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A nonsurgical approach to the treatment of vaginal agenesis

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Introduction

Vaginal dilator pressure treatment is a nonsurgical treatment method to extend or create a vagina for patients with vaginal agenesis. In this chapter, the term dilation is used to describe the extension of width and length of the vaginal pit (dilatation). The dilator is a cylindrical instrument of moulded plastic, which is repeatedly applied with pressure. Treatment to develop a short or absent vagina is offered to women who desire the capacity for sexual activity that includes sexual intercourse or other vaginal penetration. Dilation treatment relies upon patient adherence and, therefore, requires a scrupulous patient-centred approach by the multidisciplinary team.

History of dilation

Since the first descriptions of congenital absence of the vagina, physicians have described and performed various techniques for the creation of a neovagina in order that women can achieve sexual function including vaginal penetration. Frank was the first to describe treating young women with vaginal agenesis using a vaginal pressure dilation technique (Frank, 1938). He reported the treatment of six patients using vaginal dilators. Dilation treatment occurred two to three times per day and dilators were placed in the vagina throughout the night. Frank reported that five of his patients achieved a vaginal length of 6.5–7 cm within six to eight weeks of treatment and three of the women had sexual intercourse after treatment.

Since Frank detailed his method, there have been variations of his pressure dilation technique. Ingram (1981) described a bicycle stool method whereby patients were instructed to sit on a bicycle seat-shaped stool for short periods with a vaginal dilator held in position in or at the vaginal opening to stretch the vaginal tissue. This was thought to supersede the Frank method by virtue of the fact that the patient was not required to maintain direct pressure by hand, a process that can be uncomfortable and tiring.

Variations of dilators have been developed in recent years and many are commercially available. Most are produced in sets in a range of sizes. They can, however, be expensive and difficult to source. As a result, some centres including our own, have produced their own sets of dilators (Fig. 13.1), often based on the needs of individual patients. Dilator design continues to be influenced by Frank and Ingram, who both emphasized the need for a range of dilator width as well as length. They describe the importance of first creating a narrow vaginal canal and only then progressing to using wider dilators. This method prevents dilatation of the urethral meatus or dorsal angulation of the urethra, leading to urethrocele.

A surgical development of Frank's pressure dilation by Vecchietti (1979) has received much interest in Europe and Australia. Vecchietti describes a surgically inserted tension mechanism used to stretch a neovagina. The Vecchietti procedure uses the same principles as Frank but, by developing a surgical method of applying regular pressure, aims to decrease the length of the treatment time and to circumvent the significant challenge of patient adherence to a home regimen for dilator use (Fig. 13.2). Some modified versions of this technique have been suggested. One example minimizes the surgical component and further reduces the treatment time to an average of 8 days (Fedele et al., 2000; Keckstein et al., 1995). A central argument for the

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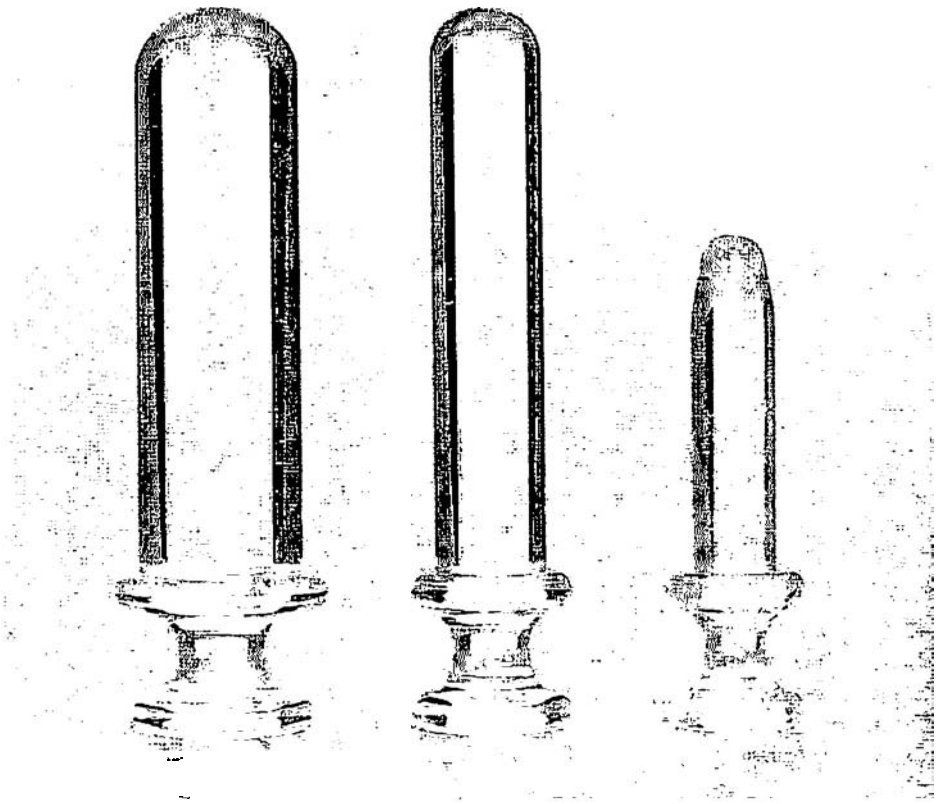

Fig. 13.1. Dilators.

