial colposcopy with either low-grade or high-grade cytology; had not had another colposcopy prior to recruitment to the quantitative study; and had completed at least one psychological questionnaire as part of the study. They were eligible irrespective of their initial colposcopy findings (i.e. normal or abnormal transformation zone) and procedures undergone at, or as a result of, the initial colposcopy findings. Women's initial colposcopy and histology results were obtained from colposcopy clinic records.

Purposive sampling was used to ensure that the sample was heterogeneous with respect to marital status and psychological wellbeing; women who were married or cohabiting, as well as those who were in relationships or not were included. Women with a range of anxiety scores on the HADS were also included (Hospital Anxiety and Depression Scale (HADS); Zigmond & Snaith, 1983). 144 women purposively sampled from respondents to the 8 and 12-month

questionnaires were sent a letter inviting them to take part in an interview. Interested women (n = 31) returned a reply slip to the research team, and the interviewer (name) contacted them to arrange the interview. Ethical approval was provided by the research ethics committee for each participating hospital. All participants provided written informed consent before interview.

Interviews

Interviews were conducted face-to-face during January-June 2013 at women's homes or another convenient location. A semi-structured topic guide (see Appendix A), developed from literature review, guided the interviews. The topic guide was not used prescriptively across interviews. Instead the discussion with each woman was different and allowed to evolve organically. The specific questions asked and probes used varied from woman to woman.. Women were asked about their socio-demographic characteristics; screening history; experiences of colposcopy and related procedures, including how they felt before, during and after the procedure(s); and whether or not they had had any physical after-effects (such as pain or bleeding). . Interviews lasted 30-70 minutes (median length 42 minutes) and were audio-recorded with the woman's consent. They were transcribed verbatim, checked for accuracy, and anonymised. Saturation of data was considered to have been reached after 23 interviews since no new themes or issues had arisen in the last three interviews (Francis et al., 2010). MO'C and another researcher independently reviewed and coded transcripts of the first two interviews, discussed these to reach consensus, and combined codes into initial themes. These codes were then applied to the remaining interviews, with code lists refined as analysis progressed.

Analysis

Interview transcripts were analysed thematically (Braun & Clarke, 2006). Analysis was ongoing and iterative, such that analysis of early interviews informed the content of future interviews. The Framework Approach was used to summarise and organise the data and identify emerging higher-order themes (Ritchie & Spencer, 1994). This involved the development of a matrix, with themes or subthemes comprising the columns, and participants the rows. The differing psychological after-effects experienced by the women were explored within the framework. Groups of women with differing experiences of distress were

examined and factors (i.e. themes) that influenced these experiences were identified. Analysis involved close inspection of the data in the Framework by theme and by participant. In addition, socio-demographic factors (age, children, education and marital status) and clinical factors (initial histology result and whether women had treatment or not) were examined to ascertain whether or not they were useful in explaining women's experiences of distress. Illustrative quotes are included throughout the results section. The term "colposcopy" has been used to encompass colposcopy with or without related procedures (such as biopsies or loop excision).

Results

Demographic characteristics of the sample

The socio-demographic characteristics of the participants and their colposcopy and histology results and management received at the initial colposcopy are shown in Table 1. Two women were pregnant at the time of their interviews. The time elapsed since each woman's most recent colposcopy varied; for some it was ≥ 12 months, for others only a few months.

Overall psychological response to colposcopy

A key construct that emerged as important in understanding women's experiences of distress was duration. Women's descriptions of short- and long-term distress following colposcopy were very distinct and our analysis is presented separately for these two types of distress. In each case, we sought explanations for distress within women's accounts, and also explored possible demographic patterning of experience.

Short-term distress was experienced immediately after the colposcopy appointment (i.e. while still at the clinic) and in the days that followed. Women described being upset while still at the clinic or when they got home. They often described crying or being in 'shock' after the procedure, and their distress related mainly to the physical experience of the colposcopy and the immediate impact in the days that followed.

Long-term distress was distress that was present for the first time after a considerable amount of time, or persisted for a considerable period (i.e. several weeks, months or in some cases years), after the colposcopy, and was related to concerns about issues like fertility, cervical cancer and having sex. For many women, these concerns dissipated over time; but for others, they persisted and remained for months after the colposcopy. Concerns sometimes fluctuated

over time and/or were exacerbated by specific events, for example, waiting for the results of follow-up cytology tests or an upcoming colposcopy clinic appointment.

Our sample included women who had experienced: no distress; only short-term distress; only long-term distress; or both long- and short-term distress. Below, we describe themes that were associated with experiencing or not experiencing short- and long-term distress (Table 2). Distinct differences between the factors associated with short- and long-term distress emerged.

