

Living with an incomplete vagina and womb: an interpretative phenomenological analysis of the experience of vaginal agenesis

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Abstract *The objective of this study was to explore women's personal experiences of living with vaginal agenesis to gain insight in to psychological, social and emotional consequences of diagnosis and treatment. It employed interpretative phenomenological analysis for an in-depth exploratory study of a small sample of women with vaginal agenesis. The verbatim transcripts of semi-structured interviews with seven women diagnosed with vaginal agenesis were used as data for an interpretative phenomenological analysis. Four themes emerged which are described under the following headings: dealing with loss, the experience of medical services, sharing with others, and the role of time. Participants struggled to understand the meaning of their diagnosis and to incorporate it in to a new sense of self. Contact with medical services generally enhanced feelings of uncertainty and isolation. Emotional distress was managed through cognitive strategies and choices about disclosure to others. Participants described how the experience of their loss recurred over time in different ways depending on the salience of their sexual and reproductive identities. Some implications for health care professionals are discussed.*

Introduction

Vaginal agenesis refers to the congenital absence of the vagina. Although it may occur with Androgen Insensitivity Syndrome and other inter-sex disorders (Jackson & Rosenblatt, 1994), most instances are due to partial or complete failure of mullerian duct development (Mayer-Rokitansky-Kuster-Hauser syndrome or MRKH). The mullerian ducts are crucially involved in the generation of the uterus, fallopian tubes and a significant part of the vagina. MRKH has an estimated incidence of between 1 in 5,000 to 1 in 10,000 births of female infants (Rock & Azziz, 1987). Typically, vaginal agenesis results in the external genitalia developing but there is no uterus or cervix and in place of the vagina is a small pouch or dimple approximately 1–4cm in length. However, functional ovaries are present so that the affected woman experiences pubertal growth and development and ovulation (Alessandrescu *et al.*, 1996).

A number of surgical and non-surgical techniques have been described for the formation of a neovagina in cases of congenital absence. These seek to create a canal between the bladder

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and the rectum by either pressure from dilators or surgical dissection (Fliegner, 1987). The 'Frank' approach (Frank, 1938) uses intermittent pressure with graduated sizes of vaginal dilators. Sometimes this is used in conjunction with a specially designed bicycle seat for patients to sit on to put pressure on the dilator when it is being used (Ingram, 1981). This 'pressure' approach continues to be a popular first choice for treatment rather than surgery with its associated risk of postoperative scarring and the need for painful skin grafting (e.g. Ingram, 1981; Williams *et al.*, 1985). Drawbacks to the approach include the length of time needed to create the canal and the potential for treatment to be tiring, embarrassing and practically difficult to engage in. It has been found difficult to persuade some patients to use a vaginal dilator accurately and diligently for long enough to give what is identified as a 'good' result. It has been suggested, perhaps rather perjoratively, that treatment adherence may in part depend on the emotional maturity and motivation of the woman concerned (Fliegner, 1987). In reality, there has been little systematic investigation as to what may be the relevant factors in successful treatment outcome.

Treatment evaluation for vaginal agenesis tends to be quantitative and focuses on anatomic (depth of the constructed vagina) and functional (sexual satisfaction) criteria (e.g. Alessandrescu *et al.*, 1996; Fliegner, 1996; Hojsgaard & Villadsen, 1995). There have been few studies which have considered the emotional and psychological sequelae of vaginal agenesis and its treatment. Those which have, either do not discuss the details of psychological adjustment involved (Fliegner, 1996; Langer *et al.*, 1990) or are largely anecdotal, providing interesting ideas but lacking in systematic analysis of the data or application of a theoretical approach (David *et al.*, 1975; Hecker & McGuire, 1977; Poland & Evans, 1985). There is also a lack of discussion about how treatment methods are perceived by the women themselves, and what factors may need to be provided to help them use these methods or choose alternative courses of action if they so wish.