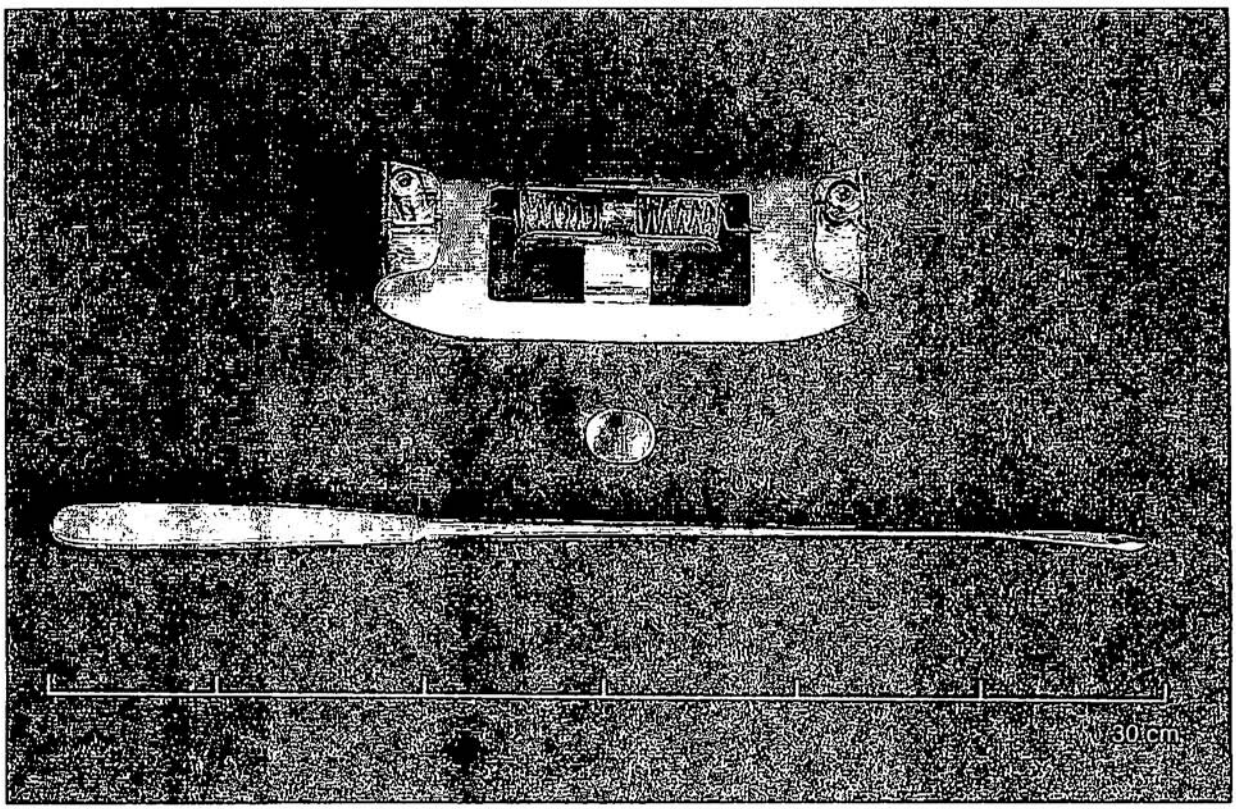

Fig. 13.2. Vaginal olive used with the Vecchietti method for vaginal dilatation.

development of surgical stretch techniques such as these is that, while manual stretch-based treatments can be effective, the level of committed adherence required for treatment success is too great.

