

Dilation as treatment for vaginal agenesis and hypoplasia: A pilot exploration of benefits and barriers as perceived by patients

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Summary

Reconstructive surgery has been the traditional treatment for the short vagina. Recently vaginal dilation has been recommended due to its low morbidity. Small retrospective studies have reported success rates of up to 80% but include neither clear definitions of 'success' nor exploration of factors associated with compliance and outcome. The first 10 women prescribed vaginal dilation treatment at a specialist gynaecological clinic during the study period were interviewed and asked to complete the Multi-dimensional Sexuality Questionnaire (MSQ), with an assessment of perceived vaginal characteristics. The participants scored lower scores on sexual esteem, sexual assertiveness and sexual satisfaction and higher scores in sexual anxiety, sexual depression and fear of sexual relationships in comparison with the standardisation sample. Dilator treatment must be subject to the same scrutiny as any intervention. Vaginal dilation can have a negative emotional impact on women and psychological intervention may be needed to maximise efficacy.

Introduction

A shortened or absent vagina is associated with a number of conditions. Some of these conditions are classified as intersex (e.g. androgen insensitivity syndrome, AIS) and some not (e.g. Meyer–Rokitansky–Kuster–Hauser syndrome, MRKH). Historically, reconstructive surgery has been the main treatment option. More recently, vaginal dilation has been recommended as the treatment of choice.

Surgical procedures usually involve dissection and lining of a neovaginal space (Minto and Creighton 2003). Tissues used to line the neovagina have included skin grafts (usually taken from thigh or buttock) or a section of intestine. These are major procedures and postoperative complications can include contracture in case of skin graft, persistent bloody and/or offensive discharge in the case of intestine, and scarring in both cases (Syed et al. 2001). Malignant change in the neovagina has also been reported (Munkara et al. 1994). Although long-term follow-up studies have reported 'normal' sexual function in 80–90% of women following these procedures (Cali and Pratt 1968; Martinez-Mora et al. 1992), there is little information available as to how this was assessed.

Due to the complex nature of reconstructive surgery and the fact that vaginal dilation often has to take place post-surgery, dilation itself has gradually taken over as the first line of treatment. First described by Frank (1938), the low rate of associated complications has made the technique popular. Vaginal dilators are cylindrical shapes graduating in size and usually made out of plastic (Figure 1) although glass and Perspex are also used. As with surgery, data on efficacy of this technique are scant. Success rates of up to 80% have been reported in retrospective studies (Costa et al. 1997), but how success is defined is unclear

with no report on compliance rates or subsequent sexual function.

In a recent study of women with complete androgen insensitivity syndrome, most of whom had tried to dilate in order to increase vaginal volume or to maintain volume post-surgery, 37.5% of the sample rated their compliance as poor and only one-third of the participants expressed satisfaction with dilation treatment (Minto et al. 2003). Sexual difficulties were common. The low rate of physical complications associated with dilation should not lull us into prescribing a treatment that may not be effective. Dilation treatment should be subjected to the same scrutiny as any intervention.

Dilation differs from operative procedures in that it has to be actively managed by the patient and that sustained effort is required, while progress is slow. Research in psychology of chronic illnesses suggests that success in self-management relates to some extent to how benefits of treatment balance against costs to the individual (Horne and Weinman 2002). Although in accepting treatments, many benefits may be reaped, there are also sacrifices involved and barriers to overcome. The idea is that only when benefits of performing the regime substantially outweigh the costs, is the individual likely to sustain action. This line of thinking resonates with psychotherapeutic interventions developed in the past two decades that have come to be known as 'motivational interviewing' (Miller and Rollnick 1991). According to this framework, not only does the cost-benefit balance need to be favourable, but confidence in the ability to perform the action also needs to be high. Motivation is not static and clinicians can help patients move towards action, e.g. by giving information that makes the benefits more salient, by helping the patient to solve problems so as to reduce



Figure 1. Amielle Dilators (Owen Mumford, Banbury, Oxon).

the disadvantages of performing the treatment regime, and by increasing support to boost the patient's confidence.

This model of self-management can offer useful pointers for understanding compliance difficulties with vaginal dilation. Although women may be motivated towards achieving greater vaginal volume and the benefits perceived to be associated with this change, they may be equally motivated to avoid the perceived or experienced costs of dilation (time and effort).