This study aimed to address some of these gaps in knowledge through adopting an interpretative phenomenological analytic approach (IPA) (Smith, 1995; 1996a; 1996b), which was chosen over other qualitative methods due to its concern with subjective realities and the assumption that a person's emotions, cognitions and experiences can be inferred through analysis of language. This approach recognizes the dynamic nature of the research process, with the aim being to get close to the 'insider's perspective' through the interpretative activity of the researcher (Conrad, 1987). IPA has been increasingly used in the field of health psychology research in order to explore people's relationships with their bodies (Smith, 1996a; Smith *et al.*, 1999) and offers a theoretical paradigm which fits with the exploratory nature of this research project.

Method

Participants

Participants were seven women who opted in to the study out of a potential sample of 40 participants diagnosed with MRKH syndrome across two outpatient gynaecological clinics. All participants had been diagnosed through hospital gynaecological services as a result of investigations in to primary amenorrhea.

Potential participants were contacted through an information sheet which was sent out with a covering letter from their consultant gynaecologist. Participants opted in by returning a reply slip if they wished to know more about the study and to give their permission to be contacted directly by the researcher. Fifteen individuals (38%) returned the reply slip and, of these, eight (20%) indicated they were interested in participating. Informal telephone contact

was carried out with all interested participants who were encouraged to ask any questions about the study, following which they were asked to give written confirmation if they wished to take part. One person declined to participate and so seven interviews were carried out overall (17.5% of original sample).

The participants were all white and of British origin. Table 1 indicates their relative ages at the time of diagnosis and time of interview, using pseudonyms as identifiers. Further information is not included in order to protect participant anonymity.

Interviews

The theoretical approach of IPA favours the use of a semi-structured interview procedure as outlined by Smith (1995). A schedule was constructed to outline the areas of interest to be discussed which included asking participants about the following; how they understood and thought about vaginal agenesis, how they experienced their treatment and what effects if any did they feel the diagnosis and treatment had on their lifestyle, relationships and self-perceptions.

Interviews were carried out at a place agreed with each participant, usually at the participant's home. Interviews were taperecorded and transcribed, with the transcripts used as the raw data to be analyzed using the IPA approach.

Analysis

Each interview was analyzed separately, following an ideographic approach which starts with specific examples before moving up to more general categorizations (see Smith *et al.*, 1995; 1999). The analytic procedure involved a number of steps and was iterative in that each level of analysis informed the understanding of other levels. For a description of the standard IPA procedure, see Smith *et al.* (1999).

The validity of this study is not compromised despite the small sample size because of the different assumptions which underlie the philosophy of qualitative inquiry. The validity of a qualitative study should not be judged with reference to sample size and selection or statistical power, but rather in terms of the applicability of the concepts for describing similar experiences in other situations (Conrad, 1990). The internal validity and reliability of this qualitative approach was aimed for through meeting a number of different criteria. These included using reflective listening skills to check understanding and interpretations during the interview (Stiles, 1993) and clearly documenting each stage of analysis thus allowing chains of inference and interpretation to be open to scrutiny and reflection. To ensure the internal coherence of the arguments made, loose ends and contradictions in the data were noticed and

Table 1. *Participant profile using pseudonyms*

Pseudonym	Age at interview	Age at diagnosis
Mary	25	17
Pat	37	15
Susie	18	14
Rose	18	15–16
Anne	29	14–15
Joanne	35	16
Becky	20	18

included in the analysis and the interpretations of the researcher were constantly checked back to ensure that they were warranted by the data. The documentation for each level of analysis was also looked at independently by colleagues to allow verification that the analysis had been systematically achieved and was supported by the data.

Results

Four superordinate themes emerged from the analysis which were: dealing with loss, the experience of medical services, sharing with others, and the role of time.

Dealing with loss

This theme describes the multiple losses that participants faced in learning about their condition. These ranged from perceived loss of body parts to the loss of social and sexual roles, loss of privacy in relation to sex and sexuality and loss of a sense of normality and equality with peers. This section then goes on to consider some of the strategies participants described using to help them cope with their losses.

Receiving the diagnosis of vaginal agenesis was reported by all participants as being an unanticipated event. Participants tended to have thought they were just starting their periods late and explained their lack of a vaginal opening to themselves as being due to the hymen not having broken. This new diagnosis seemed to change their perceptions of the self and threatened sexual, social and reproductive functioning. In a literal, physical and symbolic sense it was akin to being given an absence which meant participants no longer felt 'whole':

'Cause, you know, you think you're abnormal don't you, don't think you're sort of, I don't know you've been born without something, I suppose it's as if you've been born without legs or arms or you know (Anne).