Timing of treatment

The timing of any treatment of vaginal agenesis must be acutely sensitive to the psychological and social development of the girl or young woman. Not only must she undergo what may feel like invasive procedures, she must be extremely active in her treatment and must remain active in the process over a period of months. She must be able to commit to an initial training period, regular monitoring, follow-up appointments and regular use of the dilators at home. There has been debate regarding whether any treatment for vaginal agenesis, including pressure dilation, should take place before a young woman is sexually active or once she has established a personal (potentially sexual) relationship (Mobus et al., 1993). Shah et al. (1992) recommended that surgical treatment for vaginal agenesis should occur when the patient has decided to become sexually active. Garden (1998), however, believed that it is obvious that girls should have a functioning vagina before they start a sexual relationship, adding that having intercourse will increase the length of the vagina. This suggests that confidence to begin intercourse may be established during the treatment process and in a sense may form part of the treatment. Harkins et al. (1981), writing about surgery, said that treatment for vaginal agenesis should take place when the patient is physically and emotionally mature enough. Foley and Morley (1992) echoed this and guarded against the use of dilators for younger patients long before the start of sexual activity. It is not a prerequisite that a patient be in a heterosexual relationship prior to the commencement of vaginal dilation. Rather, decisions about timing of treatment must be based primarily on an assessment of the individual patient's desire and ability to undertake the treatment procedures. This individual-based approach needs skilful evaluation and negotiation with the patient and in some cases her parents or partner. For many girls and perhaps sexually immature women, the desire to progress with treatment and develop a functioning vagina will be countered by anxiety about the need to penetrate the introitus with the dilator. For others, specific psychological or practical barriers may complicate the use of dilators. If these problems can be identified and countered before the start of treatment, then the likelihood of a positive outcome will be increased. An appropriate timing of treatment should help to prevent fear of failure, limited adherence, treatment drop out and consequent loss of confidence in the dilation process.

Consent and decision making

To ensure that a patient is able to consent to the treatment with a clear understanding of its demands, it is necessary to help her to gain a thorough appreciation of the dilation process (for full discussion of competency to consent and decision making see Ch. 17). This is a task for each of the clinicians involved and begins when the possibility of vaginal dilation is introduced. It is important to present the benefits of pressure dilation without minimizing the challenges of the process. At this point, it is useful for the specialist nurse to show the patient examples of dilators, give written information about their use and answer initial questions. Dilation should be presented to the patient as a treatment process that includes joint decision making and regular contact with the team of clinicians. Deciding whether to go ahead with treatment, careful consideration of the timing of the start of treatment, training in the use of dilators, regular monitoring examinations, and recognition of a treatment end point and follow-up are all necessary elements of the nonsurgical vaginal dilation process. In this manner, patients must be made aware that dilation is a lengthy process, and that poor adherence will limit success. They may then be able to appreciate that it is necessary to undertake dilation at the optimal time, considering both practical and psychological aspects of their situation.

Psychological preparation and support

After dilation is proposed, the patient can be given a separate appointment for a more detailed discussion of the procedures. It is useful if this appointment occurs at least one week after the initial clinic appointment and presentation of the dilator and written information, leaving time for the patient (and parents) to have considered her initial thoughts and also to have identified concerns and preliminary questions.

The aims of the initial preparation appointment are:

- to ensure that the patient understands that the decision to take up the offered dilation treatment is her own; treatment is neither compulsory nor life saving, but elective
- to ensure that the patient is aware of the treatment process including consent, the initial training, the self-administered regimen and the monitoring appointments
- to anticipate the demands of the dilation process and if possible to begin to consider ways of meeting those demands

- to consider the woman's desires and expectations of treatment and outcome
- to assess any psychological contraindications to commencing dilator use
- to identify any psychological intervention needed prior to dilator use
- to think psychologically and practically about the optimum timing of the start of the treatment process
- to offer and discuss support group or other voluntary agency information.

Depending on the staffing or referral pathways of the service, this consultation might be conducted by a clinical psychologist, counselling psychologist, a heath psychologist, counsellor, psychotherapist or member of a liaison psychiatry team. However, in some services, the specialist gynaecology or endocrinology nurse will be trained and supervised to perform this task. Often the aims of the initial preparation appointment can be met within one extended appointment, usually lasting 50–90 minutes. When working with girls or adolescents, additional liaison with parents will be necessary and will extend the duration of the initial preparation consultation.

When offered treatment for vaginal agenesis, patients and their parents are likely to reconsider the advice they have been given by other health workers prior to referral to the current service. It can be helpful to begin with a review of their journey since initial presentation. In our experience, we often find that patients have been given conflicting advice, for example about the likelihood or timing of surgery; they may have established certain expectations and perhaps made consequent adaptations such as limiting social contacts or withdrawing from personal relationships. Dilation or dilators may have been mentioned by previous clinicians, perhaps in relation to surgery or may have been used in the past. A review of any existing feelings and beliefs about dilators will assist in the assessment of possible hurdles to adherence. This detailed history approach leads on to a discussion of the previous clinic appointment, what was understood, the patient's initial thoughts and her concerns since. Once any misunderstandings have been corrected, the patient's response to the prospect of dilation should be discussed in detail. Throughout this discussion, the clinical psychologist or equivalent will focus on trying to understand the patient's experiences, both of the past and of the present task of talking about the issue of adaptation to and treatment of vaginal agenesis. The listener's genuine struggle for empathic understanding will mean that this consultation might not only be informative but also psychologically therapeutic in relation to distress associated with the matters discussed.

