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Primary care

Referral for menstrual problems: cross sectional survey of symptoms, reasons for referral, and management

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Abstract

Objectives To describe the menstrual experience of women referred for menstrual problems, in particular menorrhagia (excessive menstrual loss), and to assess associations with reasons for referral given by their general practitioners, the women's understanding of the reasons for their attendance at the hospital clinics, and clinic outcome.

Design Questionnaire survey, with partial review of case notes after 8 months.

Setting Three hospital gynaecology clinics in Glasgow and Edinburgh.

Participants 952 women completed the questionnaire, and the first 665 were reviewed.

Outcome measures Reason for referral, women's reported menstrual problems and reason for clinic attendance, diagnosis, and treatment.

Results Only 38% (95% confidence interval 34% to 41%) of women reported excessive menstrual loss as a severe problem. However 60% (57-63%) gave it as reason for attending a clinic, and 76% (73-79%) of general practitioners gave it as reason for referral. Reason for referral was significantly biased towards bleeding (McNemar odds ratio 4.01, 3.0 to 5.3, $P < 0.001$) and against pain (0.54, 0.4 to 0.7, $P < 0.001$). Dysfunctional uterine bleeding was diagnosed in 37% (31-42%) of the 259 women who gave as reason for attendance something other than bleeding. Women who were economically disadvantaged differed in prevalence of the main diagnoses and were more likely to fail to reattend. Hysterectomy was associated with referral for bleeding (relative risk 4.9, 1.6 to 15.6, $P < 0.001$) but not with the patient stating bleeding as the reason for clinic attendance.

Conclusions Intolerance of the volume of their bleeding is not a key feature among women attending clinics for bleeding problems. Broad menstrual complaint tends to be reframed as excessive bleeding at referral and during management. This may result in women receiving inappropriate care.

Conceptualisation and assessment of menorrhagia requires reconsideration.

Introduction

Menstrual problems account for much of the morbidity that occurs in women of reproductive age, being

one of the four most common reasons for consulting a general practitioner.¹ Specifically, menorrhagia (excessive menstrual loss) is one of the most common reasons for referral to gynaecology clinics.² Organic disease is relatively uncommon with menorrhagia, but treatment typically involves powerful drugs or invasive surgery.³⁻⁴ The formal clinical definition of menorrhagia is blood loss exceeding 80 ml per period, but objective measurement is rarely undertaken in routine clinical practice, despite reports that women are unreliable judges of their menstrual loss.³ Unease has been expressed that management of menorrhagia is so dependent on "the personal history of the patient."⁴

Menstrual complaints typically present a complex clinical picture. A population survey among women of reproductive age found that 24% reported a recent painful period and 20% a heavy period, with about half experiencing both.⁵ Mood changes around the time of a period were reported by 56% of those with heavy periods and 44% of those with pain.⁵ The overlap of symptoms was similar in women referred to clinics with menstrual problems.⁶ Such comorbidity among the three main menstrual complaints is likely to complicate healthcare seeking and management. Indeed, substantial variation in referral rates for menorrhagia has been reported, both nationally and internationally, and discordance has been found between symptoms and reasons for referral.⁶⁻⁷ This is of concern because referral for menorrhagia is associated with a 60% probability of hysterectomy in the ensuing 5 years.⁸ The pathway to the care for menorrhagia warrants careful study.

We undertook a cross sectional survey of women referred for menstrual complaints to hospital gynaecology clinics to assess the relation between symptoms, referral, and early management of menstrual problems. We aimed to ascertain whether patients and their general practitioners are concordant as to the reason for referral and whether subjectively reported excessive volume of menstrual loss is the basis for referral for menorrhagia.

Participants and methods

Study design

From 1996 to 1999 we undertook a cross sectional questionnaire survey of women aged 25 to 49 newly

referred for menstrual complaints to gynaecology clinics at Edinburgh and Glasgow Royal Infirmary and Glasgow Western Infirmary. Exclusion criteria were attendance at the clinic for a menstrual problem in the previous year and a history of drug misuse or known to have HIV, or both. The ability to read simple English was a requirement for completion of the questionnaire.

We followed up and reviewed the case notes of the subset of women recruited early enough for eight months to have elapsed between initial appointment and the end of data collection. Our study was given ethical approval, and participants received written information about the study and provided informed consent.

Methods

The questionnaire assessed menstrual experience in several ways, including a subjective evaluation of blood loss. Women were also asked to report how problematic they considered various aspects of menstruation and the main reason for seeking help. We derived four summary variables from these responses, indicating whether there was a “severe problem” with volume of bleeding, pain, or cycle related changes and whether volume of bleeding had been noted as the reason for seeking help.