Aim of current study

This is the pilot phase of an ongoing strategy to improve our dilation service. The overall objective was to gather initial information to design a more women-centred service and in particular, to help us examine whether aspects of motivational interviewing can provide a useful framework for improving treatment compliance in our context. We were interested in the following questions:

1. What benefits or advantages and what costs or barriers – practical and psychological – do our patients perceive or experience in taking up regular vaginal dilation?
2. How confident do they feel about being able to carry out the treatment?
3. What would increase their confidence?

In order to put responses to these questions in context, we also asked additional questions about whether our patients differ psychosexually from women without vaginal agenesis and to explore perceptions about the vagina. We felt that their views about their sexuality and their vagina might also impact upon how dilation is experienced and how confident they felt about carrying out dilation.

Methods

Participants

The first 10 women prescribed vaginal dilation treatment within the audit period were asked to participate in piloting our baseline treatment protocol. The mean age of the group was 25 (range 17–36). Eight of the participants had a diagnosis of MRKH, one had AIS and one was using vaginal dilation following radiotherapy for cervical cancer.

All had attempted dilation in the past. Current vaginal measurements were recorded.

Assessment

Decisional balance interview. The participants took part in a brief semi-structured interview in which they were asked about their experiences of vaginal dilation.

a. Assessing perceived importance

Participants were asked to report on the benefits and barriers in vaginal dilatation, as well as costs and benefits in not taking up dilation.

b. Assessing perceived confidence.

Participants rated how confident they felt about being able to take up the dilation treatment programme on a scale of 1–10 (1 = Not at all confident; 10 = Totally confident). They were also asked the open question, 'If your confidence was to move up by just one point, what would need to happen?'

Multi-dimensional Sexuality Questionnaire (MSQ). This is an assessment of 'psychological tendencies associated with sexual relationships' (Snell et al. 1995). Responses could be based on a current, past or imagined relationship, thus patients who are not currently sexually active are not excluded in the assessment. The MSQ has been standardised on the general population and have high internal and concurrent consistency. For women, it has also been found to correlate moderately/highly with sexual behaviour.

Due to its length and applicability, however, only 6 of the 12 subscales were used in the current study: sexual esteem, sexual anxiety, sexual depression, sexual assertiveness, fear of sexual relationships, and sexual satisfaction. Each subscale comprises five statement-items and respondents are asked to indicate on a 5-point scale the degree to which the statement is characteristic of them. Each item is scored 0–4 producing a range of scores of 0–20 with higher scores reflecting greater level of the respective tendency.

Perception of vaginal characteristics. Participants reported their beliefs about their vagina from a list of six statements: (1) My vagina is more or less normal. (2) I don't know or I'm not sure. (3) My vagina is tiny or non-existent. (4) My vagina is small (short or narrow). (5) A sexual partner would notice that it is different from other women. (6) I would like my vagina to be bigger (longer or wider).

Results

Benefits and barriers of taking up and not taking up vaginal dilation

The pros and cons of treatment uptake and non-uptake were content-analysed. Each statement was recorded verbatim and emerging themes were drawn out. Each theme was then cross-referenced with the initial statements to ensure that these adequately reflected the original verbal data. The number of individuals endorsing each theme was then recorded and the results are summarised in Table I. Some participants endorsed more than one theme.

Table I. Dilation treatment decisional balance

	Participants endorsing theme
Benefits of dilation	
Normal/pain free sex: e.g. 'To have a normal sex life' or 'So I won't have painful sex'	9/10
Feel better as woman: e.g. 'To be as normal as the next woman' and 'To feel better as a woman'	4/10
Ability to attract: e.g. 'To feel relaxed or confident enough to pursue a relationship' or 'If you can't have sex, they (men) are not going to want you'	3/10
Have a vagina: No further explanation	3/10
Better than surgery	1/10
Ease anxiety in general	1/10
Disadvantages or costs of uptake	
Chore/boring	6/10
Discomfort/pain	5/10
Unpleasant reminder of something preferably forgotten: e.g. 'It (dilation) reminds me of being abnormal'	3/10
Fears and worries about dilators: e.g. 'Fear of pushing too hard or hurting myself'; 'Fear of breaking it (dilator)'	2/10
Dilators not made for women: e.g. 'Need to be more bendy'	1/10
If don't continue with use then lose progress	1/10
Others think it is weird	1/10
Doing it for sex, but sex not pleasurable	1/10
Advantages of non-uptake	
Feel normal: e.g. 'Be normal for a day'	4/10
Saves time	3/10
No advantage	3/10
Avoid pain/discomfort	2/10
Disadvantages of non-uptake	
Won't be able to have 'normal' sex: e.g. 'Having to push men away because not able to have sex'	7/10
Lose any progress already made	3/10
Continue to have worries about relationship that are not specific to sex (1/10): e.g. 'Always worrying about engaging in a relationship'	
Have to have surgery	1/10
Won't be a 'normal' woman	1/10