Patients' attitudes to dilator treatment

There is a range of frequent responses to the offer of dilator treatment. Some women, girls and parents express relief when offered an alternative to surgery. Some see dilation as an easier option while others are disappointed that they have not been offered an operation that in their perception would "get it all over with". Patients with a very short vagina may have difficulty accepting that dilation can be effective. It is common for younger women or teenagers to be quite appalled by the idea of inserting an instrument into the vulval region. It may be that, despite concerns about amenorrhoea, the girl has not explored her genitalia or may even have developed a phobic response to her genital area. It is necessary to explore the nature and extent of these fears, to offer information or reassurance wherever possible and to estimate the impact of remaining anxiety on adherence to therapy. It is common to have fear of pain, concern about hospitalization and repeat appointments. It is important at this stage to help the patient to accept these concerns as appropriate and useful considerations for discussion. It is only by becoming aware of anxieties that adequate preparation and well-founded decisions about treatment can be made. A brief explanation and demonstration of the use of dilators is likely to be insufficient. Some patients recall being given dilators as embarrassing, confusing and painful, and they confess to disposing of the dilators after very little use. Others have recalled how they had found the idea of using dilators abhorrent or frightening and had failed to use their dilators on more than the rare occasion (Alderson, 2000). Had these patients been able to talk openly about their concerns with the clinicians providing their care, they may have been helped to make better use of the dilators and the process may have been much less distressing.

When the clinician presents the dilation procedure in detail, he or she invites the patient to imagine her own experience of the process at each stage. By this mechanism, anxieties and possible barriers can be anticipated. For example, the practicalities such as hospitalization and home administration may raise the issue of the degree of disclosure and openness regarding the underlying condition, or the importance of regular privacy and time to use the dilators at home. In some cases, this careful consideration will reveal specific psychological problems that may need addressing before dilator use can take place, may require onward referral or may effect the expected outcome of dilation. These can include trauma responses to child sexual abuse, hospital anxiety or procedural distress, body dysmorphia or psychosexual problems.

A decision to go ahead with dilation treatment is made when the girl or woman fully understands and consents to the proposed procedure, the demands it places upon her and the range of possible outcomes. Further preparation may include additional appointments or telephone discussions with the nurse specialist to discuss treatment and sessions of psychological intervention such as cognitive behavioural therapy to ameliorate specific anxieties for the reduction of procedural distress. Dilation treatment may be delayed by the presence of psychological disorder such as depression, which would be likely to mitigate against adherence and, therefore, treatment outcome. Treatment could then be commenced after psychotherapeutic or pharmacological treatment.

Additional psychological support may be beneficial as the dilation process begins. It is sometimes helpful for the patient to be seen by the psychologist immediately before the initial dilation demonstration by the specialist nurse. Anxiety management techniques can be revised, and as treatment begins the psychologist can help the patient to maximize her motivation gained from its initial impact. Robinson et al. (1999) recommended the provision of psychological support for younger women during dilator treatment. Following a randomized control trial of a psychoeducational group, they concluded that most women, particularly younger women, are unlikely to follow the recommendation to use a dilator unless they are given assistance in overcoming their fears and are taught behavioural skills.

Vaginal dilator treatment

It is essential that patients undergoing dilator therapy are properly instructed, supervised and supported by a trained and skilled nurse or doctor. A specialist nurse can often best combine the role of trainer and supporter of the patient and family. The nurse specialist provides continuity of care via frequent contact with the patient while liasing with other members of the multidisciplinary team and making onward referrals when appropriate.

A philosophy of care that emphasizes the necessary partnership between patient and nurse is essential in the practice of dilation treatment. A useful nursing model that may be applied throughout the treatment process is that of Orem (1995). Orem describes three types of nursing system where the responsibility for patient care is differently apportioned to the nurse and the patient depending on the needs of the patient at a particular time or situation. Dilator treatment exemplifies Orem's supportive–educative system, where the patient, having learned to perform the needed self-care from the nurse, is then competent in that care but still requires periodic guidance. This approach is in line with the Nursing and Midwifery Council Code of Professional Conduct (2002): "You must recognize and respect the role of patients and clients as partners in their care and the contribution they make to it. This involves identifying their preferences regarding care and respecting these within the limits of professional practice, existing legislation, resources and the goals of the therapeutic relationship." Information leaflets with diagrams, anatomical models and example dilators can all be used to inform patients fully about the treatment process. Such explanation forms part of the preparation and consent processes but should be reviewed at the start of treatment. As it is common for patients to feel able to express anxieties and discuss sensitive subjects with a nurse, by remaining accessible the nurse can encourage the patient to seek nursing, psychological or medical advice at the earliest stage. Box 13.1 summarizes the recommendations for dilator treatment.