The loss was likened to the loss of other body parts, and yet was different because participants had to deal with the tension between appearing 'normal' from the outside and yet knowing that hidden inside, they were different:

I mean from the outside obviously nobody ever knew, everything were perfect, you know I just looked like a little girl, a baby girl and all that, everything were normal (Pat).

Participants' struggles to relate with this new vision of their body as being different and unpredictable was mirrored in their difficulties integrating the diagnosis and its implications for their sense of themselves as sexual and social beings:

... You feel like your world's been took off you, don't you, sort of thing, 'cause I mean really when you think about it, it's a natural thing isn't it, get married and have kids ... and then I mean not just having children, there were like the sex side of it, you can't sort of, have a normal sort of sex life (Anne).

Not being able to have children affected how participants related to other women. Most reported having jealous feelings towards women who could have children but found it hard to accept these difficult feelings as part of themselves, not wanting to be what Anne calls 'bitter and twisted'. This sense of being different from and denied the same choices as other

women led to a sense of isolation and an accompanying sense of insecurity about their own self worth:

Um, I just didn't feel like I was worth as much, um, I still think that now sometimes, like if I have a fight with my boyfriend or something I always think oh no, you know, he's got a right to treat me like that because of this (Sue).

The diagnosis brought the intimate and private issue of sex and sexuality in to a more public arena at a time when sexual exploration begins for most young women. The issue of choosing and sharing the diagnosis with partners is discussed in a later section, but beyond this there was a sense of the diagnosis increasing the young women's sense of insecurity about their emerging sexual identity. Becky talked of feeling more 'unattractive' and making herself 'unapproachable', which she related to feeling different from her peers and not wanting to have a sexual relationship. This increased her sense of isolation; 'I feel really on my own. And I do feel a bit abnormal', whilst at the same time she felt her adjusting values meant she was more mature and self-aware: 'I feel more of a person now'. Such contradictions about sense of self were also part of Par's account in that she talked of not feeling different: 'I didn't feel as if I were, I was a freak kind of thing, you know what I mean, I didn't feel like that at all' and four pages later in talking about not knowing anyone else with the condition says: 'this is another thing why I thought God I must be a right freak you know, we'd never heard of it before'.

Using dilators as the prescribed treatment seemed to symbolically reflect the loss of a 'normal' life for these women. Their use also seemed to have a powerful shaming effect because of associations with sexuality, privacy and intimacy. When referring to using dilators participants' descriptions were scattered with words such as: 'dirty', 'obscene', 'degrading', 'clinical and cold', 'embarrassing' and 'not very nice'. For many of the participants the feelings their use evoked expressed some of the core dilemmas which receiving a diagnosis of vaginal agenesis had raised for them:

Sometimes . . . I just sit there and look and think is this my life, I can't be bothered to do any more of this it's just so, a drag and you try to think positive when you're doing it like 'it'll be all right and when you've done this one you'll be fine, when you've finished this one you get a break' and then you just sit there and think I don't want anything else anymore to do with anything and you just, I don't know, this is not my life, I want to be normal (Rose).

Participants reported various ways of trying to deal with their multiple losses. Initially, this most commonly involved avoidance as participants felt shock and denial around the time of diagnosis and tried not to think about it. Many vividly recalled their first reactions where they could not take in the information presented:

I was like [the doctor] was telling one like, the worst news of my life and I'm just staring at the wall, at the pictures on the wall, I wasn't even looking it was weird . . . I could not listen to it all, all the terrible stuff. I just didn't want to listen (Becky).

Avoidance of thinking about it might continue for months or even years, as with Joanne who 'just switched it off for 18 years' until later in life when she became more preoccupied with what she had lost. Other styles of thinking which participants used to manage the impact of their diagnosis included searching for certainty or a sense of meaning with a condition that had not been heard of before by either the participants and sometimes the

medical services too. Without a medical understanding or explanation for their condition, many participants talked about it in terms of fate or chance; Anne talked of it being ‘nobody’s fault is it, it’s nature’ and Mary talked of thinking that ‘it’s just fate really, it’s just meant to be for some obscure reason’.

