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The role of primary care in the diagnosis and management of menorrhagia: a qualitative study of women with menorrhagia

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There is increasing emphasis on including patients in decision making about treatment. In order to do this, they need to have access to appropriate information about treatment options. The study reported here reports initial work carried out in the development of a decision analysis tool to assist women about treatment for menorrhagia. Women referred to secondary care with a diagnosis of heavy menstrual bleeding were interviewed. Our study shows that women had limited and often inaccurate knowledge of most treatment options. They expressed feelings of diagnostic uncertainty, the need for a 'label' for their symptoms and a perception of the failure of the general practitioner (GP) to provide this. The women in our study referred to secondary care with a diagnosis of menorrhagia do not seem to have had their concerns about their menstrual symptoms addressed prior to the referral. In addition, the women in this study do not feel that their GP has communicated a diagnosis to them. Women must be able to feel that they have been diagnosed in order that treatment options can then be properly discussed, and a shared management decision reached. Reasons for the apparent lack of adherence to guidelines are discussed. There is a need for a decision aid for use in primary care to assist women and their doctors in the management of menorrhagia.

Key words: menorrhagia; patient information; treatment options

Introduction

Heavy menstrual bleeding or menorrhagia, defined as excessive menstrual loss of greater than 80 ml per period, is a common reason for a woman to consult her general practitioner (GP), with over 5% of women aged 30–49 consulting their GP each year in the UK (Coulter *et al*., 1995; Tudor Hart, 1997). Menstrual loss is self-reported and subjective, as it is impractical to measure it routinely, an 'unequivocal' diagnosis of menorrhagia is unlikely in either primary or secondary care. Many women are subsequently referred to gynaecologists which often results in surgical treatment (Coulter *et al*., 1991; Grant *et al*., 2000). Research looking at the association between reported heavy loss and objective measurement of heavy blood loss reports that fewer than half of the women referred to the gynaecologist have losses greater than 80 ml (Higham, 1999). In the great majority of these cases of menorrhagia there is no underlying pathology (Stirrat, 1999).

The aims of treatment for menorrhagia are to reduce menstrual flow, improve the quality of life and reduce the likelihood of iron deficiency anaemia (Effective Health Care, 1995). The Royal College of Obstetrics and Gynaecologists (RCOG) have produced guidelines that outline effective treatments of menorrhagia. These suggest that at least one option should be tried, for a minimum of three months, before referral for a gynaecological opinion (Royal College of Obstetricians and Gynaecologists, 1998). A recent study investigating

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the management of menorrhagia in primary care reported that of 885 women from 11 GPs, almost a quarter received no medical treatment (23%) and over a third received norethisterone (37%), described as ineffective by both the Effective Health Care Bulletin, and the RCOG (Grant *et al*., 2000).

Shared decision making has been widely accepted as the goal for effective clinical management, particularly in the treatment of menorrhagia, which has many equally effective treatments (Department of Health, 1996; Royal College of Obstetricians and Gynaecologists, 1998). For a patient to take part in decision making about treatments, he/she needs to know, or be given information about the various treatment options in order to make an informed choice (Coulter, 1997). Indeed a recent randomized trial of an information booklet for women with menorrhagia did show a positive impact on active decision making (Vuorma *et al*., 2003). The study reported here was undertaken as a prelude to a large randomized controlled trial of treatment information provision and decision analysis in menorrhagia (the MENTIP trial, Medical Research Council, funded study of the place of a decision aid in the management of menorrhagia, started 2003). The study was necessary because there is little previous literature looking specifically at what patients currently know about the treatment options for menorrhagia and the place of a decision aid in the management of menorrhagia.

The aim of this research was to examine women's knowledge and attitudes towards treatment for menorrhagia, to explore where they obtain their information from, and to determine how accurate (according to current best evidence) is this information. In particular, women's experience of primary care as a source of information about the management of menorrhagia was explored.

Methods

Sampling

Purposive (systematic, non-probabilistic) sampling was used to ensure that women of a variety of ages, socio-economic groups, and ethnic groups were sampled for the study. Fifteen women at the point of entry to secondary care, attending for their first gynaecology outpatient appointment for excessive menstrual loss (in the absence of identified significant medical pathology) were recruited to the study.

Contacting patients at the point of referral to secondary care was a pragmatic choice, based on the following theoretical assumption: The study aimed to answer questions about what women know, and understand, about treatment for menorrhagia from their experience in primary care. The assumption being made is that prior to being referred to a specialist, the women will have had some experience of the different treatments available in primary care.

