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**Help-seeking behaviour**

**in sufferers of vaginismus**

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## **Summary**

The aim of the study was to examine the help-seeking behaviour of sufferers of vaginismus and to explore their experiences of professional intervention. A postal questionnaire was completed by sufferers (n=67) and ex-sufferers (n=22) of vaginismus through a newspaper advert, self help groups, psychotherapists and professional organisations asking them about their help seeking behaviour. The results indicate that finding help can be difficult. Although most sufferers contacted their G.P. (69.7%) the G.P. was regarded as least helpful. Subjects show a wide variability in their experiences of professional help, with both satisfaction and dissatisfaction being expressed with both doctor centred and patient centred approaches. In addition, the experience and expectations of professional intervention may deter further help seeking behaviour. The results suggest that there is widespread dissatisfaction with professional interventions for vaginismus which may reflect an incongruence between the beliefs of the sufferers and those of the professionals.

## **Introduction**

Vaginismus is an involuntary spasm of the outer third of the vagina and prevents a woman from engaging in penetrative sex. It can be transient but is frequently of long duration. Research into this dysfunction attributes the cause of vaginismus to multiple factors such as social learning, trauma, phobia, psychodynamic conflict, relationship problems, and fear of intimacy, (Duddle, 1977., Eicher, 1980., Friedman, 1962., Jehu and Gazan, 1983., Sheldrick, 1991., Ward and Ogden, 1994). However, whilst causes are seen as multi-dimensional, treatment approaches are persistently goal directed, focusing mainly on the removal of the physiological spasm. Accordingly, successful therapy is predominantly rated in terms of penetrative sex; a goal which is rarely challenged (Bezemer, 1987., Ussher and Baker, 1993, van de Wiel, 1990). This reflects the historical conceptualisation of vaginismus within the medical model as a health problem with symptoms and a pathology which should be treated and cured. However, although the spasm is certainly a disturbing symptom, it is only a part of the whole of the psychosocial experience of vaginismus which could be conceptualised as a fear of intimacy at many levels (Ward and Ogden, 1994).

The problem of vaginismus highlights the conflict between medical and psychosocial perspectives in terms of causality and treatment. Such perspectives influence both the sufferer in terms of how they make sense of their problem, and where they seek treatment and also influences the kind of treatment they receive from the health professionals. Any disparity between the beliefs of the patient and those of the doctor could affect the usefulness of any professional intervention. The aim of the present study was to examine the processes of diagnosis, help seeking behaviour, satisfaction

with care and desired help from the sufferers' perspective in the context of the interplay between medical and psychosocial models of vaginismus and different types of professional intervention.

### **Methods**

Two matched questionnaires (for sufferers and ex-sufferers) were developed to collect subjects' responses to a number of questions including demographic information, the duration of vaginismus, details of their diagnosis, and experiences of help-seeking and of any professional interventions. In addition the questionnaires asked about the beliefs about the causes and effects of vaginismus. The latter data have been published elsewhere (Ward and Ogden, 1994). Subjects were also encouraged to elaborate their experiences in their own words. Questionnaires were sent to subjects in the U.K, Australia and the USA. Access to the British subjects was through i) an advertisement in a national newspaper (The Guardian) whose readership is predominantly professional and middle class, ii) Resolve, which is a self help support group specifically for sufferers of vaginismus, iii) Relate, an organisation which offers individual counselling for relationship problems, iv) the Institute of Psychosexual Medicine, which provides psychotherapy for psychosexual problems, v) a psychosexual therapist based in Manchester. The Australian subjects were accessed through a gynaecologist based in Sydney and the American subjects were contacted through a psychosexual therapist based in Michigan.

The data was analysed quantitatively using descriptive statistics (SPSS/PC+). The

free comments were categorised into themes.

## **Results**

### Subjects

Questionnaires were sent to subjects through i) a newspaper advertisement (28 sent, 22 returned), ii) Resolve support group (55 sent, 33 returned), iii) Relate (50 sent, 11 returned), iv) the Institute of Psychosexual Medicine (13 sent, 2 returned) v) psychosexual therapists: in Manchester (12 sent, 0 returned); in the USA (15 sent, 2 returned), and vi) through a gynaecologist in Australia (50 sent, 21 returned). A total of 91 questionnaires were returned in time for analysis. Two were inadequately completed for the quantitative analysis, however these and a further three late questionnaires were included in the qualitative analysis. The final 89 subjects consisted of 67 sufferers and 22 ex-sufferers aged from 21 to 71 with a mean age of 33.6 years ( $SD \pm 9.74$ ). They reported a variety of backgrounds and occupations and included librarians, housewives, clerks, lecturers, secretaries, teachers, nurses, hairdressers, civil servants and administrators.

Most subjects were married or cohabiting (71.9%, n=64) or in a stable relationship (7.9%, n=7), some were single (14.6%, n=13), others were separated or divorced (4.5%, n=4) or widowed (1.1%, n=1). The women were almost exclusively heterosexual (95%, n=85) although two described themselves as bisexual. Subjects did not always clearly state the duration of their vaginismus, but estimations indicate an average of 14 years ranging from one year to a whole lifetime.