Short-term distress

Three themes relating to short-term distress were identified: (1) Level of preparation for the procedure; (2) Experience of the procedure; and (3) Attending the colposcopy clinic alone vs. with someone.

Level of preparation for the procedure

Short-term distress was associated with not feeling adequately prepared for how the colposcopy would feel or ‘what it entailed’ (N163). A few women became upset following the procedure as they had been taken ‘by surprise’ by things that happened during it. For example, one woman described how being told during the appointment that she would be having a biopsy taken led her to becoming upset:

I felt if I’d known that [would be having a biopsy taken] in advance I would have been more prepared whereas it kind of took me, it took me quite by surprise actually and I got quite upset because I hadn’t been expecting it. (N099)

Some women felt that had they known that it would be painful, they could have ‘prepared ..mentally for it’ (N163), but for others, the fact that the pain was ‘over in a split second’ (N148) meant that it did not cause distress even when it was unexpected.

Women who felt adequately prepared were less likely to find the colposcopy distressing. Those who lacked medical knowledge were pleased that the procedure was explained to them ‘at an idiot level, which is what I need’ (N194). Having questions answered in advance provided reassurance and made the experience more positive.

Experience of the procedure

Women who described short-term distress often had negative experiences of the procedure and were frequently upset during the procedure itself. This was sometimes as a result of what a doctor or nurse told them during the procedure:

I was a bit upset about it, well the doctor was having a look and he could see the cells and he was like, “Ok, I, you know, do you want me to perform the procedure [LLETZ] now, you know, as opposed to...” you know, he said, “I can perform it now or else you can come back and have it done at a later date. (N270)

For other women, the position they were in on the colposcopy chair was distressing.

Some women described the procedure as particularly (and unexpectedly) painful, in a way that was shocking or ‘horrific’ and this contributed to short-term distress. This was particularly true for women who reported they had received treatment for their abnormal cytology: ‘It was worse than having a baby for me’ (N105). For a few women, the unexpected pain caused panic: ‘I started to hyperventilate and I couldn’t handle it’ (N223).

These women subsequently became embarrassed about having panicked and wanted to get away from the clinic as soon as possible.

Women who did not experience short-term distress generally described the colposcopy as 'no big deal' (P094). They often felt their physical experience of the procedure was not as bad as they had anticipated. Adequate preparation (described above) contributed to a less distressing experience during the appointment.

Attending the clinic alone vs. with someone

Attending the clinic with someone else (usually a partner or husband) seemed to protect women from short-term distress: 'I went on my own for the smears but for the colposcopy my husband came. Just because one of my friends had one and she thought it was awful' (N173). Some felt that if they had not had someone with them, it would have been upsetting for them.

Most women who experienced short-term distress had attended the clinic alone. Some of these women explained that while they would have liked to have someone with them, they did not tell their loved ones about their procedure or ask to be accompanied to the clinic, as they did not want them to worry. For example, one woman who had attended her first colposcopy alone and was distressed immediately after it wished that she had had someone with her. She brought her mother along for her second colposcopy and had a better experience:

A few women attended their clinic appointments alone but did not experience distress. For example, one woman went on her own because her husband would have had to take time off work. She felt there was no need for him to come to the clinic with her:

These women had often discussed their upcoming colposcopy appointments with friends or family which enabled them to feel they could attend their clinic appointments alone. This may also have helped to prepare them better for their colposcopy and decrease the likelihood of short-term distress afterwards; none reported feeling unprepared for the procedure.

Long-term distress

Three main factors that were associated with long-term post-colposcopy distress were identified: (1) Reproductive plans; (2) Impact of physical after-effects; and (3) On-going clinic surveillance.

Reproductive plans

Concern about fertility was an important element of long-term distress and was typically experienced by women who had not yet started or completed their families. These women were often in their 30s. Their reproductive concerns were sometimes bound up with fears about developing cervical cancer:

If I got cervical cancer I would imagine that you wouldn't be able to have children or it would be very hard. I didn't know, it was just so important to me to have another child, that to have that taken away, to have any obstacle in the way of that was very stressful.

(N053)

Others were worried about the impact that the treatment they had received might have on their future fertility and birth outcomes. A few women found information on the Internet relating to treatment for CIN and preterm delivery risk. Some of the women's fertility concerns were exacerbated by their age and their perception of the time they had left to conceive: one 35 year-old woman was worried about her 'reproductive time' for her husband following her colposcopy.

Where women had completed their families, or did not intend to have (more) children, these fears were not present, and this reduced the likelihood of long-term distress.