Participants responses have been given as examples when a range of answers are encompassed in one theme.

Confidence in carrying out vaginal dilation treatment

The mean confidence rating on a scale of 1–10 was 6 (range 1–9). When asked how their rating could increase by one point, the women made a number of suggestions and these are summarised in Table II.

MSQ

Four of the participants based their responses on an imaginary relationship, three on a past relationship and one on a current relationship. Scores on the MSQ were compared with a standardisation sample in Table III. Compared with the standardised sample, our participants yielded lower scores on sexual esteem, sexual assertiveness and sexual satisfaction; and higher scores in sexual anxiety, sexual depression and fear of sexual relationships.

Vaginal dimensions and perceptions

The mean vaginal length was 5.9 cm (range 1–14 cm). The results of the vaginal perception questions are given in Table IV. All of the eight participants who answered the perception questions indicated that they would like their vaginas to be bigger (i.e. longer or wider). Two participants felt that their vaginas were 'more or less normal', one of whom was prescribed dilation following cervical cancer, the second was a patient who had been using dilation for some time, had a vagina length of 14 cm and was able to use the largest dilator available.

Table II. What would increase confidence in ability to dilate?

Theme	Participants endorsing theme
Knowing where the dilators are going/what they are doing	3/10
Evidence that it works: e.g. Information of the time it takes, ability to see progress, or successful intercourse	3/10
Knowing about others' experience	2/10
Being more organised	2/10
Making it more fun	1/10
Making it more comfortable	1/10

Discussion

This preliminary exploration highlights the fact that when asked, women named not just benefits but also barriers in performing dilation. Some of the barriers were expected, such as lack of privacy or time constraints, but half of the women also mentioned pain and discomfort as barriers in performing dilation. A degree of discomfort or pain may be avoidable. Bergeron et al. (2001) successfully made use of psychological techniques in the treatment of dyspareunia associated with other gynaecological conditions such as vulvar vestibulitis. These included cognitive techniques to elicit and modify thoughts and emotions in relation to

Table III. Mean scores on the MSQ for the clinic sample in comparison to a standardisation sample

MSQ subscale	Current sample (Mean) (<i>n</i> = 8)*	Current sample (Range) (Min = 0, Max = 20)	Standardisation sample (<i>n</i> = 265) [†]
Sexual esteem	6.5	0–12	12.4
Sexual anxiety	9.9	0–18	5.3
Sexual assertiveness	8.1	1–16	10.2
Sexual depression	9.6	0–15	3.9
Fear of sexual relationships	11.5	0–19	8.6
Sexual satisfaction	7	0–12	13

*Questionnaire data is missing for two participants.

[†]Standardisation sample consists of 265 female undergraduate students attending a North American University as reported by Snell (1993). Data has been rounded up to the nearest decimal point.

Table IV. Perceptions of vagina

Perceptions of vagina	<i>n</i> = 8
Vagina is more or less normal	2
Don't know/not sure	0
Vagina is tiny or non-existent	2
Vagina is small (short or narrow)	6
A sexual partner would notice the difference	6
Would like vagina to be bigger (longer or wider)	8

anticipation and experience of pain, for example by suggesting that pain/discomfort does not necessarily reflect damage. Indeed a number of our participants did express worries about causing damage to existing vaginal tissue. In general, anticipation of pain can exacerbate pain experience by intensifying muscular spasms, resulting in a vicious cycle. Relaxation training can be a useful adjunct in pain management. It is well to remember that successful outcome of dilation is in the distant future but demand of patient effort is immediate, frequent and over a prolonged period. Record-keeping could be adopted to highlight progress (e.g. reduction in pain ratings, increase in size of dilator) and act as a more immediate form of reinforcement.