The results showed no differences between the sufferers and the ex-sufferers, so the results are presented for both these groups together.

### Diagnosis

Subjects were asked who had 'first diagnosed their vaginismus'. Most subjects had diagnosed their own problem (48.9%, n=44), others had been diagnosed by their G.P. (17.8%, n=16), a gynaecologist (12.2%, n=11), a sex therapist (10%, n=9), a counsellor (3.3%, n=3), a family planning practitioner (3.3%, n=3) and a psychotherapist (1.1%, n=1).

### Help seeking behaviour

When asked who they had approached for help, many women had sought help from more than one source, with an average of three sources per person, however 2 subjects had sought help from 7 sources. The most frequent appeal for help was to the G.P. (69.7%, n=62), followed by a sex therapist (47.2%, n=42), a psychotherapist (37.1%, n=33), a counsellor (30.3%, n=27), a gynaecologist (30.3%, n=27), a family planning doctor or nurse (21.3%, n=19), friends (19.1%, n=17) and family (5.6%, n=5). 5 subjects reported no help-seeking behaviour. In addition subjects reported getting help from books and magazine articles.

### Professional contact

Subjects were asked for details of their professional contact in terms of the number of

sessions, the content of the sessions and the usefulness of the sessions.

### **Number of sessions.**

Subjects went for between 1 and 60+ sessions of therapy, the majority being with sex therapists (38.2%) or psychotherapists (30.3%). 18% of sessions were with G.P.s, 17% with counsellors, 14.6% with gynaecologists, and 6.7% with other professionals (e.g. hypnotherapist, clinical psychologist). Over half the sample's partners were either included in the therapy sessions or offered support on their own (53.9%).

### **Content of therapy.**

Subjects were asked to describe whether their feelings were discussed in their sessions with a professional. 51.1% (n=46) stated that their feelings had been discussed in detail, 25.6% (n=23) replied 'somewhat', 8.9% (n=8) replied 'hardly', and 6.7% (n=6) replied 'not at all'. Subjects were also asked whether they were offered emotional support. 40% (n=36) replied 'yes a lot', 26.7% replied 'yes a little', 15.6% (n=14) replied 'not much', 11.1% (n=10) replied 'not at all'.

### **Helpfulness.**

Although the G.P. was the most frequently sought source of help, the subjects perceived this as being least helpful with only 22.6% (n=14) of the subjects who had visited their G.P. saying that they found this contact helpful. Of the subjects who had visited a counsellor 51.8% (n=14) found this helpful, and 55.6% (n=15) of the subjects who had visited a gynaecologist, 61.9% (n=26) of those who had visited a sex therapist, and 75.8% (n=25) of those who had visited a psychotherapist found these contacts

helpful.

The subjects were also encouraged to write freely about their experiences of professional help. 85 of the subjects elaborated on their experiences of professional intervention. Assessment of these comments suggests both positive and negative experiences of both a traditional directive professional centred approach and a more patient centred approach.

### **Positive comments**

Analysis of the subjects comments indicates some positive experiences of contact with professionals and illustrates the different forms of helpful professional intervention.

14 subjects made positive comments specific to their G.P. and other comments related to other unspecified health professionals.

### **A professional centred approach.**

Many positive comments reflected satisfaction with a traditional directive professional centred approach in terms of receiving information, having a problem diagnosed, being normalised and problem solving. Comments which reflected the importance of information included: learning about vaginismus; discussing possible causes; learning about treatments; learning about the body and genitalia, using examples with diagrams; learning about other sufferers.

One subject wrote:

"my current gynaecologist says ... that the problem is extremely common ... have talked a lot about my anatomy and that of a man ... I have therefore been properly educated."

Comments highlighting the importance of a diagnosis and normalisation included: reassurance of physical normality; reassured me I was not a failure; reduced the feelings of being isolated or feeling a freak.

One woman wrote:

"He gave my problem a name, explained how it could be treated, then proceeded to treat me in an atmosphere of trust and caring."

The comments also reflected a more problem solving approach such as: important to work through the problems step by step; offering solutions; identifying irrational beliefs; treating the problem seriously; giving time/space to delve into the problem; accepting or confronting the problem; learning relaxation, yogic breathing.

#### **A patient centred approach.**

Other positive comments reflected satisfaction with a more patient centred approach in terms of emotional support such as: doctors / therapists accepted feelings and problems; showed empathy; gave confidence and security; were kind; were understanding; did not apply pressure; were patient; and in terms of the role of communication: talking frankly about their experience and / or feelings. Being listened to was also appreciated, especially when this was done sympathetically, giving the woman permission to

express fears, anger and other feelings.

### Negative comments

However, many subjects reported negative experiences where a professional was found to be unhelpful or positively destructive. Sometimes this was because of difficulties with accessibility such as a lack of time or a series of referrals. 29 subjects made comments specific to G.P.s who were cited as having attitudes which were unhelpful: dismissive; unapproachable; brusque; unsympathetic; misunderstanding; and making destructive comments. Other negative comments were made about professionals generally.