Reasons for referral were ascertained from the referral letters received from the general practitioners: as just over half (55%, 521 of 952) cited more than one reason, the research nurses recorded and coded the first two reasons. These codes were converted into four variables, indicating referral or not for excessive bleeding, pain, cycle related changes, or other reasons (for example, fibroids, endometriosis, irregular periods). In the same way the patient’s understanding of the reason for attendance at the clinic was converted into four indicators.

We derived a Carstairs deprivation score (1 to 7) for each patient from their postcode sector.⁹ Deprivation subgroups were combined as necessary to obtain fewer but larger strata (1 with 2 (most affluent), 3 with 4, and 6 with 7 (most deprived)). We reviewed the patients’ case notes to ascertain management up to eight months after referral.

Statistical analysis

We tested for association in 2×2 tables by χ^2 with correction for continuity, by Fisher’s exact test, or by McNemar’s test if data were paired, and in tables with one binary and one ordinal variable by the χ^2 test for trend (χ^2_{trend} , $df=1$). We used SPSS version 9.0. Data for duration are reported as medians and interquartile ranges. A small proportion (<4%) of information was missing; we report the effective (non-missing) sample size if different from the total sample size.

Results

Recruitment

We identified 1506 potential participants from the referral letters (fig 1). Only 4% of those invited to participate refused, but of those consenting 28% (368 of 1320) took the questionnaire home and failed to complete it, despite being reminded by telephone or letter. The 952 participants comprised 63% of eligible patients. Table 1 summarises the personal characteristics of the patients. The participants were similar to the 554 referrals who did not participate for age, depriva-

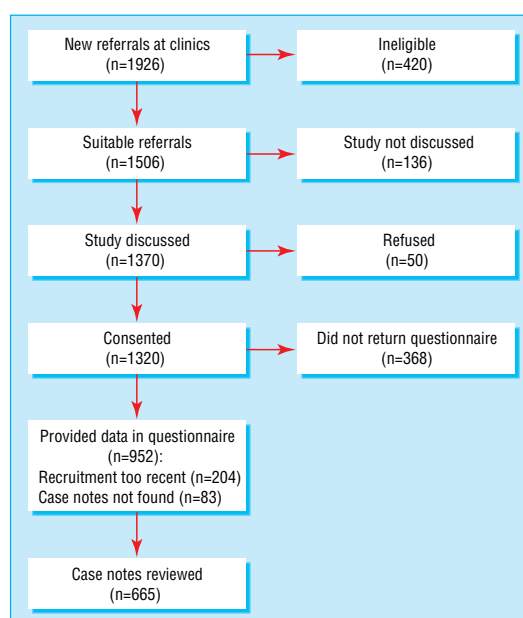


Fig 1 Study profile

Table 1 Personal characteristics of participants and non-participants

| | No (%) of participants (n=952) | No (%) of non-participants* (n=554) |
|--------------------------------------|-----------------------------------|--|
| Age group (years) | | |
| 25-29 | 90 (9) | 58 (10) |
| 30-34 | 164 (17) | 93 (17) |
| 35-39 | 224 (24) | 124 (22) |
| 40-44 | 257 (27) | 152 (28) |
| 45-49 | 217 (23) | 127 (23) |
| Carstairs deprivation score | (n=934) | (n=544) |
| 1 and 2 (least deprived) | 179 (19) | 91 (16) |
| 3 and 4 | 327 (35) | 179 (33) |
| 5 | 183 (20) | 135 (25) |
| 6 and 7 (most deprived) | 245 (26) | 141 (26) |
| Parity | (n=950) | |
| No births | 210 (22) | |
| 1-6 births | 742 (78) | |
| Reported heaviness of periods | (n=945) | |
| Light | 30 (3) | |
| Moderate | 152 (16) | |
| Heavy | 420 (44) | |
| Very heavy | 343 (36) | |

*Eligible but not asked, refused, or defaulted.

tion score, and main reasons for referral. We reviewed the case notes of 665 (89%) of the 748 women recruited early enough for eight months to have elapsed before the completion of data collection.

Menstrual experience

A minority (36%; n=343) of participants rated their periods as “very heavy” (table 1). The median duration of the current problem was two years (interquartile range 10 months to six years). Roughly equal proportions of women reported a severe problem with excessive bleeding, pain, or cycle related changes (fig 2), with considerable overlap between these. Overall, 587 of 948 (62%) reported at least one of these problems, 353 (37%) more than one, and 150 (16%) all three. A third of the women (32%, 301 of 940) had previously attended clinics for period problems, most of these (75%, 222 of 285) for the “same problem” as now.