There seemed to be a tension between participants believing it to be an accidental unpreventable event, but also having an expectation that because it is a medicalized condition, there must be a physical reason why it came about that perhaps hasn’t been shared with them. This made it difficult for some participants to make sense of, as Joanne said:

I’ve always looked at it, this is how I was meant to be, it’s like a quirk of nature if you want. But at the end of the day it isn’t, there is a medical name for it, it isn’t just me that’s got this (Joanne).

A sense of resignation about their losses seemed to be both a stage that was reached over time but also a style of thinking that for some participants helped them avoid confronting their feelings. Anne, for example, frequently used phrases such as ‘you just keep going’ or ‘you’ve just got to get on with it’; ‘I mean I used to get upset but you just keep plodding on, you know, just keep going sort of thing’.

Many participants tried to minimize the significance of their loss by comparing their condition with others which they viewed as worse or by making comparisons with other disabilities:

There are so many terrible things, you know, like you see somebody in the street and know that they are really badly deformed or you can see that they are having a problem and I think, oh, you know, who am I to worry about what’s wrong with me (Mary).

Participants here isolated two important factors—that their condition is not visible and not threatening to life, and used these to compare themselves with others they construed as more unfortunate in a strategy to enhance their own self-esteem.

The experience of medical services

Participants’ experiences of medical services emerged as being important in providing the context through which participants were introduced to the uncertainties surrounding their condition and difficulties in communicating about and integrating it with their sense of self.

The initial period of contact with the medical services was experienced as a time of uncertainty, with participants facing different medical procedures and personnel, culminating in a diagnosis that all participants had never heard of before. Many spoke of not being able to understand the language the doctors used, as Rose expresses:

Some of the words that doctors say, I don’t use them or understand them.

Some participants actively sought information and advice but felt frustrated in their efforts:

Well, just sometimes I’d phone up and say can I come and see whoever like . . . and it were, well, we have to get your notes and send you an appointment through, which is like in 5 months time or whatever, and you don’t want it then, you need someone to speak to like now (Mary).

This lack of accessible and appropriate information exchange left many women feeling isolated, unsupported and unprepared for dealing with the longer-term implications of their diagnosis. Treatment was experienced as focused upon procedures and the physical side to the condition and participants described almost learning a way of interacting with the medical staff which maintained this physical focus and patient passivity:

I went when they told me to go and did what they told me to do but I didn't . . . I didn't participate fully, d'you know what I mean, I did the basics to get me through it an' then just . . . that were it (Joanne).

The impersonal nature of such interaction meant that most participants did not feel they could be open and honest with medical staff. This was most apparent with the issue of using dilators which, as described previously, participants found an uncomfortable experience. Rather than feeling able to talk about these difficulties of use with medical staff, some participants tended to use dilators sporadically if at all, whilst pretending to staff they were using them regularly. As Mary remembers:

Nobody said are you using them or aren't you using them, or are you having sex or aren't you having sex. It was like we've given her the dilators, she's obviously using them and things are great. And that was, you know, as much as was said. And I don't think today that I've told anybody that I never used them [laughing], just put them in a drawer and then threw them away (Mary).

In contrast, where communication was available, appropriate and not just focused upon medical procedures, one participant had felt able to speak more openly and honestly about her experiences and in turn felt listened to and accepted:

We'd just sit and chat about, like other things, and they'd remembered bits of your life you know, to ask you about the next time . . . I used to be really honest with [the nurse], they used to say have you used them [dilators] this week and, no I haven't, and [the nurse] just used to laugh and it was all right (Sue).

Most participants offered ideas for what they would have liked more of from medical services which included such things as practical facts and advice, to meet other women with similar conditions and to be able to talk about their feelings with someone both after diagnosis and in the longer term.

Sharing with others

How participants chose to share information about their diagnosis was a means of managing and coping with its impact as well as a reflection of their adjustment. Most didn't have a name for their condition or not one they felt comfortable using, and also found it difficult to mention because of its intimate and sexual nature. There were concerns about how others might react; for example Becky went through a phase of telling other people in order to try and feel supported or understood, but experienced their reactions as quite rejecting:

I think I just wanted a hug, I just wanted someone to go 'oh, it's all right' and not a lot of people just, they were just like, uh huh, right, let's change the subject and I was sitting their going mmm, and people didn't know how to take it (Becky).