Interviews

The patients were invited to attend for a semi-structured qualitative interview prior to their appointment with the gynaecologist. The interviews were conducted by the first author, and audiotaped, with the patient's consent. Each interview lasted between 30 minutes and one hour.

Data analysis

The typed transcripts of the audiotapes, in conjunction with the reflexive notes and the fieldwork diary, were analysed by constant comparison, using an interpretive stance most closely allied to that of Layder's 'adaptive theory' (Layder, 1998). The analysis was enhanced by the use of computer assisted data analysis, using Atlas Ti. The interviews were continued until category saturation was achieved. In this study, although the respondents were offered the opportunity to receive a copy of the research findings, only one actually asked for a copy, so member checking in this way was not possible. However throughout the interview the researcher's interpretations of what was being said was checked with the respondent.

Disconfirming cases, those that do not appear to follow the emerging explanatory theory, were actively sought through sampling of women and modification of the interview schedule, as well as through careful analysis of the data, and used to modify themes in order to increase validity and reliability. The first and second author coded separately then discussed the analysis, and agreed upon salient themes.

Results

Fifteen women, seven Caucasian, three Pakistani, two Black-African, one Black-Caribbean, one

East-African Asian and one mixed race, aged 21–49 (median 38 yr) of mixed socio-economic status and mixed educational background were interviewed.

In common with previous studies (Marshall, 1998), the women were more concerned about the *change* in their periods than about the *amount* of blood loss *per se*. They reported presenting to their GP for an explanation of their symptoms and a diagnosis, or a 'label', for their condition. The women did not consider that their GP was in a position to fulfil this need, and were looking to the specialist to answer their questions.

What the women knew about the treatment of menorrhagia

The women had limited, and sometimes inaccurate, knowledge of most treatment options, but they all were aware of hysterectomy as a potential treatment option. Respondents' attitudes varied between the women but the strongest attitudes and beliefs were regarding hysterectomy:

> … I'd have a hysterectomy, you know. I would. But do people say you still get period pains when you've had a hysterectomy? 'Cos Mary O'R (*friend*) had one, but they left her ovaries in, I think, so she says she still suffers with pains, even though she's had a hysterectomy.… (ID 11)

Some women reported not liking the possibility of surgery, but felt that it was inevitable:

> Well I've been thinking about it (*hysterectomy*) for twelve months really and obviously the reason I've been thinking about it for so long is that I didn't want to have it done…you know, I'm quite terrified about having it done really but I've been so poorly, you know, in the last few months that I've decided, you know, I thought that would be the best thing to do.… (ID 04)

Two women had been prescribed medication, but denied having tried any 'treatment' for their heavy menstrual bleeding:

Q: *Did you try any treatment at all over the last twelve years?*
A: No.… They've just been giving me tablets to like, slow my periods down … (ID 12)

It is not clear why these women did not consider taking tablets to be a 'treatment', but it is possible that some women may only see something done *to them* to be 'treatment', rather than something they can do for themselves such as taking tablets. Other women who had been prescribed hormonal treatments within primary care raised concerns about the use of such medication. Three women, discussing the combined oral contraceptive pill, were concerned about the side effects of taking hormone tablets, and one woman was concerned about the prospect of taking hormone tablets when the cause of her heavy bleeding had not been found:

> Its just I didn't understand why I was being put on hormones without being tested were my hormones wrong. You know, I might be completely wrong on that, but I felt as if, well, why give me a medication when is it that? … (ID 12)

Thus of all the possible treatment options available, the only one that all the respondents knew about was hysterectomy, a major surgical procedure. This might be linked to the high rates of hysterectomy undertaken in the UK for menorrhagia (Box 1).

Box 1 Treatment options for menorrhagia

MEDICAL TREATMENT OPTIONS

Non Hormonal:

Non Steroidal Anti-Inflammatory Drugs: e.g., Mefenamic acid, Ibuprofen
Anti-Fibrinolytics: e.g., Tranexamic acid

Hormonal:

Oral Cyclical Progestogens: e.g., Norethisterone
Combined Oral Contraceptive Pill
Androgens: e.g., Danazol
Intra-uterine Progestogens: e.g., Levonorgestrel Intra-uterine System (Mirena coil)

SURGICAL TREATMENT OPTIONS

Endometrial Ablation
Hysterectomy

Note: This is a list of possible treatments, and as such does not contain prescribing instructions.

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Where the women obtained their information

One of the aims of the study was to explore where women were getting their information from about treatment for menorrhagia. As might be predicted, the woman described a variety of sources of information. A couple of women described reading newspapers and magazines; one read about endometrial ablation in a newspaper, and one had read about the Mirena intrauterine device. Interestingly both of these women had queries about what they had read which they did not address with their GP. Most women described discussing their condition and treatment with their family, friends or colleagues.