Impact of physical after effects

Some women experienced physical after-effects of their colposcopy that negatively impacted on them and contributed to on-going distress following their colposcopy. Pain and bleeding impacted on some women's sex lives. Some women delayed having sex because they had

experienced pain following their colposcopies. These women were fearful of having sex in case it hurt them or they bled afterwards:

And I couldn't like, with [husband] for like, ages and I mean weeks and weeks because of that.. it just wasn't nice, you know. And like [husband] is great, like he knew, he understood. But I just, I was just afraid, literally I was afraid. I was absolutely terrified to. I was afraid of my life in case it [having sex] would hurt me more or I'd start bleeding. (N014)

One woman who had bleeding following her colposcopy and subsequently had heavy periods for a few months had worried that she was going through an early menopause.

Most women who did not have physical after-effects which impacted on them did not experience long-term distress.

On-going clinic surveillance

Most women who described long-term distress were still attending the clinic for follow-up. Some women who were awaiting cytology test results were anxious that they would receive a normal result. One woman described a 'bitter sweet feeling' she had because although her most recent cytology test result was normal, she worried that her next result could be abnormal. The ongoing surveillance meant that worries were not resolved and this contributed to long-term distress. One woman thought she would feel 'a lot better' once she no longer had to go back to the clinic:

It is a little bit of a relief if they say okay, I don't have to go back [to the clinic], it feels like, okay, well maybe it's [abnormal cytology] not developing into something more serious. So I think I would feel a lot better about that. (N163)

Women who had been discharged from the clinic were less likely to have anxiety relating to cytology results: the fact that they were no longer under intensive surveillance at the clinic and were returned to their regular doctor for screening also resolved worries for some women. As a result, these women were at a decreased risk of having long-term distress. Women often expressed relief and happiness upon hearing they would be discharged to routine screening.

Discussion

This study explored women's differing experiences of psychological distress post-colposcopy and sought to understand the factors associated with, or protective against, it. We have – for the first time – characterised two different forms of post-colposcopy distress: short-term distress which is experienced immediately after the colposcopy and in the days following and long-term distress which can persist for a considerable period of time. We have also provided unique insight into factors related to short and long-term distress; of note is the fact that the drivers (and protective factors) differed for the two forms of distress.

Women who felt unprepared for the procedure, in terms of what it would entail and how it would feel, often experienced short-term distress, while those who felt prepared often did not. Research in other contexts demonstrates that patients who are facing threatening medical procedures require detailed preparatory information to enable them to cope (Suls & Wan, 1989). Moreover, the provision of both sensory (i.e. how the procedure will feel) and procedural (i.e. what exactly the procedure will involve) information, results in reduced anxiety, pain and distress, and faster recovery with fewer complications (Suls & Wan, 1989; Hathaway, 1986). These findings suggest that, in order to help better prepare women for colposcopy and minimise distress afterwards, screening programmes and colposcopy clinics should consider modifying existing written patient information to incorporate details of the actual procedure, particularly in relation to the sensory aspects.

Social support has been associated with better coping with upsetting events and psychological adjustment (Mattson et al., 2011). Specifically, a lack of social support, and dissatisfaction with support, have been found to predict post-colposcopy distress in quantitative studies (Sharp et al., 2013; Tiersma et al., 2005). Our findings extend these by showing that women who lacked social support while attending the colposcopy clinic (i.e. they attended alone)

often had short-term distress, whereas those who were accompanied generally did not. However, not all women who were unaccompanied experienced short-term distress. Those who did not described talking about their colposcopy appointment with friends or family prior to attending; this may have prepared them better for their colposcopy and empowered them to attend the clinic alone. These findings suggest that encouraging women to discuss their upcoming colposcopy appointment with others, particularly if they are attending their appointment alone, and/or to bring someone with them to the appointment if they can, could help protect against short-term distress afterwards.

Although a few quantitative studies have investigated psychological wellbeing a year or more post-colposcopy (Hellsten et al., 2008; Sharp et al., 2011; Kitchener et al., 2004), substantial gaps remain in the evidence-base surrounding long-term post-colposcopy distress, particularly as regards determinants. In this study worry about future fertility was an important influence on whether women experienced long-term distress; women who had completed their families or did not intend to have children less often had long-term distress. Fertility worries among women who receive an abnormal cervical cytology result are well documented (Somerset & Peters, 1998; Quilliam, 1990; Gray et al., 2006) but, as far as we are aware, this is the first time a relationship between fertility worries and post-colposcopy distress has been reported. Colposcopy clinics could seek to identify and “counsel” women who have not yet started or completed their families. Emerging evidence that treatment of CIN is associated with only a very small increased risk of preterm delivery (Castanon et al., 2012) could be communicated to women to reassure them, along with reassurance that colposcopy alone does not have an impact on time to conceive (Spracklen et al., 2013).