### **A professional centred approach.**

Some negative comments suggested dissatisfaction with a professional centred approach such as: imposed a physical examination on me (impatient, unsympathetic); no discussion offered; mechanistic approach taken; seen as hysterical; told to relax and all would be well. Several women felt that some responses from professionals were not meeting their needs and were either the result of insufficient understanding, or a way of being 'fobbed off'.

### **A patient centred approach.**

Other comments indicated dissatisfaction with a more patient centred approach which involved inappropriate psychological analyses such as: relationship deemed faulty; being pitied.

One woman commented:

I waited for 20 years to see this counsellor as, when I first went to a doctor, one doctor slapped my bum and said 'go and get drunk' and another doctor, who wasn't able to give me an internal examination told me to 'come back when you've grown up'. I felt so humiliated I didn't tell anyone else.

The statements also suggest that help-seeking was sometimes hindered by previous bad experiences, as well as by anticipated bad experiences. Again these comments reflected a combination of worries about an overtly medical approach such as: fearful of pain on examination; of being offered inappropriate treatment; being seen as a nuisance; of finding that no cure was possible. Additional worries centred around fears of discussion and counselling such as: discovering repressed events; fear of being humiliated; being judged neurotic; fear of ridicule, of being misunderstood; feeling ashamed.

### **Discussion**

The aim of the present study was to examine the help seeking behaviour of sufferers of vaginismus. Methodological problems, such the representativeness of the sample used, may limit generalisations to all sufferers. However, at present, due to the secrecy and guilt associated with the problem, the prevalence of vaginismus is unclear, and in addition, contact with health professionals by these sufferers has not been studied. The results of the present study therefore provide preliminary insights into

help seeking behaviour and experiences of professional intervention and have implications for improving patient satisfaction with the consultation for a wide variety of disorders.

The results indicate that almost three-quarters of the sufferers in the present study consulted their G.P. for treatment. Other sources of help included sex therapists, gynaecologists and psychotherapists. This suggests that although vaginismus may be regarded as a psychosocial problem (Ward and Ogden, 1994), many sufferers attempt to find help from a medical source. This supports the concept of the G.P. as a gatekeeper to other health professionals and perhaps also reflects sufferers' lack of knowledge of alternative sources of help.

The results also suggest that the women's satisfaction with professional intervention was extremely varied, with psychotherapists reported as most helpful and G.P.s reported as being the least helpful. Some women reported that the interventions were helpful in terms of gaining information, having a diagnosis and feeling 'normalised'. This type of intervention represents a traditional directive doctor-centred approach to care which is obviously satisfactory to some sufferers of vaginismus. Other subjects emphasised the benefits of a more patient-centred approach in terms of emotional support. Patient satisfaction can therefore be seen for both types of professional intervention. However, some women reported that the interventions were inappropriate and did not meet their needs. In particular they mentioned painful examinations, a mechanistic approach, not enough time for discussion, and

inappropriate comments about their psychological state. These critical comments reflect dissatisfaction with both the professional and patient centred approaches to dealing with patients.

Perhaps the variability in experience of professional help reflects the complexity of the theoretical perspectives which have been developed to explain vaginismus. Such theories will influence the beliefs of both the patient and the professional. If the perspective of the doctor is congruent with that of the sufferer, whether with a medical or psychosocial emphasis, the resulting help may be constructive. For example, a woman who requires a medical diagnosis and information would benefit from an intervention which focused on the physical problem and analysed this problem in terms of cause and treatment - a professional centred approach. Furthermore, a sufferer who required time and emotional support would benefit from an intervention which emphasised counselling - a patient centred approach. However such approaches would be deemed unhelpful if the sufferer needed emotional support in the first instance, and a medical diagnosis in the second. The possible incongruence between the beliefs and behaviours of patient and doctor may explain the range of experiences of vaginismus sufferers' help seeking behaviour. Thus, regardless which approach is acceptable to the client, comments from the women highlight the importance of mutual understanding both in terms of the experience of vaginismus and expectations about the therapeutic intervention.

The results from the present study suggest that helpful professional intervention was

perceived by the women in terms of information, diagnosis, emotional support, problem solving, communication and more generally being made to feel normal. This has obvious implications in terms of developing health professionals' skills in dealing with sufferers of vaginismus. Further research is needed to evaluate the prevalence of vaginismus and to examine these beliefs in a wider sample of sufferers. In addition, the results indicate that satisfactory professional intervention is probably best achieved by matching the professional approach with that required by the patient. Therefore, as G.P.s are often the first point of contact for sufferers of vaginismus, an appropriate approach for them may be initially to determine the expectations and needs of the sufferer in terms of type of professional intervention, to assess the relative appropriateness of a discussion of emotional and relationship problems and / or a medical diagnosis and to negotiate with the patient a treatment / referral which best suits their own view of the problem. Such an approach would help to minimise any incongruity between the beliefs of the G.P. and those of the patient and has implications for improving interventions by a variety of health professionals for a diversity of disorders.

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