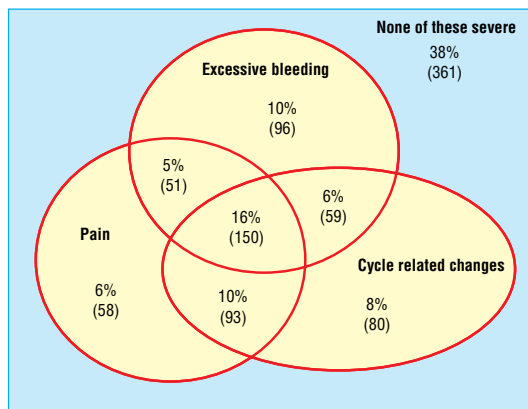


Fig 2 Percentages (numbers) of women experiencing as a “severe problem” one or more of excessive bleeding, pain around periods, or cycle related changes (n=948)

Table 2 Discordance between reason for referral by general practitioner and woman’s stated reason for attendance

| Reason for attendance | No (%) of discordant cases* (n=952) | Ratio (95% CI) of discordant reasons† |
|-----------------------|-------------------------------------|---------------------------------------|
| Bleeding | 261 (27.4) | 4.01‡ (3.0 to 5.3) |
| Pain | 225 (23.6) | 0.54‡ (0.4 to 0.7) |
| Cycle related changes | 47 (4.9) | 1.04 (0.6 to 1.9) |

*Either doctor or woman cites reason but not both.
 †Doctor only divided by woman only (McNemar odds ratio).
 ‡P<0.001 by McNemar’s test.

Reasons for clinic attendance and referral by general practitioner

Each participant reported her belief as to the reason for attendance at the clinic: 568 of 952 (60%) stated bleeding problem, 283 (30%) period pains, and 67 (7%) cycle related changes, with 163 (17%) overall mentioning two. Referral letters cited excessive bleeding problems in 725 cases (76%), pain in 216 (23%), and cycle related changes in 68 (7%). In 27% of cases the referring doctor and the patient disagreed as to whether bleeding was the reason, and there was significant imbalance in the direction of discordance, with a ratio of 4:1 that it would be the doctor rather than the patient citing bleeding (table 2). There was a similar level of discordance about pain, but in the opposite direction, so that in discordant cases general practitioners were significantly less likely to mention pain.

Figure 3 illustrates the pathway to referral for menorrhagia. Among those who reported bleeding neither as a severe problem nor as a reason for seeking help, 63% were nevertheless referred for bleeding. Overall, of the 725 women referred for excessive bleeding, less than half (46%, n=330) had noted it as reason for seeking help, and this percentage breaks down as 60% (187 of 311) of those who reported bleeding as a severe problem compared with 34% (143 of 414) of those who did not.

Clinic outcome

Eight months after initial attendance at the clinic, no cancers had been detected in the participants, 53% (n=353) had been discharged, and 15% (n=98) failed to return for a further appointment. Table 3 shows that failure to return was strongly related to deprivation score, being more likely in disadvantaged groups, whereas there was an opposite gradient for diagnosis of fibroids, an association that persisted after controlling for age. Dysfunctional uterine bleeding (a diagnosis of exclusion, that no disease, such as fibroids, had been found that could account for reported abnormal bleeding) was the most common diagnosis (51%, 331 of 647; 175 with a “regular cycle” and 146 with an “irregular cycle”). After failure to return for further appointments, the most common final outcome was hysterectomy (12%, 79 of 661), with dysfunctional uterine bleeding or fibroids the most common indication.

Clinic outcome

Dysfunctional uterine bleeding was diagnosed for 34% (60 of 174) of the women who neither reported periods as very heavy nor reported excessive bleeding as a severe problem nor gave bleeding as reason for attending the clinic. In those referred by their doctor for something other than excessive bleeding, dysfunctional uterine bleeding was nevertheless diagnosed for 29% (46 of 158). Hysterectomy was likely if fibroids were diagnosed (39%, 33 of the 85 patients with fibroids). Among the remainder without fibroids, hysterectomy was strongly associated with referral for bleeding (relative risk 4.9, 95% confidence interval 1.6 to 15.6, Fisher’s exact test