Box 13.1 Recommendations for practice

- Dilation treatment of vaginal agenesis should be undertaken within a multidisciplinary context.
- Informed consent and psychological preparation processes must take place before treatment begins.
- The clinician should be aware of individual patient factors (including cultural beliefs and values) that may influence adherence.
- Dilation training and ongoing review should be provided by a named clinician with the support of other team members.
- Psychological approaches to the promotion of adherence should be considered.
- Evaluation of multidisciplinary outcome should be undertaken and disseminated.

Inpatient training

Instruction and training in the use of vaginal dilators is aimed at establishing effective independent use by the patient. Some UK centres have found that this process is more effective when the patient is admitted to hospital to undertake intensive training over a period of two to four days. Admission enables supervised trials three times a day and ensures that the patient has adequate privacy to practise locating the vaginal pit and using the dilators. The initial progress achieved within the first few days of intensive

treatment can be a strong motivating factor that promotes future adherence. Extended training periods with feedback on the patient's own performance can develop confidence in her ability to use the dilators correctly. This is likely to increase confidence and establish habitual use once at home. Inpatient training is also useful when the patient must travel a considerable distance to the treatment centre and attendance at frequent appointments is difficult.

Initial instruction

The dilation training session should begin with a relaxed discussion of the patient's expectations and the aims of the treatment. The specialist nurse can encourage the patient to express her anxieties and ask questions. The patient is advised to be in a semirecumbant position (on the bed or chair) and is shown how to locate her vaginal dimple or introitus using a mirror. The nurse demonstrates the placing of the dilator, including its angle; the pressure to be applied; and the use of local anaesthetic gel and lubricants as required. The rounded end of the dilator is inserted parallel to the normal axis of the vagina and intermittent pressure is applied for 10 to 15 minutes, gradually stretching the vaginal tissue. Some patients may prefer the bicycle seat method, which eliminates the hand fatigue that can occur during this exercise. The patient starts using the smallest dilator dependent upon the start size of the vaginal pit. The dilators increase in size in 5 mm width sizes until approximately 30 mm width and 100 mm length can be used with comfort (or until the patient is happy with the size of dilator used). At initial sessions, the patient may require oral analgesia prior to the procedure, as the dilation process can be painful. Pain or discomfort appears to occur less frequently and usually resolves as the dilation therapy progresses. Relaxation exercises may be taught in addition or in place of analgesia as required, and used throughout the subsequent dilation. The training process includes supervised trials by the patient and the patient's independent practice. During and after practice, the patient can ask any questions and check that she has used the dilator correctly. Common questions concern the correct amount of pressure to be applied and enquiries about the nature and commonality of the physical sensations experienced during therapy. Whether inpatient or outpatient based, the training process should develop the patient's confident independent use of the dilators.

Ongoing use of dilators

On discharge, the patient is advised to establish a habitual routine of dilation at home and the nurse and patient agree the periodicity of further reviews. Frank (1938) recommended use for 30 minutes per session and nighttime use while Ingram recommended that patients sit on the bicycle seat with the dilator in place for at least 2 hours per day. The frequency and duration of dilation must be planned with the patient, based on a detailed discussion of her daily schedule. Our practice is to recommend routine use three times daily for 15 minutes per session. The initial estimation of the most appropriate and convenient times to use the dilators can be revised during later discussions in clinic. It is vital for adequate adherence that the patient and the specialist nurse continue to review the most convenient times for home dilation and to counter any difficulties as they arise. The same specialist nurse should review the patient's progress at an outpatient nurse-led clinic. In this clinic, the patient would be seen by the specialist nurse only, unless the nurse and patient have requested the presence of an additional member of the multidisciplinary team. Loftus and Weston (2001) suggest that there is evidence that a positive impact on the quality of outpatient care can occur when a service is led by a specialist nurse. Their conclusion that nurse-led clinics are "developed to meet unmet patient need, solve actual or potential patient problems and improve the quality of a service" concords with the rationale for the development of dilation treatment services. Initial reviews should occur approximately every two weeks and then more or less frequently, depending on progress, the level of support needed, and the patient's travelling distance, school or work commitments, etc. Patients are encouraged to contact the nurse between appointments to ask questions, seek advice or reassurance or to arrange the most convenient review appointment times.