Referral for a colposcopy examination is often just the start of a lengthy follow-up process; over an extended period of time; many women will require biopsies, excisional treatment and

follow-up by further colposcopies or cytology tests, all within the colposcopy clinic setting. We found that women undergoing ongoing monitoring in the clinic often reported long-term distress and this was less frequent in women who had been discharged. In addition, we also found that in relation to long-term distress, worries fluctuated over time and distress was sometimes exacerbated by specific events, such as an upcoming colposcopy clinic appointment or, waiting for cytology or colposcopy results. Such events are known to negatively impact on women's psychological wellbeing (Bosgraaf et al., 2013). The development of safe strategies to more rapidly discharge at least some women from clinic follow-up could help prevent or alleviate long-term distress. Discharge from ongoing surveillance provides part of the rationale for human papillomavirus (HPV) testing in the post-treatment setting which has been introduced in some screening programmes (National Health Service [NHS], 2013; CervicalCheck, 2012; National Services Division [NHS Scottish Cervical Screening Programme], 2012).. Whether this strategy proves to be reassuring and alleviate long-term distress remains to be established. In the meantime, for women who need to remain under surveillance, clinics could do more to identify those with long-term distress and provide on-going support and reassurance.

Strengths and limitations

To our knowledge, this is the first study to focus specifically on women's differing experiences of post-colposcopy distress and factors that are associated with, and protective against, this. Although recruited from just two clinics, participants' were diverse in terms of their socio-demographic characteristics and colposcopy and histology results. The creditability of the process, including the sampling, is evidenced in the diverse opinions and responses expressed in the interviews, suggesting the themes identified will be transferrable to other settings. A few women were interviewed several months (and in some cases more than 12 months), following their most recent clinic visit and it is possible that any immediate

post-procedure negative psychological impact had dissipated by the time of the interview, and hence was unreported. In addition, as in other qualitative studies, the relative weight or importance of themes and subthemes is not clear.

Implications for Practice and/or Policy

Our findings could be the first step in developing a tool to help clinicians and other medical professionals involved in the care of women with abnormal cervical cytology to better identify those that are at greater risk of experiencing psychological distress following colposcopy. However, clear and standardised definitions of short-term and long-term distress need to be established. In addition, there is a prerequisite for consensus on a standardised approach to assess long- and short-term distress following colposcopy. Our study also provided unique insight into the factors that seem to protect some women against post-colposcopy distress. Further research surrounding these protective factors may be required but they could be useful in informing the development of interventions to alleviate distress following colposcopy. An intervention could, for example, be aimed at better preparing women for what the procedure will involve and how it will feel. In terms of addressing more long-term distress, a psycho-educational intervention that targets women with fertility worries might be beneficial.

Conclusions

This qualitative study reveals that women have differing experiences of distress following colposcopy for abnormal cervical cytology and provides rich data on the factors associated with, and which may protect against, short- and long-term distress post-colposcopy. The results may inform the development of strategies or interventions aimed at alleviating distress following colposcopy.

Acknowledgements

We thank the clinicians and staff at the two colposcopy clinics. We are grateful to the women who participated in the study.

Conflict of Interest

None

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Table 1
Demographics of participants interviewed

Characteristic	Status	Number
Age	Less than 30 years	1
	30-39 years	11
	40-49 years	6
	50-59 years	4
	60 and older	1
Marital status	Married/cohabiting	16
	Single (in a relationship)	4
	Single (not in a relationship)	2
	Widowed	1
Education level	Third level-higher	11
	Third level-lower	3
	Secondary/leaving cert	5
	Junior cert/intermediate cert	4
Children	No	9
	Yes	14
Initial colposcopy result	Normal TZ*	4
	Abnormal TZ	16
	Unsatisfactory	2
	Missing	1
Initial histology result	No CIN or CIN 1	14
	CIN 2/3	4
	Missing/inadequate or unsatisfactory	5
Initial management received	Colposcopy only	3
	Coposcopy plus punch biopsies	18
	Colposcopy plus LLETZ*†	2

Abbreviations: TZ, transformation zone

*A further 4 women disclosed they had received treatment when interviewed

†LLETZ; Large Loop Excision of the Transformation Zone

Table 2
Summary of themes

	Characteristics of distress	Factors increasing the risk	Factors decreasing the risk
Short-term distress	Immediate distress following the procedure, often relating to the physical experience	Feeling unprepared for the procedure Negative experience of the procedure Attending the clinic alone	Feeling well-prepared for procedure Finding the procedure better than expected Being accompanied to the clinic
Long-term distress	For some, these concerns dissipated over time; for others they persisted. Concern about long-term issues including fertility, cancer and sexual relationships	Intending to have (more) children in the future Having physical after-effects that impacted on them Being under continued clinic surveillance	Not intending to have (more) children Not having physical after-effects that impacted on them Having been discharged from the clinic