Q: But you want to get that (*information about the Mirena coil*) from here (*Gynaecologist*), not your own GP?
A: Yeah.… I don't think they (*GPs*) know enough…. (ID 08)

Only three women mentioned the internet as a source of information, one woman said that she would like to use it, if she had access to a computer, another said that she would consider it, and another had used it, but only for information about her husbands' heart complaint. Other sources of information mentioned were family planning clinics and health food shops.

No one had seen any written information, or patient information leaflets, specifically relating to heavy menstrual bleeding and its treatment. None of the women reported having received a leaflet about their condition from the GP. Respondents felt that such leaflets may well be useful, except by one woman who admitted that she 'wouldn't want to be bothered' (ID 15), yet she had been 'bothered' to attend an outpatient appointment.

The biggest theme emerging from the data was the apparent failure by these women to consider the GP as a source of information on either the condition or its treatment. The reasons for this warranted further analysis, and are described below.

Why not from the GP?

The Royal College of Obstetricians and Gynaecologists considers menorrhagia should be primarily managed in primary care.

The reasons described by the women in this study for not seeking information on treatment options from the GP are divided into three main categories: (i) women not feeling that they have a diagnosis because they do not consider that the GP has the specialist knowledge to make the diagnosis; (ii) women not feeling able to bother the GP who is short of time, or being too embarrassed to trouble the GP; and (iii) women expressing dissatisfaction with their GP.

(i) *No diagnosis yet:* Women who do not consider their symptoms to have been diagnosed and a label applied will not feel in a position to discuss treatments with their GP. Some respondents implied that the GP was not in a position to make the diagnosis, even though they were 'diagnosed' as having menorrhagia in the GP's referral letter to the consultant.

Q: Have you ever been given a label for your period problems, a name or something?
A: No cos my doctor didn't know, more or less probably think I'll just find out today what's the cause or why…. (ID 07)

That the women were expecting their appointment with the gynaecologist to provide this explanation could be viewed as a failure of the general practice consultation. It must also have an impact on what the women knew and felt about possible treatments for menorrhagia.

> I just think that a gynaecologist probably has a lot more experience in that field and they'll see a lot more patients perhaps with similar problems, and know the sort treatments that have worked in one case that did not work for another patient…. (ID 09)

> And if they say 'Well, its age' and 'tough' that's fine. I can cope with that … (ID 12)

Q: Right. What about if your GP had said to you, 'well its age' and 'tough'?
A: Well I wouldn't have believed that cos how would she know without having taken a look?
Q: Right. So what way would you take a look?
A: I don't know what they do, just scan, look…. (ID 12)

> I think they are GPs, as the title implies, and that they're not specialists in every field, and I think it's perhaps better that they refer people on to the specialists. (ID 09)

More disturbingly perhaps, some women considered their GPs had not bothered to try to make a diagnosis and were 'fobbing them off' (ID 13 & 15) with different treatments.

> … You know, because of my initial experience with going to the doctor's and 'Try this and try that.' And not really trying to find out what's really wrong with you. You know, they didn't have the time like, 'Oh, that's Mrs (…) coming in with a back ache.'… (ID 13)

> *They say* … 'Well, what do you want to do, we can stop your periods if that's what you want, we can give you the injection and that will stop your periods for three months. Or we can put you on the pill.' And that's just really like, you know, its just always upset me, cos I thought, I'm not asking you to stop me periods, I'm just asking you to find out why I'm suffering like this.…Cos its just like 'okay, well have the pill'. You know, 'Run along'…. (ID 14)

> Well, the thing is, sometimes they are rushing and you've got to say what you want, you know, and then get out. And when maybe you want.…I just don't bother, in case I get fobbed off or something like that. So I just don't bother…. (ID 15)

This data demonstrates that these women felt that their GPs did not have the necessary expertise, or did not appear to be interested, to identify the cause of their symptoms. The respondents emphasise that their condition, menorrhagia, is similar to other problems in primary care which GPs may find difficult to manage.