Assessment of progress is made by vaginal examination and by measuring the width and length of the dilator that can be inserted by the patient at each stage. Measurements are recorded on the nursing assessment sheet at each visit. The patient can be asked to contribute to the monitoring process by charting the frequency of home dilation. Such a diary chart may aid adherence by serving as a reminder to the patient, and patchy completion might highlight patterns of adherence. Central to the nursing follow-up is a discussion of the patient's assessment of her progress. Both objective and subjective progress form the basis of the goals for the next stage of treatment, the amount of time before return to clinic and the inclusion of telephone contact with the nurse or additional support from any other member of the team.

Counselling

Both during the inpatient-training phase and during outpatient reviews, the nurse specialist needs significant

Table 13.1. Summary of the nurse specialist role

Activity	Components
Nursing process	Assessment, planning, implementation and evaluation
Assessment of individual needs	Flexible appointment times fitted around college or work commitments; awareness of social situation and support; choice of dilation method and instruments
Self-care planning	Promotion of active participation by patient in own care planning (e.g. start of treatment, frequency of dilation, frequency of review appointments); patient information, education and supervision
Continuity of care	Named nurse leads the team involvement throughout the treatment process
Access	Telephone contact for appointments or counselling; long-term follow up; treatment breaks
Support	Patient support and encouragement; support for other family members and partners
Liaison	With other members of multidisciplinary team; with appropriate support groups
Evaluation and dissemination	Monitor and audit treatment process and outcomes; professional links with other centres (benchmarking); share clinical experience

counselling skills to instruct, motivate and support the patient. The nurse specialist role includes maintaining the therapeutic relationship, monitoring behavioural programmes for adherence and referring on to the clinical psychologist or other psychological staff when appropriate (Table 13.1). Telephone counselling skills as well as face-to-face counselling skills may be needed. Supervision of this counselling role can be provided by a clinical psychologist or by a nursing clinical supervisor with training and expertise in counselling relationships. Reasons for psychological referral might include continued poor adherence, increased anxiety, awareness of previously undetected psychosexual problems or the patient's desire to talk in depth about her feelings and thoughts regarding adjustment to the underlying condition promoted by the treatment process. The specialist nurse should be able to assess the need for onward referral and be able to discuss this with the patient. Liaison with the wider clinical team allows the nurse to answer many of the patient's questions regarding treatment and promotes continuity of care when other team members are directly involved (Table 13.1).

When the desired vaginal length and width has been achieved a review appointment in the main clinic can mark success for the patient and allows the whole team, including the consultant, to be involved in the review. This permits discussion of each patient's treatment process and outcome, which then informs future practise.

In an ongoing review of dilator treatment in our unit, over three years (February 1998 to February 2002), 19 women used dilators as a nonsurgical approach to the treatment of vaginal agenesis. The women were aged between 15 years 6 months and 50 years 3 months (average age 20 years 1 month). Of those 19, two were still ongoing with the process at the time of writing and one woman had dropped out.

Table 13.2. Changes in patient's vaginal lengths and widths achieved by dilator treatment

	Pretreatment mean (range)	Posttreatment mean (range)	Change achieved mean (range)[a]
Length (mm)	36 (25–60)	83 (25–100)	68 (20–75)
width (mm)	20 (10–25)	28 (25–35)	10 (0–20)

[a]Results from 16 of the 19 women treated; one woman dropped out of the study and two were still undergoing treatment.

Sixteen women (84%) had completed treatment to their satisfaction. The women used the dilators over an average period (from first examination to last) of 8.9 months. Those who had completed treatment did so within an average period of 7.4 months. Table 13.2 shows the patient's vaginal lengths and widths pre- and posttreatment and the changes they achieved.

None of the women was able to experience penetrative sex at the start of treatment, whereas by posttreatment follow-up (approximately three months after last examination) 62% of those who completed dilation were sexually active (i.e. 11 (57%) of the original 19).

Adherence

The non-surgical creation of a vagina via pressure dilation techniques is largely dependent upon the patient's correct and conscientious use of the dilation instruments. The woman must be active in the training process and negotiate aspects of the process with the specialist nurse. The term adherence refers to the extent to which the negotiated health-related behaviours (such as repeating

an exercise-taking medication) is undertaken towards achievement of an agreed therapeutic goal. This conceptualization of adherence implies more than a passive compliance to a given treatment regimen and emphasizes the patient's active involvement. It is, of course, very difficult for women and adolescents to sustain the use of vaginal dilators and the high level of commitment needed for success. It is vital that, with the introduction of vaginal pressure dilation treatment, the whole team is aware that they are not merely *applying* a treatment but are working to maximize the patient's commitment and promote her continued adherence. Because adherence underpins the effectiveness and efficiency of vaginal dilation, it is extremely influential in clinical decision making, as in other areas of healthcare (Rapoff, 2001). Poor adherence to the demands of nonsurgical vaginal dilation have significantly contributed to the development of surgical stretch methods for the creation of a neovagina (Fedele et al., 2000; Keckstein et al., 1995; Vecchietti, 1979).