Mary experienced others' reactions as more dramatic and upsetting than her own initial feelings:

It was something that I didn't really want to talk about 'cause whenever I spoke about it people were upset or, like, people kept coming to the house with flowers and, 'are you all right?' And you know, it was upsetting everyone around me and it was like, yeah, yeah I really am, I'm OK (Mary).

In this case the implications of the diagnosis produced a grief reaction throughout the whole family, which was at odds with Mary's own feelings of initial shock and denial and left her feeling isolated:

I didn't want to talk about it, I didn't want to say anything grateful [for mum's support] or, it was my little thing and I wanted to keep it all a big secret (Mary).

Other participants chose to only tell certain members of the family in order to minimize the impact and this enabled them to have some control about when and with whom they talked about it. Choosing not to tell people was a way of reducing the number of difficult or rejecting reactions, especially with potential sexual partners. For example, Becky who had told one new partner:

He was just 'oh my God' he didn't know how to take it, and he got really upset and he was like I really like you but I can't, obviously do anything like that, can I? . . . he just said 'well you can't have sex' . . . and I feel a bit like a lot of people think like that, and I get scared, especially when it's with men (Becky).

Whereas others had not actually experienced negative reactions but feared they might and so had plans not to tell or to tell only at a certain stage:

If it got serious then I would say something, but if it's just, I won't tell them on the first day you know, it would probably just scare them off, but if it were like someone I'd known for quite a while, um, and we were really good friends and all that, then I'd tell him (Rose).

Most participants had only had one or two sexual partners and it would seem that reducing the number of partners was a deliberate decision in order to avoid the potential difficulties in having to tell someone new:

They [partner] know all about it and it's like very easy just to cling to them and it's like, well they understand so best not risk it because if I lose them then someone else might not, does that make sense? (Sue).

Participants had often thought carefully about how they worded their disclosure and most indicated that they only spoke about their womb and/or not being able to have children, with this being the more easily understandable and least sexual aspect of the condition:

I just say, if someone asks me, I just say I've got no womb, it's like simple 'cause then people can understand (Rose).

Where participants had received positive or accepting reactions from others they described the beneficial effects this had on their self-esteem:

[My family], they reassured me, yeah, that's right and I felt all right. And as I said through, um, your boyfriend telling you things and my boyfriend telling me things and saying that you know, he still thought I were all right and you know there were no problems there (Pat).

The role of time

Although this was not a longitudinal study, participants often adopted a chronological framework for talking about their experiences. The challenges created by having vaginal agenesis seemed to evolve and change over time with re-emerging crises according to what was most salient for a particular woman. For example, as teenage women most participants talked of their lack of understanding about the diagnosis and its implications, which corresponded with a lack of assertiveness in relation to the medical services and a sense of having little choice or control over what was happening. Participants wondered if they could have coped better if they had been older and more assertive in seeking out support:

I think that was the main problem really, how young I was, 'cause there's a lot of things going on anyway when you're that age, your body's changing and it's all a bit frightening and then, you've got doctors speaking all these terrible words and, it just ends up a complete mess . . . if I'd have found out now then it's a different thing 'cause I'd ask questions and I'd want answers and I'd get answers (Mary).

Some of the older participants talked of how their sense of difference and potential loss became most apparent when friends of a similar age started to have children:

Early twenties, late teens I would say, when, um, my friends started having children and getting married you know and I thought, well, I'm never going to be able to do any of that, you know, didn't think anyone would want to marry me because I didn't, couldn't have children, all that (Pat).

As they approached an age where they felt too old to have children, grief for lost opportunities in life seemed to strengthen, as in this excerpt from Joanne, who looks back with sadness and regret, and touches upon many of the issues discussed in previous sections:

I think I should have been given that, that option, that choice or whatever, and them actually instead of just saying, well you're not going to have periods and, you'll never have children, you know, actually said you know you're not going to have children, you're going to have to live with this until you're 35 or 40, it's going to affect your personal life, instead of just saying I'm sorry but you're never going to have kids [laughs]. I mean and, it was like, you're never going to have to have a scrape [cervical smear test] as if that's, I mean I suppose it is a plus [laughs], I don't know because I've never had one (Joanne).