Clinicians may often feel the avoidance of complex surgery is a significant advantage in promoting dilation therapy, yet interestingly, only one participant cited this as a perceived benefit. In contrast, four out of ten patients mentioned the use of dilators as a constant reminder of their 'abnormality'. The necessary examination, treatment and monitoring of the genitalia could inadvertently communicate notions of deformity and contribute to a sense of aversion. Clinical services should best avoid a sole preoccupation with the patient's sexual apparatus and offer opportunity for debriefing. Consultations that are skilfully and sensitively conducted could minimise potential negative psychological effects on women's sexuality.

One of our participants rightly pointed out that dilators are 'not made for women', i.e. they are made for 'patients'. Indeed, dilators tend to have a clinical appearance and could reinforce women's feelings of freakishness. More research is needed regarding the potential use of erotic aids (e.g. vibrators) which are made for ordinary women, as a substitute for dilators (Crouch et al. 2003).

The women did not express an overriding sense of confidence in being able to carry out treatment successfully, as indicated by an average rating of 6 out of 10. A number of

patients felt that information about the success rate of this type of treatment (i.e. how long they would have to dilate for how much increase in volume) would increase their confidence. This highlights the importance of future research in the efficacy of dilation and in identifying gynaecological and psychological factors that could influence treatment success.

Despite clear information and open discussion during their gynaecological consultations, several participants expressed a desire for more information about the mechanics of dilation. This may reflect previously unexpressed anxiety and doubt. In a consultation, as well as giving information, it may also be important to address factors that could impede information processing such as patient anxiety, shame or embarrassment that may not be obvious.

Successful self management in healthcare contexts is often enhanced by social support (DiMatteo 2004) and where appropriate, patients should be encouraged to maximise support from their personal contexts. However, the nature of the problem means that this is less for many of our patients. Several participants expressed the wish to hear about other patients' experience with dilation treatment. Workshops and groups led or supervised by psychologists could provide a useful resource for women to discuss concerns with each other. Regular individual appointments with a specialist nurse or psychosexual counsellor could provide opportunities for addressing residual anxiety, for problem-solving practical difficulties and for receiving positive feedback.

The main benefits of dilation as perceived by the women were centred on being able to access relationships. But the desired change in vaginal dimensions will not in itself lead to relationships. This is eloquently summarised by a participant in an interview study (May 1998):

'I hadn't learnt all the sorts of skills that were needed to establish a relationship and that maybe was the main problem and having a vagina wouldn't help'

Dilation treatment is probably best delivered as part of a broader service that also enables women to address issues relating to intimacy, choice and personal control. In particular, service delivery should aim at increasing awareness and interpersonal skills that can enhance effectiveness in sexual relationships. Such an approach would also fit clearly with the modern approaches to management of chronic disease as outlined in 'The Expert Patient' (Department of Health 2001).

Conclusions

Potentially, vaginal dilation can have a negative emotional impact on women whose sexuality is compromised by their medical condition and, while many patients may follow advice to address the mechanical aspects of the problem, some may not take up or adhere to treatment for practical or emotional reasons.

In this pilot exploration, we have made use of the idea that patient motivation to self manage a treatment regime is not all-or-none, rather an equation of pros and cons. We believe that the clinician's role here is to shift that equation in a positive direction by encouraging patients to explore their 'ambivalence' without pressurising them to take-up or continue with treatment. It should be remembered that a decision *not* to adopt a regime is also a viable option. It is arguably preferable for women to decline a treatment that they are emotionally ill prepared for, rather than compound feelings of sexual inadequacy.

Vaginal dilation treatment is probably best delivered within a healthcare context that is also committed to assist women in exploring their thoughts, feelings and behaviour relating to intimacy. Treatment can be made more positive if viewed as an opportunity to increase sexual awareness, to discuss hopes and fears and to learn to value individual choice. In that sense, whether or not the woman succeeds in dilating her vagina in the present time, she would have gained useful knowledge and skills for negotiating the most optimal sexual life possible in future.

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