(ii) *Not bothering the GP:* several women felt that the GPs were too busy to discuss treatments, or that a busy surgery wasn't the right place for such a discussion:

> It's just not the right place, it is not, I've always got children with me anyway, so you know its hard to talk, so…. (ID 08)

> I think it's just the system, I think it's just the time. It's much easier to refer us in five minutes, say 'I'm going to refer you to somebody' than talk to you about what other things you can take…. (ID 08)

> Mm. No. I think that's what the real problem is, because you don't have enough time with the doctor. You know, you know you go there and within five minutes you're out. You know, he just prescribes you quickly and out you go. So … I think that's also one of the reasons why you don't tend to confide in telling what's your problem, you think you're wasting his time…. (ID 13)

Some women reported that they were embarrassed to talk about periods, particularly if their GP was male. One woman said she was reluctant to talk about periods in general, and had brought her mother to the consultation with the gynaecologist because of this reluctance to speak. Other women said they found it easier to talk to a female GP as they 'understand the symptoms', but the majority of the interviewees did not feel that the gender of the GP was an issue, 'particularly after having children' (ID 9). Other women also felt that they should not be bothering the GP with what was essentially part of a 'woman's lot', yet they were prepared to subject themselves to referral to secondary care.

> Yeah. She's gotta have periods, she's gotta bear children, she's gotta cook, she's gotta clean (laughter). Look after the family. That sort of thing, you know…. (ID 13)

These women felt that they could not discuss their menstrual problems in any depth with their GP because there wasn't enough time in surgery, or they were too embarrassed to bring the subject up, or the subject was not a 'medical' problem; yet they were happy to be referred to hospital to discuss them.

(iii) *Dissatisfied with their GP:* four women suggested that they didn't discuss things with their GP because they were 'unhappy with their GP'. We have already described how a few women appear to feel 'fobbed off' by their GPs, another woman told how her GP did not listen to her, and had suggested to her that she could always change her GP. One woman had resorted to just this when her GP refused to do a blood test at her request to

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see if she was menopausal, and another again felt that her GP did not listen to her:

> He really doesn't, and I've been with him a long time and he doesn't listen to me. Cos I've had the complaint for twelve years and I'm still suffering now, so obviously summat's wrong somewhere…. (ID 11)

This was the most important and significant theme, to emerge from this study: the women's feelings of diagnostic uncertainty, the lack of an explanation and need for a 'label' for symptoms, and, most significantly, the women's perception that it is not the role of the GP to provide this.

Discussion

The data in this study represent the views of a heterogenous group of women, all of whom had been referred by their GP, to the gynaecologist, with excessive menstrual loss in the absence of already identified significant medical pathology; in other words, a diagnosis of menorrhagia. No conclusions can be drawn about those women who do not present to their GP in the first place, which the literature suggests may be a sizeable proportion of women with menorrhagia (Chapple, 1999; Shapley *et al*., 2000), or about those women who are successfully managed in primary care, without recourse to referral to secondary care. Obviously the women in the study represent a select group of women, however, we shall see that some of the emergent themes from this data, particularly in reference to the women's perception of the role of the GP, have important implications for primary care.

One of the main aims of this study was to determine women's knowledge of and attitudes towards the various different treatment options for menorrhagia. Sufficient knowledge would be vital in order to fully participate in shared decision making about the management of their menstrual symptoms. The data show that a proportion of women referred from primary care reported not receiving enough information about treatment options but also insufficient information about the causes and meanings of their symptoms.

The data show that the only treatment that all the women were aware of was hysterectomy. Their knowledge regarding other treatment options was limited and often misleading. The information that these women did have on treatment options was lay information obtained from family, friends and magazines articles, not from their GP, nor any medical patient information leaflets. The issue of what was considered to be a 'treatment' by these women was interesting, as treatments suggested by the management guidelines (Royal College of Obstetricians and Gynaecologists, 1998) such as 'watchful waiting' or the combined oral contraceptive pill, were not considered to be 'treatment' by these women. This may result in entirely clinically correct treatment leading to dissatisfaction in some women.

The literature has suggested that many hysterectomies are performed in this country with no underlying organic pathology, and that women have high expectations of surgery compared with their expectations of other treatments (Marchant-Haycox *et al*., 1998; Stirrat, 1999). This data would suggest that women have high expectations of surgery in the *absence* of adequate knowledge of other treatment options. They are relying on secondary care to provide both diagnosis and management, and previous studies have found that once a woman is referred to a gynaecologist, the likelihood of surgery can be as high as 60%, even in the absence of underlying pathology (Coulter *et al*., 1991; Grant *et al*., 2000). The reasons given for not considering this information to be a part of the GP's role included: not feeling the GP had the specialist knowledge to make the diagnosis; not feeling able to broach the subject with the GP for reasons of lack of time or embarrassment and feeling that their GP simply did not listen to them. It is plain from the guidelines issued by the RCOG on the management of menorrhagia (1998) that diagnosis and initial medical management of menorrhagia is firmly placed in primary care and is the role of the GP. That this is not perceived to be the case is either a failure of the guidelines, or a failure of primary care itself. There is evidence that guidelines *imposed* on primary care are not successful (Little and Williamson, 1996). There may well be a place for guidelines developed in partnership with primary care, thereby engendering a feeling of 'ownership' of the guidelines, perhaps alongside improved training, both in terms of clinical management of menorrhagia, and communication of diagnoses that fit in with patient expectations, values and preferences (Kennedy *et al*., 2002). Other reasons for this

perceived failure may be due to the constraints in primary care such as short consultations and difficulty negotiating appointment systems.

