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Feature article

When Women Talk and Doctors Don’t Believe Them

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Communication and mutual respect between health care professionals and the people they provide care for is an important part of the healing process. Unfortunately, many factors can influence the effectiveness of patient-doctor interactions. This article discusses the findings from a qualitative study about women’s experiences of contraceptive surgery, commonly called ‘tubal ligation’. It particularly focuses on how doctors responded when participants raised concerns about a range of issues that could be broadly defined as ‘women’s problems’. The findings highlight the need for doctors to listen to women, taking seriously their health concerns and the knowledge they have of their own bodies. They also raise issues about the role gender and power play in medical encounters.

The study, Surgical Sterilisation: Medical Power, Women’s Knowledge, was conducted in 1994 as research for an unfunded Doctorate. It investigated the experiences that 159 women from across Australia had of tubal ligation. The women responded to a media base call for participants, mainly from The Australian (Dow 1994) but also articles and interviews in other media sources including the Geelong Advertiser, Queenscliff Army Newsletter, The Australian Nursing Journal, Deakin News and radio stations 5AD and 5AN. These reported how a review of the medical and scientific literature (Turney, 1993) discovered an absence of women’s voices and experiences in medical reports about the safety and efficacy of tubal ligation.

The study collected data through a semi-structured questionnaire, letters and in-depth interviews where women recounted their experiences. The questionnaire sought to report both the positive and negative aspects of each participant’s experience of surgical sterilisation while the interviews explored the negative experience in more depth. In both the questionnaire and interviews, information was sought concerning reproductive health, menstruation, pre-menstrual tension and menopause including any changes since tubal ligation, the participant’s interpretation of these changes, whether they reported changes to their doctor and the doctor’s response. How their doctor responded to these women’s reports of menstrual and mid-cycle pain and irregular bleeding patterns is the focus of this article.

‘Old Wives’ Tales’

Many women reported that they did not bother to tell their doctor about their problems because they anticipated an adverse or a non-helpful response. Of those who did talk to their doctor, especially when they related their side effects to tubal ligation, the overwhelming majority were dissatisfied with the responses they received. Overall women appeared to be most unhappy about not being believed in relation to their side effects; being told that their symptoms were all in their minds; or that the problems they experienced were individual and idiosyncratic.

Many women were concerned that when they reported abnormal or different menstrual patterns that caused pain, discomfort or inconvenience, their doctor did not believe there was a problem. Disillusioned by their doctors’ lack of understanding of their symptoms, they were often told that side effects as a result of their surgery were non-existent – ‘old wives tales’. This is in spite a plethora of side-effects for tubal ligation reported in the scientific literature which included; changed menstrual patterns, period and mid-cycle pain, perimenopausal
symptoms and increased risk of hysterectomy. (Birdsall et al 1994; Goldhaber et al 1993; Peterson et al 1996; Vivanathan & Wyshak 2000).

The consequences of doctors not accepting the knowledge women had of their own bodies as ‘real’ sometimes meant that symptoms became very severe before they were attended to, as in the case of undiagnosed ectopic pregnancy (a pregnancy occurring outside the uterus usually in the fallopian tubes). But, perhaps more often, it caused women unnecessary anxiety about the cause of their menstrual problems.

“I feel that not enough is known. My doctors just reassure me that my health is good. My doctors see me as healthy and strong; that I haven't any real worries; I am okay. [I feel] always uneasy – I worry something will be wrong and it won't be found until it is too late”.

In other contexts – such as pregnancy and breast health – women are actively encouraged to become aware of what is ‘normal’ for their body, to self-monitor and to report problems, symptoms and changes to their doctor. But the findings suggest that when women do so in the context of reporting menstrual problems, which are often distressful for them, they are simply dismissed out of hand. Women in turn consider practitioners who dismiss their concerns to be ‘uninformed and uninterested’ in them and their problems.

‘It’s All In Your Mind’

Closely associated with doctors not believing their reports of physical symptoms such as pain or heavy bleeding, women reported that they were treated as if the doctors thought their symptoms were ‘all in their minds’. Participants felt that doctors dismissed them as neurotic, sometimes even referring them for psychiatric or psychological treatment as a remedy for their physical symptoms. The gender–based nature of such lack of understanding is evident in what participants said, although a few women reported that female doctors are no more helpful. Women in traditional roles felt particularly disempowered in such clinical encounters.

“I’ve been made to feel like I am a neurotic housewife. I’ve come home in tears. ... Even women doctors – you would expect women doctors to be more understanding. I have had some – the only way to put it is – bitches. They are all trained in the same sort of manner. You have to put people into little boxes and, as a housewife, you do have more time on your hands so maybe something that somebody else will brush aside you don't because you have got more time on your hands”.