Discussion

This section will be used to summarize the main findings of the study and relate them to existing psychological and medical sociological literature. Each superordinate theme will be discussed in turn.

Dealing with loss

Receiving the diagnosis of vaginal agenesis meant that participants were introduced to the idea of their body as different, with the physical manifestation being the absence of the womb and vagina. As is commonly found in people's reactions to traumatic events, participants' sense of self and the world was shaken by their diagnosis (Janoff-Bulman, 1992). Similar to the findings of Charmaz (1983), participants seemed to experience a loss of self through losses of control and action and a sense of isolation. Research on other gynaecological conditions, for example polycystic ovarian syndrome, has also found that women perceive themselves as somehow different from other women and the feminine ideal (Willmott, 2000). This reflects social discourses whereby women are socialized to view their self-worth and femininity as linked to reproductive potential (Baruch *et al.*, 1983) and therefore not being able to reproduce somehow diminishes a woman's sense of self.

Recovery from traumatic experiences entails the rebuilding of stable and safe assumptions about the self and the world. Osborn and Smith (1998) discuss how this theme is one which many recent studies on a range of chronic conditions identify as challenging and potentially problematic. In the face of their losses, participants tried to reappraise and look for the certainties and positives about their condition in order to understand and adjust to its meaning. Participants' oscillating sense of self seemed rooted in the tensions between acknowledging and facing the threats and losses implied by diagnosis, whilst also having to deal with the uncertainties and invisibility of the condition. Participants seemed to struggle to interpret themselves in a stable way, seemingly alternating between polarities such as normal–abnormal, female–not female, different–not different, disabled–not disabled and ill–not ill. Movement between the poles of these different dimensions may be influenced by various factors such as the social and cultural context in which participants grew up as well as current lifestyle factors.

Participants used strategies such as denial, avoidance and searching for an explanation to interpret their situations. Initial denial is a common psychological defence reported in literature on serious illness, as it allows people to minimize their distress through blocking their awareness of threat and loss and repressing thoughts which arouse emotional response. Nichols (1993) points out how denial may collapse after a while, leading to more accurate perceptions and then perhaps anxiety or depression. The presence of this denial may lead to the initial underestimation of levels of psychological distress in patients.

Where denial of having vaginal agenesis was prolonged, it could be seen to have problematic consequences as it prevented the woman from integrating this new knowledge with her existing sense of self and grieving the losses this entailed. Other potential negative consequences are considered in the literature on complicated grief reactions. For example, Worden (1983) describes how a person may be overwhelmed by their grief reaction which, if delayed, may have been triggered off by some subsequent and immediate loss which carries forward previously unexpressed grief (pp. 70–72). In this study, Joanne found that her doctor telling her she might be going through the menopause, and thus reaching a stage associated with the end of a woman's fertility, triggered off her previously unexpressed feelings about her condition and the equivalent losses it had meant for her.

The participants in this study actively tried to make sense of their experience and search for an explanation, but were left feeling uncertain and confused. According to attribution theory, humans have an in-built desire to explain their world in order to try and gain control over it, with the search for causal explanations being particularly strong when anything unusual or unpleasant occurs such as an accident or illness (Brewin, 1990). Similar to the experience of participants with chronic pain studied by Osborn and Smith (1998), participants in this study struggled to attribute any useful cause or explanation to their diagnosis or their subsequent emotional reactions/symptoms. Thus they swayed between believing the cause of their condition and associated distress to be internal or external to them, temporary or permanent and controllable or uncontrollable (Brewin, 1990, p. 108). Their frustrations reflect how the biomedical model they had been given did not facilitate their ability to conceptualise their experience or to understand and accommodate their situation (see Osborn & Smith, 1998).

Many participants seemed to reach a stage of resignation in the face of their uncertainty, not as a sign of acceptance and adjustment but more in recognition of their own helplessness to understand, control or make sense of their situation. Participants also used downward social comparison which has been shown to help people find meaning, enhance self-esteem and engender feelings of wellbeing when there is uncertainty and anxiety in the face of limited information (Affleck & Tennen, 1991). Studies suggest that downward comparisons can indeed promote positive affect but may also be problematic in terms of individuals actually identifying too closely with the 'worse world' they seek to compare themselves with (see Osborn & Smith (1998) for discussion of this). It is not clear whether in this study the use of downward comparison had a discrete effect on participants' self-esteem, and all that can be concluded is that its use represents one way in which participants tried to manage their distress and uncertainty.