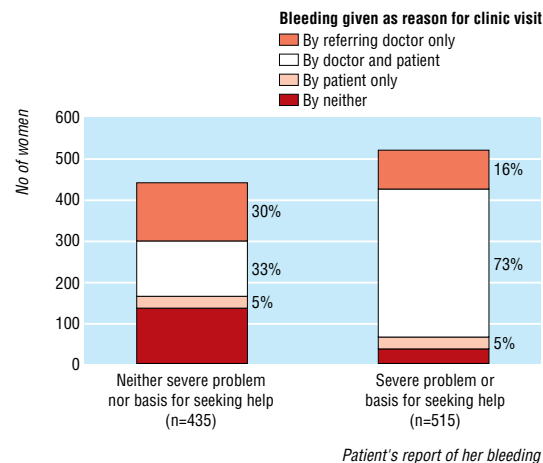


Fig 3 Frequency with which doctor, or patient, or both give “excessive bleeding” as reason for clinic visit, separately for two subgroups

Table 3 Failure to return for appointments and diagnosis of fibroids at eight months’ follow up by deprivation subgroup

| Deprivation subgroup | Did not return for appointment | | | Fibroids diagnosed | | |
|----------------------|--------------------------------|-----|-----------------|--------------------|----|-----------------|
| | No in subgroup | No | % (95% CI) | No in subgroup | No | % (95% CI) |
| 1 and 2 (affluent) | 133 | 11 | 8.3 (4 to 13) | 125 | 28 | 22.4 (15 to 29) |
| 3 and 4 | 228 | 27 | 11.8 (8 to 16) | 215 | 27 | 12.6 (8 to 17) |
| 5 | 127 | 21 | 16.5 (10 to 23) | 125 | 19 | 15.2 (9 to 21) |
| 6 and 7 (deprived) | 158 | 41 | 25.9 (19 to 33) | 155 | 9 | 5.8 (2 to 9) |
| Overall | 646 | 100 | 15.5 (13 to 18) | 620 | 83 | 13.4 (11 to 16) |

χ² trend df=1, 18.1, P<0.0005 χ² trend df=1, 14.9, P<0.0005

$P < 0.001$) but was only marginally associated with reporting volume of loss a severe problem (1.8, 1.02 to 3.2, $P = 0.051$), and was not associated with excessive bleeding as the patient's reason for attendance.

Discussion

We found discordance as to the rationale for referral of women to gynaecology clinics. In over a quarter of cases the patient and general practitioner disagreed as to whether excessive menstruation was a reason, with the doctor four times more likely to be the only one citing bleeding. The proportions of women who reported severe problems with pain, volume of bleeding, or cycle related changes were similar (37% to 40%), with considerable overlap, and yet the predominant reason given for referral was bleeding problems (76%). Furthermore, this tendency for general menstrual complaint to be reframed as excessive bleeding seems to intensify within the clinic setting. Dysfunctional uterine bleeding is defined as "excessive bleeding for which no pathology can be found,"¹⁰ yet dysfunctional uterine bleeding was diagnosed in 35% of women who had cited excessive bleeding neither as a reason for attendance nor as a severe problem. It was also diagnosed in 30% of women whose doctors had not given problematic bleeding as the reason for referral. Variation in referral rates for menorrhagia has been taken to reflect "clinical uncertainty about whether and how the problem should be treated."⁸ Our data suggest more fundamental uncertainty about the concept of menorrhagia.

While acknowledging that objective measurement of volume of bleeding is rarely undertaken in routine clinical practice, guidelines on the management of menorrhagia do not offer alternative strategies for assessment of the complaint.^{3 11 12} Rather, the requirement for a "convincing clinical history" is presumed to be uniformly understood and implemented. Yet we found that more than half (57%) of those referred for bleeding do not even judge their periods as very heavy. Perhaps this partly explains the "normal" measured blood losses commonly reported in women referred with menorrhagia.¹³⁻¹⁵

Strengths and weaknesses

Reasons for referral were extracted from general practitioners' letters, ensuring naturalistic data. The recording of two reasons when given, and the general brevity of the letters, minimised the need for subjective judgment. Participants were also asked their reason for attendance at the clinic, because earlier research found divergence between menstrual problems and presentation at a clinic.⁶ That questionnaires were not returned by 28% of those recruited raises concerns, but participants were similar to non-participants for age, deprivation score, and reason for referral. Questionnaire surveys can deter those with poor literacy, but the questionnaire was brief and support was provided by a research nurse, ensuring broad participation. Deprivation scores have been utilised as a proxy for individual socioeconomic status, because the detail required for determination of social class can not be gleaned from a brief questionnaire. Although time constraints meant follow up was confined to the first 79% recruited, these women were similar to the entire study group for all key variables.

