

# Size Matters: Experiences of Atypical Genital and Sexual Development in Males

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## Abstract

The psychological, emotional and social consequences of disrupted reproductive and sexual development in men are poorly understood. Interview data from eight men who had experienced gender atypical sexual development were analysed using the framework of Interpretative Phenomenological Analysis. The concept of 'discreditation' appeared to dominate these men's experience of themselves and others. Emotional distress was most keenly felt when doubt was cast upon the men's identity as sexually mature males. The extent to which absent sexual development was conspicuous or visible appeared to be an important factor in negative experiences.

## Keywords

*gender, genitalia, hypogonadism, puberty, sexual development*

## Introduction

PHYSIOLOGICAL changes along the hypothalamic-pituitary-gonadal axis trigger sexual maturation. This process is commonly known as puberty. In the male, hypothalamic and pituitary hormones stimulate the release of testosterone from the testes. Testosterone in turn stimulates the production of sperm and the growth of secondary sexual characteristics. When this pathway is disrupted before or during the onset of puberty, a common problem is *hypogonadism* whereby the body does not produce sufficient testosterone to induce normative sexual development. The bodily manifestations of hypogonadism could include: absence of sexual hair in the face and body, a high voice, reduced muscularity, breast development, an under-developed penis and under-developed or absent testes. Administration of replacement testosterone therapy can induce some degree of sexual development however the majority of men treated for this condition retain smaller than average genitalia and experience fertility problems (Albanese & Stanhope, 1995).

The psychological, social and emotional consequences of atypical sexual development for both sexes are at present not well understood, though poor psychosocial outcome is generally assumed (Rekers, 1992). For hypogonadal men such conclusions are based on a few descriptive studies focusing on the relationship between penis size and psychosexual outcome (Money & Clopper, 1975,  $N = 5$ ; Money, Clopper, & Menefee, 1980,  $N = 5$ ; Money, Lehne, & Pierre-Jerome, 1985,  $N = 9$ ). These studies concluded that concerns about small penis size were central to the experience of psychological distress. However, most of the men described in this series of studies had experienced delayed puberty and also presented other sexual development problems, not just small penis size. These studies have failed to examine systematically the relative impact of other aspects of atypical sexual development.

This premature focus upon penis size as the aetiological factor for the distress experienced by this population reflects the potential of these men to influence a much wider and contentious debate about the management of individuals presenting with atypical genitalia. The presumed poor psychosocial outcome of hypogonadal men

has been used to justify the surgical reassignment to the female sex of male infants presenting with micropenis and other genital anomalies. The decision to reassign is based upon the functional morphology of the penis as the best criterion for determining the sex of a baby. Functionality in this sense has been defined as the capacity of the penis to achieve vaginal penetrative intercourse (Kessler, 1997). The continued practice of surgical reassignment is now the subject of a fiercely contested debate (Kessler, 1997), the outcome of which rests heavily on the debate about how best to understand and measure the psychosocial outcomes of individuals who experience atypical sexual development in either sex, irrespective of whether they have undergone normalizing surgery. Thus the nature of the presumed psychological distress experienced by men with atypical sexual development is a timely but under-researched issue.

### *Aims of current investigation*

This study presents one part of a larger mixed methodology study looking at the long-term psychosocial outcomes of men who experienced atypical genital and reproductive development prior to puberty (Chadwick, 2001). The study aimed to contribute an empirical account of the lived experience of atypical genital development. In developing a narrative about some of the challenges of living with sexual underdevelopment we were concerned to prioritize the men's personal meanings over professionally driven concerns.

### *Interpretative phenomenological analysis*

The framework chosen for this analysis, interpretative phenomenological analysis (IPA), is ideally suited for the task of investigating personal meanings (Smith, 1996; Smith, Jarman, & Osborn, 1999). The outcome of an IPA is an analytical account of how a particular set of circumstances is experienced by one or more individuals. This account is 'phenomenological' inasmuch as it is 'concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself' (Smith et al., 1999). The account is 'interpretative' because it recognizes that it is the shared

conceptual resources of the researcher and participant that enable the former to describe and analyse the experience of the latter.

IPA shares some similarities with other qualitative research methods in that it does not assume that another person's experience can be directly known and it is concerned with the meanings given by individuals to their experiences. These meanings are primarily understood through accounts given in *language* and involve a process of *intersubjective interpretation*. The roles played by these two aspects of IPA in the generation of a research account need to be clarified in order to distinguish it from other qualitative approaches.