Practice implications

These findings suggest that more effort may need to be made by the GP to understand the women's concerns and expectations regarding her menstrual symptoms, and to explain the nature of bodily functions and likely causes of these symptoms. Women must be able to feel first that they have been listened to and then diagnosed in order that treatment options can then be properly discussed, and a shared management decision reached.

Menorrhagia may be seen to represent an exemplar of other problems that also cannot be objectively diagnosed, such as irritable bowel syndrome and chronic lower back pain, that are presented in primary care and which GPs may be insufficiently skilled in managing. The place of a decision aid to assist both the GP and the woman with menorrhagia needs careful but urgent evaluation.

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References

Chapple, A. 1999: Menorrhagia: women's perceptions of this condition and its treatment. *Journal of Advanced Nursing* 29, 1500–506.

Coulter, A. 1997: Partnerships with patients: the pros and cons of shared clinical decision-making, *Journal of Health Service Research and Policy* 2, 112–21.

Coulter, A., Bradlow, J., Agass, M., Martin-Bates, C. and **Tulloch, A.** 1991: Outcomes of referrals to gynaecology outpatient clinics for menstrual problems: an audit of general practice records. *British Journal of Obstetrics and Gynaecology* 98, 789–96.

Coulter, A., Kelland, J., Peto, V. and **Rees, M.** 1995: Treating menorrhagia in primary care: an overview of drug trials and a survey of prescribing practice. *International Journal of Technology Assessment in Health Care* 11, 456–71.

Department of Health. 1996: *NHS Executive. Patient Partnership: building a collaberative strategy*. Leeds: Department of Health.

Effective Health Care. 1995: The management of menorrhagia. *Effective Health Care Bulletin* 9, 1–14.

Grant, C., Gallier, L., Fahey, T., Pearson, N. and **Sarangi, J.** 2000: Management of menorrhagia in primary care – impact on referral and hysterectomy: data from the Somerset Morbidity Project. *Journal of Epidemiology and Community Health* 54, 709–13.

Higham, J.M. 1999: Clinical associations with objective menstrual blood loss. *European Journal of Obstetrics, Gynaecology and Reproductive Biology* 82, 73–76.

Kennedy, A.D.M., Sculpher, M.J., Coulter, A., Dwyer, N., Rees, M., Abrams, K.R., Horsley, S., Cowley, D., Kidson, C., Kirwin, C., Naish, C. and **Stirrat, G.** 2002: Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs. *Journal of the American Medical Association* 288, 2701–708.

Layder, D. 1998: *Sociological practice: linking theory and social research*. London: Sage.

Little, P. and **Williamson, I.** 1996: Sore throat management in general practice. *Family Practice* 13, 317–21.

Marchant-Haycox, S., Liu, D., Nicholas, N. and **Salmon, P.** 1998: Patients' expectations of outcome of hysterectomy and alternative treatments for menstrual problems. *Journal of Behavioural Medicine* 21, 283–97.

Marshall, J. 1998: An exploration of women's concerns about heavy menstrual blood loss and their expectations regarding treatment. *Journal of Reproductive and Infant Psychology* 16, 259–76.

Royal College of Obstetricians and Gynaecologists. 1998: *The initial management of menorrhagia*. London: RCOG Press.

Shapley, M., Croft, P.R., McCarney, R. and **Lewis, M.** 2000: Does psychological status predict the presentation in primary care of women with a menstrual disturbance? *British Journal of General Practice* 50, 491–92.

Stirrat, G. 1999: Choice of treatment for menorrhagia. *The Lancet* 353, 2175–76.

Tudor Hart, J. 1997: What evidence do we need for evidence based medicine?. *Journal of Epidemiology and Community Health* 51, 623–29.

Vuorma, S., Rissanen, P., Aalto, A.M., Hurskainen, R., Kujansuu, E. and **Teperi, J.** 2003: Impact of patient information booklet on treatment decision – a randomized trial among women with heavy menstruation. *Health Expectation* 6, 290–97.