Although very unhappy about being stereotyped in this way, this woman did concede to the imposed categorisation. This illustrates the power relationship inherent in the clinical encounter that can easily undermine women’s self-confidence. Other women reported that some doctors openly “scoffed at”, “laughed at” and “ridiculed” their concerns. For example, one reported being treated with “humorous contempt” and another, when suggesting a direct link between her tubal ligation and hormonal problems, was told “that’s nonsense”. Other participants described their doctors as “uncaring”, “uninterested”, “indifferent” and generally dismissive of their problems, which were made to seem trivial. Individual women also reported feeling that they were seen as “a nuisance and a hypochondriac”, “a silly neurotic woman” and were “wasting the doctor’s time”.

Problems as Individual and Idiosyncratic

Along with the charge that a woman’s problems are imaginary, is the tendency to individualise the problem. This approach implies that she is the only one who has ever reported any side effects of the surgery and is therefore different and lacking resilience. This is how one woman describes telling her doctor about the mid-cycle pain she experienced:
“I was finally referred back to [the doctor] after one year, who treated me like I was some sort of alien, claiming that he had never heard of any complaints from his sterilisation procedure, and that perhaps I was imagining the pain. He claimed that I could not possibly feel the clamps, that hundreds and hundreds of women had undergone this procedure and I was the only one who had ever complained about the pain on my tubes”.

This response contradicts the evidence in the literature suggesting that misapplication of the occlusive device or clip can cause such pain (Birdsall et al 1994). Sometimes the doctor responded by locating the problem within the idiosyncrasies of the woman's own body shape or size or by pointing out that tubal ligation was her own choice, thus transferring both causality and blame to the woman rather than to the surgical intervention. When one woman experienced problems at surgery she was told by the surgeon that “the cut blood vessel was unusual and normally is not located where he cuts” hence laying the blame on her variability in body shape.

In another case the doctor suggested that the problems the woman encountered at surgery were “due to her small stature”. Although women are anatomically different, making the procedure difficult to perform with precision in some women (Gorton 1994) to lay the blame for errors with women’s anatomical difference is completely overlooking the skill of the surgeon who should be adept at applying the correct techniques to a variety of women. Other women reported on doctor’s explanations for heavy menstrual bleeding in ways that located the problem with the fault of the woman’s own organs, for example, one doctor told a woman that her “ovaries are overactive”. Another was told that she should have known about these side effects and as it was her choice to have the operation, she should “put up with the consequences”.

The Silent Treatment

Participants commonly reported that some doctors avoided giving any explanation at all for their symptoms. That is, the doctor actually ignores what a woman has said and simply responds with silence.

“I’ve told the doctors and they haven't even bothered to really answer. It's just like I haven't said anything, tick the next thing on their piece of paper and ask the next question.”

These evasive non-responses suggest that women’s problems are dismissed as non-problems, as non-existent, and therefore unworthy of comment. Letting women talk about what are essentially private, personal and sometimes embarrassing matters and then using silence or non-responses is a powerful strategy for undermining a woman’s position in the clinical setting. It leaves women angry, demeaned and feeling let down, particularly by male doctors who “don’t understand, relate to, or cope well with women’s symptoms”.

“I just find that talking to a male doctor you quite often come up against a brick wall because they don't know how you're feeling, and it's enough to go to a male doctor and discuss the problems that you’re having I find. It’s hard enough to do that”.

It seems though, that a doctors’ lack of understanding of menstrual patterns and problems does not prevent them from making overt claims to be more knowledgeable than women themselves, refuting women’s self-knowledge about their own bodies

“Male doctors are sceptical of 'heavy' bleeds. [I was] told by one that women only lose a few teaspoonfuls of blood per day. [I felt] misunderstood – as though I was incompetent of judging my own menstrual loss. [I felt] helpless to improve matters.”
This is particularly the case when doctors tell women that their ‘perceived’ heavy bleeding is due to them forgetting what their periods were like before going onto the pill.

“I complained [to the doctor] but he said [tubal ligation] wasn't the cause necessarily. He said I wouldn't know what my periods used to be like because I took the pill for such a long time.”

Although doctors and researchers frequently resort to this as ‘conventional wisdom’ women generally found this explanation insufficient and totally ignorant of their reality and experience.

**Trivialising and Normalising Women’s Problems**

Another key theme that emerged was the trivialising nature of the treatment doctors recommended for menstrual problems. Women reported that the advice given to alleviate ongoing menstrual or mid-cycle pain often included things like: “take two Aspro and forget about it”; “take a Panadol and go to bed”; and “wait and it will fix itself”. This approach suggests that such problems are seen as simply side effects of being a woman rather than as medical problems that require attention (Pollack 1989). It was also frequently linked to women’s traditional role when they were told things like “you should expect to feel tired and depressed with children and no help”.