Of course the development of the vagina via pressure dilation is not a single event but is extended over a period of months during which adherence is likely to reduce (La Greca and Schuman, 1995; Rapoff and Barnard, 1991). In a study of cancer patients undergoing vaginal dilation, Bruner found that patients reported a rapid decline in adherence even after receiving counselling (Bruner et al., 1993; Flay and Matthews, 1995; Schover, 1989). Another follow-up study of oncology patients found that 57% of the group still used the dilator at 6 months but only 14% reported adherence to the recommended frequency of three times per week (Robinson et al., 1999). The demands of home dilation can be compared to those of physiotherapy regimens. A study of compliance to prescribed physiotherapy noted that up to two-thirds of adult patients were compliant during supervised treatment, but there was a fall in self-reported compliance from 64% to only 23% once supervision ended (Sluijs and Kuiper, 1990). Robinson et al. (1999), therefore, recommended that close follow-up is needed to maintain compliance. Another physiotherapy study concluded that a lack of multidisciplinary support contributed to a reduction in adherence to a prescribed exercise regimen.

The personal nature of vaginal dilation is likely to compound the adherence challenge, along with other factors such as the speed of change and invisible consequences of less than optimal adherence. In addition, measurement of the level of adherence can be made only by means of self-report, clinical judgement and clinical outcome. Patient account is considered the most unreliable and is believed to grossly overestimate adherence (Gordis et al., 1969; Sheiner et al., 1974). Even the reliability of clinical outcome as a measure of adherence is said to vary depending upon the individual, the underlying condition and the clinical acumen of the clinician. However, while outcome may be considered to be of limited value as a stand-alone measure of compliance to health behaviour advice (McGavoc, 1996), it is perhaps the best measure of the appropriate use of vaginal dilators. This distinction highlights both the difference between compliance and adherence and the emphasis of collaborative working with the patient. It is more important that the patient uses her vaginal dilators in the way that produces the best clinical outcome in her case (adherence to working towards a negotiated clinical goal) than it is for her to follow the nurse specialist's advice to the letter (compliance to a given regimen).

Adherence by adolescents

While recognized as a challenge to all patient groups, it has been suggested that adherence further reduces in adolescence (Koocher et al., 1990), when dilation is likely to commence. Central to child or adolescent adherence is that treatment must be recognized as a family issue (Lemanek, 2001). Health- and treatment-related behaviours take place in the family home, are prompted by a parent and are timed around the family schedule. In many cases, even the older child will in practical terms be adhering to the advice of both parent and clinician. At times, the patient, parents and physician may have subtly different goals for treatment, such as achieving normalcy, the capacity to use tampons or the capacity for sexual intercourse (Bryon, 1998; Gordis et al., 1969; Reid and Appleton, 1991). It is important, therefore, to work with parents to promote their understanding and beliefs in the efficacy of treatment, to reduce any ambivalence and to improve their motivation to provide proper support for their daughter's motivation.

A review of 27 studies of the efficacy of interventions to promote adherence in paediatric care found that only three showed clear improvements in disease outcomes (Rapoff and Barnard, 1999). In general, the studies supported behavioural strategies. Glasgow and Anderson (1995), Johnson et al. (1986) and La Greca and Schuman (1995) each recommend focusing adherence interventions on individual family needs. With either an individual or family approach it is necessary to consider the family or parent/adolescent barriers to adherence. Aspects as varied as a shared room or dilation as a focus for opposition or control within a parent–child relationship may form barriers to adherence (Rapoff and Barnard, 2001).

Overcoming adherence problems

If a patient has actively consented to the dilation treatment yet appears unable to use her dilators at home, then it is necessary to try to identify and attempt to remove her barriers to adherence. The psychological perspective on adherence has been to take a patient-centred approach, using the patient's insights as the most valuable way of understanding the mechanisms of poor adherence, and then work to alter these mechanisms. All advice following is informed by the patient's knowledge, beliefs and attitudes, which influence her decision making. Therefore, to understand adherence is to understand behaviour, its antecedents and consequences, its context, the patient's beliefs and the attitudes that underpin those beliefs. The patient's rationality might not follow medical authodoxy but if her idiosyncratic understanding and thinking can be accessed by the psychologist or other clinician then intervention can be based on discussion and explanation rather than superficially challenging the patient's behaviour. Using similar processes, qualitative studies based on patients' accounts of their beliefs and experiences have developed models of patient adherence and have advanced knowledge in this area. Some of the findings from adherence studies can shed light on adherence to vaginal dilation (concepts from research are shown in italics).