Experience of medical services

Participants mainly described their experiences of interaction with medical services as remote and impersonal. Services were seen as inadequate in terms of providing ongoing support and information to facilitate understanding of the cause and meaning of diagnosis, and participants became socialized in to being passive recipients of a treatment regime they found difficult to comply with. This medical style of relating has been widely discussed in literature from medical sociology and social psychology, which identifies how doctor-centred consultations use more closed questions and typically focus upon medical problems with a correspondingly limited response to the emotional agendas of the patient (Weinman, 1997). Doctors have also been found to give medical information that may be too detailed or complex, leading to patients not understanding or misinterpreting important information (Ley, 1988). Maguire (1985), who has written on this theme in relation to palliative care, identifies how medical staff use distancing tactics such as jollyng patients along, selective attention to narrow, physical aspects of the condition, and obstructing attempts at reassurance. These conversational ploys cut staff off from the real feelings of their patients, and act as a form of psychological defence, with the benefits of protecting them from excessive contact with other people's distress and the stresses this entails. However, such a style of communication and professional philosophy denies the importance of patient need beyond their physical systems, and may even create additional distress (Nichols, 1993).

Participants in this study found that their interactions with medical services set the scene for their broader experiences of living with vaginal agenesis. Difficulties in communicating, thinking and feeling about it and associated uncertainties about sense of self and the future

were introduced through their initial interactions with medical services, and then pervaded other aspects of their lives over time.

Problems with communication seemed to contribute to participants' difficulties in using the dilators. Similar to findings for patients with psoriasis as reported by Jobling (1988) (cited in Bury, 1991), it seems that because of the complex psychological and social consequences of living with a potentially stigmatizing condition treatment regimes may heighten the sense of 'disgrace' or 'punishment' associated with a condition. Bury (1991) points out the need to re-think the medical belief in 'rational' communication of information and compliance and to consider broader social, psychological and cultural pressures which need to be communicated and negotiated with the patient.

Where participants had positive experiences of communication with medical staff they felt more supported and valued as persons beyond their physical condition. Literature supports the positive effects of good medical communication, finding that it improves patient satisfaction and adherence to advice or treatment (Ley, 1988) and reduces patient anxiety which may lead to improved health outcome (Greenfield *et al.*, 1985; Stewart, 1995; both cited in Weinman, 1997).

Sharing with others

The management of who, when and how to tell could be seen as an important and complex part of coping with the diagnosis of vaginal agenesis that was interdependent with how secure and accepted the person felt and how they were coping in terms of their thoughts and feelings. Similarities could be drawn with those discussed by Goffman (1963), who in having a stigmatizing or discreditable condition or difference which is not immediately apparent, seek to manage information about themselves. Experiences of shame were implied by participants who sometimes decided to withdraw from others after experiencing embarrassment and rejection or in anticipation of such reactions. Struggles in using the dilators and reconstructing a vaginal opening lead to some participants choosing to restrict their sexual relationships in order to avoid issues of disclosure. This in turn may be seen as possibly reducing opportunities for constructing a valued self through receiving acceptance from others (see Charmaz, 1983). At other times, participants experienced the positive effects of sharing details of their condition during social interaction, similar to those found by Charmaz (1983), whose participants valued interaction which 'maintain[ed] continuity with the past pre-illness self' (p. 183).

Bury (1991) refers to such actions as the 'strategic management of illness' which aims to manipulate social settings and appearances to minimize the impact of illness on interaction, but also attempts to mobilize social resources. Thus participants weighed up the potential costs and benefits of disclosure and aimed to minimize the risks of rejection or embarrassment through carefully choosing who and how to tell and at what time.

The role of time

Such strategic management of illness is a dynamic process which shifts and evolves over time as an individual's social world changes. Bury (1991) discusses how meanings surrounding illness change as they interact with different stages of the life course, and how only with time does trial and error provide guidelines as to the nature of the risks involved in living with a particular condition.