A common medical response to women's reporting of menstrual problems was that their altered bleeding pattern was normal, a natural part of being a woman and that they “must expect to have erratic periods”. It was also, often inappropriately, linked with ageing. Women were told that menstrual irregularity was normal for their “time of life,” that their period pattern change was due to “early menopause,” and that “periods were meant to be painful” and, more generally, women should expect that pain and excessive bleeding were normal. Usually these women were advised to accept their pain and discomfort and get on with their lives.

“The doctor absolutely laughed at me and … said I had a fear of getting old and when was I going to accept that I was getting old”.

Another woman said that her doctor made her “feel like a whining old cow” with nothing better to occupy herself – “after all it happens to all women, it is our due, we are meant to suffer, etc, etc”. Other comments from participants included “[being treated] like a woman - treated like I am of no consequence” and “[I felt] insulted – I wanted help and he was fobbing me off”. These women went on to describe these doctors as “ignorant,” “unemotional” and “more interested in processing women” than meeting individual needs.

Women’s disempowerment in the clinical encounter leads them to become sceptical about doctors’ knowledge of women’s problems generally and very critical of the treatment they received. Participants reported that they “never expected to get a complete answer from a doctor” and basically felt that “women don’t really count”. Most of all, they felt that doctors, while acting like “gods – the all knowing,” typically “trivialised their concerns and issues” and that women were seen as “irrational and to be kept ignorant”.

**Strategies for Improving the Doctor-Patient Consultation**

A recent study (Warner et al 2001) claims that menstrual problems are one of the most common reasons for secondary referral for women and even where there was “no underlying serious disease or risk to physical health, periods can cause major distress and disability”. The study also found that many women were reticent about “discussing menstrual problems”, were anxious “about investigations” and do not believe “that medical help will be forthcoming”.

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However, something can be learnt from the very small number of women in the tubal ligation study who reported being satisfied with at least one of the doctors they consulted. Their satisfaction was expressed in terms of the doctor’s empathy, understanding and acknowledgement of their problems, particularly those that accepted the reported problems to be side effects of tubal ligation. These women found it reassuring to know that someone believed them, understood that there was a problem and recognised that it occurred in at least some women. Women respected doctors who talked sensibly to them in an egalitarian manner and who supported and helped them. They were much more likely to see these doctors as expert in dealing with and treating women’s problems.

Pre-warned is Pre-armed

In the broader study, except for the two cases of sterilisation failure, no woman in the study expressed the desire to register a formal complaint about their doctor. In fact, just over half (55%), even with hindsight, said that they would still go ahead with tubal ligation despite their sometimes-negative experience (34% said that they would not repeat the surgery because of side effects and 11% were not sure).

Participants’ overwhelming reason for agreeing to be part of the study was to ensure that their experiences would be included in the information provided to other women making a decision about the procedure. The findings presented here raise questions about how women can make an informed decision about having a tubal ligation when the information given to them is inaccurate or inadequate. If reports of side effects are not believed and not recorded, they will not be included in the body of knowledge about the procedure.

The participants greatest concerns were that women be given prior knowledge of side effects to be better able to recognise and understand their symptoms, and come to terms with their altered bodies. This information would also assist women to seek appropriate treatment earlier and avoid the traumas associated with being treated as neurotic. Given the prevalence of menstruation-related problems in primary care, the development of a “formalised clinical assessment [procedure needs to be implemented] in routine use” (Warner et al 2001).

Prompt reporting of adverse effects would be especially advantageous in the case of severe pain and, for example, in the event of a life threatening ectopic pregnancy where early recognition of symptoms would lead to speedy and appropriate treatment. The severe pain associated with ectopic pregnancy and other serious conditions in sterilised women is frequently misdiagnosed as appendicitis (Nguyen & Wilkinson, 1993). Most importantly, if women were informed of the potential side effects, making them readily identifiable, then perhaps more research could lead to ways of minimising and controlling unwanted menstrual problems resulting from the procedure.

In conclusion, it is essential that there be a systematic recording of reported adverse effects and for doctors to listen to womens’ perceptions of tubal ligation as the possible cause of their gynaecological problems rather than disregarding the symptoms and treating the woman as neurotic. If quality of care is to be seriously addressed and consumers given accurate information on which to base their health care choices then evidence of patients’ experiences of procedures needs to be gathered. To do this, it is essential that the power and gender issues present in doctor-patient consultation be addressed.

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References