What is already known on this topic

Excessive menstrual loss (menorrhagia) is one of the commonest reasons for secondary referral of women, but there is no formalised clinical assessment in routine use

Management typically involves potent drugs or invasive surgery, with 60% of women having hysterectomy within 5 years

Many women referred for menorrhagia have menstrual blood loss that is not excessive

What this study adds

Discordance exists between symptoms and both referral and diagnostic pathways, arising from a disproportionate focus on menstrual bleeding

Among women referred for menorrhagia, volume of bleeding is not a key symptom

This raises concerns about conceptualisation and assessment of menstrual complaint and the appropriateness of healthcare provision

Explanation of findings

Although there may be no underlying serious disease or risk to physical health, periods can cause major distress and disability.^{16 17} Many women are deterred from consulting by reticence about discussing menstrual problems, anxiety about investigations, or a lack of belief that medical help will be forthcoming.¹⁸ In an opinion poll of 1069 women, 60% espoused the view that not enough attention is paid to problems with periods.⁵ Patients may hold definitions of health and healthcare needs that differ from those of clinicians,¹⁹ perhaps more so with periods, an intensely private event beset with societal constraints. Health needs that remain unvoiced within the consultation have been related to poor outcomes.²⁰ We found that pain around periods is commonly reported as problematic yet relatively "invisible" in the referral and diagnostic pathways, and also that the more deprived women were less likely to be diagnosed with fibroids, more likely to be diagnosed with dysfunctional uterine bleeding, and more likely to fail to return to the clinic (table 3).

Where there is comorbidity between menstrual complaints which one the doctor selects to give as the reason for referral may seem unimportant. We found, however, that among women free of disease (as a possible indication for surgery) hysterectomy was associated with referral for bleeding but not with volume of bleeding being reported as problematic. Perhaps referral for menorrhagia is strategic, based on the knowledge that it is likely to lead to surgery and aiming to increase the likelihood of this for a particular patient.^{8 21} Nevertheless, this is an unsound process for the allocation of healthcare resource; a more explicit consensus regarding indications for such treatments would be preferable.

The divergence between menstrual experience and reasons given for referral to and attendance at a clinic reflects a disproportionate focus on excessive bleeding, a tendency that is echoed within the clinic setting. Is this reframing partly a consequence of women's beliefs that abnormal uterine bleeding is most worthy of medical attention? Or is there an astute lay understanding of what will be regarded by others as a

valid reason for attendance at a clinic? Assessment of menstrual complaints needs to be improved, and further research is required to understand the part played by the cultural beliefs of both women and clinicians. The comorbidity of menstrual complaints shows that the conventional partitioned thinking about menstrual problems will be unhelpful in most cases.

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Contributors: PW had the original idea for the study and design and led the funding application, study execution, and analysis and preparation of the manuscript. She will act as guarantor for the paper. HOC and MAL were coapplicants for funding. PW sought ethical approval in Edinburgh and MAL in Glasgow. HOC, MAL, MCB, and AD contributed to the design, management of the study, and preparation of the manuscript. AD coordinated data management. GM contributed to the analysis, interpretation, and writing.

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Primary care groups Progress in partnerships

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This is the fourth in a series of five articles

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continued over

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Partnership—between organisations, services, and frontline staff—is widely promoted as an alternative to large scale structural reorganisation of the relation between the NHS and local government. However, there is still relatively little evidence on the effectiveness and outcomes of such partnerships. One of the difficulties in establishing an evidence base is the wide variety of relationships that can be described as partnerships. A second difficulty is the risk that working in partnership may be regarded as an end in itself rather than as the means to an end. The Audit Commission identified four potential areas of focus for groups working in partnership in public services (box).¹ However, implementing these activities and measuring progress is far from easy.

The Health Act 1999 imposed a duty on all NHS organisations to work in partnership. Nowhere has working in partnership been given more backing than in the relations between the NHS and local authorities, where collaboration is required to tackle “wicked issues”²—that is, complex problems like health improvement, community safety, and community care. Primary care groups and trusts are required to give priority to forming partnerships with local authorities' social services departments, especially in developing services

Summary points

Primary care groups and trusts are expected to develop partnerships with local authorities, particularly for commissioning services and developing services for older people

Nearly half of the groups and trusts surveyed do not routinely consult with social services when commissioning community health services, and even fewer consult with social services about commissioning acute care

Relationships between frontline social services staff and community based and practice based health professionals are improving

The development of robust partnerships may be threatened by disruption to established relations as primary care groups merge or become trusts

for older people. In its plan for the NHS in England, the government announced that additional financial