The extent of *positive attitude* towards the treatment, the clinical team and the likelihood of success is thought to be influential upon adherence. Indeed, the *perceived efficacy* (her beliefs about how likely the dilation is to work) will be central to her motivation to repeat the exercises regularly. Because efficacy can be defined in different ways, it is necessary to discuss what rate of treatment effect is desirable clinically and what the patient feels is necessary for her to feel satisfied (Arluke, 1980; Falsberg, 1991). In addition, the views of others will impact on the patient's prospective judgement about the likelihood of dilation to be effective. *Lay views* of significant people such as parents and partners and any *past experience* of efficacy, either the patient's own or that of others known to her, are likely to affect her perception of the efficacy of dilation and, in turn, her adherence. The *mode of production* has been highlighted in adherence research. This often pertains to the patient's views of the unnaturalness of medicines. Similarly, some patients contemplating vaginal dilation might require help to overcome a sense that it is not right or not natural to touch her genitals or to insert a foreign body into her vagina. As with certain medicines, it may help to present dilation as a natural and gradual mode of treatment. Although professionals might see vaginal dilation as a benign treatment, patients may still feel that they are *balancing risks or benefits* when going ahead. Such concerns are most likely when dilation follows previous surgical intervention to the genital region and the patient suspects that they may be applying pressure to a vulnerable site. Even without prior surgery, a patient might still worry about harming delicate tissue. In addition, if clear beneficial effects are not observed then treatment may be stopped prematurely, especially when balanced against side effects such as pain.

A perhaps rare but significant side effect could occur in relation to previous traumatic experiences. Beginning dilation could trigger flashbacks to sexual abuse, assault or unsuccessful attempts at intercourse. Other traumatic memories might include painful medical procedures, embarrassing examinations or the diagnosis itself. If the patient experiences any of these associations, she is likely to balance them against the desired therapeutic outcome. *Social context* of any treatment is said to influence adherence. This includes the possible unorthodox meaning of the treatment within the patient's social context. For many, vaginal dilation will mean an introduction to a sexual life; for others it might mean the conclusion of an episode of medical involvement. In some cultures or subcultures, the creation or opening of the vagina when fertility is not affected might signal the desire for sexual activity aside from reproduction. If this is not openly acceptable within her culture, it will be more difficult for the patient to adhere to the demands of the treatment despite her desire or intention. Commonly, the patient's social context may include practical variables such as the amount of privacy available or the amount of family support for the patient.

Practical approaches to improving adherence

While characteristics of a certain disease are said not to determine the level of adherence, characteristics of the treatment certainly do. Efforts can be made to alter a dilation treatment regimen to promote patient's treatment-related behaviours and, therefore, the treatment outcome. A good clinician–patient relationship prevents adherence problems remaining undisclosed, but there are additional, serviced-based strategies that can be used to maximize the effectiveness of nonsurgical dilation treatments for vaginal agenesis (Table 13.3).

Summary

Nonsurgical vaginal dilation is neither an easy option for the treatment of vaginal agenesis nor is it an unachievable

Table 13.3. Practical approaches to improving adherence

Approach	Features
Individualize care	**Provide** choices regarding date time of admission and of ward environment (side room); option for parent to be resident or partner to be involved in treatment
Be sensitive to cultural differences in need	Needs of minority groups or people of different cultures may vary
Provide written information	Written information can influence adherence, correct misunderstanding and alter attitude to treatment; a well-designed and relevant leaflet can increase satisfaction with care; written information (in the patient's first language) should be supplemented by discussion
Utilize peer support opportunities	Groups for women undertaking dilation, and paired admission during training can be offered; introductions to national support groups
Recommend monitoring	Patient monitoring of dilator use and treatment progress can aid patient motivation by showing patterns of activity and progress
Use behavioural interventions	Negotiate a programme of rewards with use of dilators or treatment progress

task for many adolescents and women (Box 13.2). All professionals involved should understand the process required to maximize the patient's adherence and the outcome of this procedure.

Box 13.2 Key points

- Dilation treatment of vaginal agenesis is a genuine alternative to surgery.
- Adherence is the foundation of dilation treatment of vaginal agenesis.
- Timing of treatment must be sensitive to the psychosocial development of the patient.
- All decisions regarding treatment must be made jointly by the patient, parents and clinicians.
- An experienced nurse specialist is the most appropriate lead clinician for this treatment.

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