Receiving the diagnosis of vaginal agenesis as teenagers gave participants a sense of physical difference from their peers which had considerable implications for their development of sexual relationships and a sexual identity. Participants reported a lack of confidence and

assertiveness in their interactions with peers and also with medical services, which heightened feelings of not being understood or supported.

The role of the participant's family in helping them to adjust to the diagnosis was important in a number of ways as it provided the context which shaped how participants interpreted and communicated about themselves. This in turn seemed to either facilitate or hinder coping processes such as denial/avoidance and sharing it with others. Thus, as Conrad describes in relation to chronic illness, families act as 'interpreters, caretakers, support systems and buffers' (Conrad, 1987, p. 15).

As participants grew older their comparisons with peers became even more salient in different ways as others around them started to have children. Older participants talked of this as a time of heightened awareness of their difference, loss and restricted choice over having children, and a time when they started to weigh up other options such as surrogacy or adoption. The distress of infertility seemed to leave these women feeling incomplete and inferior to others, similar to experiences of women who are infertile for other reasons such as premature menopause (e.g. Singer & Hunter, 1999).

Implications and conclusions

Participants' experiences of vaginal agenesis portrayed feelings of shock and bewilderment and ambivalent emotional reactions as they tried to construct a new sense of self in the face of the losses implied by this condition. In trying to manage their uncertainty, participants employed specific strategies such as searching for knowledgeable people, developing their own theories about their condition and using denial or covering up. The biomedical focus of interactions with medical services impeded opportunities to express feelings and thoughts and to establish a new, positive self-concept. Participants were cautious in communicating with others about their condition in order to minimize negative reactions and to exert some control over their situation. Longer-term consequences were complex and influenced by social and cultural context.

General clinical implications concern the need to facilitate patient understanding of and coping with their condition through strengthening the alliance between medical staff and their clients. This may include the following specific areas for development:

- (1) *Adopting a collaborative bio-psycho-social approach to treatment.* This could involve staff thinking about the language they use in talking about the condition, and aiming to have patient-centred consultations to improve the level of psychological care the patient receives. Patients could be encouraged to note down and bring along any worries or requests for information they have, and thus to be active in their interactions with staff. Other considerations may include discussion of treatment options including the provision of choice, openness to and acceptance of non-compliance with use of dilators and the drawing up of a time schedule for treatment to meet individual needs. The provision of counselling or psychotherapeutic services might also be helpful.
- (2) *Flexible information provision.* Participants' desire for and receptiveness to information varies across time and individuals, with preferences for different styles and modes of information delivery. Written and verbal information needs to be readily available and appropriate to the individual's needs and value systems.
- (3) *The chance to communicate with others who have vaginal agenesis.* Participants wanted to know about and/or meet others with vaginal agenesis to reduce their sense of isolation and to share ideas, information and experiences in a supportive and safe way.

- (4) *Opportunities to receive support and follow-up long term, beyond the initial treatment period.* This is in recognition of the different stages of adjustment a woman with vaginal agenesis may go through from adolescence onwards, and their need to have access to support and information as and when it feels appropriate to them.

This study does have limitations in that the sample used was clinically derived and self-selected. This excluded those not involved with medical services, or who did not want to take part in a study being run in close liaison with medical staff. It is also probable that women who opted in to the study were those who had reached a stage of acceptance and adjustment where they felt able to talk about their experiences—as Becky said, ‘I’m starting only to come to terms with it now. I don’t think I could speak . . . could have spoken to you I’d say, a year ago’. Thus participants who are possibly struggling the most in living with their diagnosis may not be represented here. Participants were only interviewed on one occasion and it may be that if they had been interviewed more times further useful information may have been gathered. For example, participants were not directly asked about and none spontaneously mentioned their experience of sexual pleasure or choice of sexual activities. This may have been interesting and useful in terms of thinking about how these women defined and experienced their sexual identities in ways other than the ability to have penetrative intercourse. Such intimate information may only be comfortably shared with a longer time frame for data gathering and this may be useful to consider for further investigations. Further research would also be needed to evaluate any service developments to be implemented in order to determine their effectiveness.

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