### *The role of language*

Unlike other language-based approaches to meaning, for example discourse analysis (Edwards & Potter, 1992), IPA holds that language is reflective of a reality that exists beyond the linguistic account of it (Smith, 1996). While accepting that the meaning of an experience is to be primarily found in the language used to describe it, IPA also embraces the contribution that non-linguistic experience can make towards subjectivity (Yardley, 1997). Within this approach having a body is in itself a meaningful experience. The body is viewed as offering both constraints upon and possibilities for the meaning of any particular experience (Merleau-Ponty, 1962). This has implications for the way in which one uses linguistic material within a phenomenological analysis; the meaning of an experience can be communicable by language without being entirely reducible to it.

### *Intersubjectivity*

IPA is based upon the principle of intersubjectivity. It is the shared conceptual resources of the researcher and research participants that permit the former to come to an understanding of the latter. This principle organizes each stage of the research process from the construction of interview questions to the analysis. Each stage is conducted with the explicit aim of establishing a research account that is *more* reflective of the participant's experience than of the researcher's preoccupations and concerns. The use of intersubjective interpretation requires that the researcher backs up their interpretations by grounding them in the material from which they

were constructed (Banister, Burman, Parker, Taylor, & Tindall, 1994; Smith, 1996). Thus this article quotes liberally from the texts of the research interviews to help readers make judgments about the degree to which it can be thought of as being reliable and/or valid (Madill, Jordan, & Shirley, 2000).

## **Methods**

### *Participants*

Eight men were interviewed over a period of six months. Seven of the participants volunteered to be part of this study after participating in the hospital out-patient survey investigating multi-aspects of quality of life in this population (Chadwick, 2001). One participant volunteered to be part of the study in response to an advertisement posted to an Internet support group for men presenting hypogonadism.

The main criterion for inclusion in the study was that the men should have a diagnosis of hypogonadism with pre-pubertal onset and were taking replacement testosterone therapy at the time of the study. Participants were excluded if they had had multiple concurrent health problems, other endocrine conditions affecting sexual, reproductive or genital development, severe learning disability, neurological impairment or had experienced surgery during childhood to correct any form of genital anomaly. This resulted in a sample of men whose sexual development, while atypical on a range of dimensions, did not place them in that category of individuals for whom the non-standard appearance of their genitals might prevent them from being unambiguously assigned to the male sex. Table 1 details the demographic characteristics of the men and the relevant medical information.

### *Interview schedule*

A semi-structured interview schedule was used to collect information from individual participants. Questions were phrased with the principal aim of eliciting a narrative of the men's developing understanding of their condition over time and situation.

### *Ethical approval*

Ethical approval for this study was sought and obtained from ethics committees at both the

Table 1. Demographic and medical information

Name	Age	Occupation	Diagnosis	Age at diagnosis	Age of puberty onset
<i>Men who experienced delayed sexual development</i>					
John	Late 50s	Engineer	Hypogonadotropic hypogonadism	34	34
Joe	Mid 20s	Technician	Hypogonadotropic hypogonadism	16	18
Philip	Mid 30s	Engineer	Hypogonadotropic hypogonadism	23	24
Mike	Mid 30s	Self-employed	Cryptorchidism	25	26
<i>Men whose sexual development was not delayed</i>					
Alex	Mid 40s	Self-employed	Cryptorchidism	19	14
Geoff	Late 20s	Mechanic	Klinefelter syndrome	23	13
Andrew	Early 30s	Builder	Hypogonadotropic hypogonadism	15	12
Bill	Late 20s	Engineer	Multiple pituitary hormone deficiency	7	14

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**Analytic focus**

The interview schedule was constructed to elicit the personal meanings given to experiences associated with atypical sexual development. However, atypical sexual development is a complex multi-faceted process extending over a number of years. It therefore seemed ill advised to attempt to generate an account that reproduced the entire spectrum of experience recounted in the men’s narratives. The analysis therefore prioritized the development of an account that developed our understanding of the experience of presumed psychosocial distress associated with atypical sexual development. This focus seemed reasonable in light of the contentious debate surrounding the nature and origins of distress in this population. Given that previous research had neglected to account for the likely impact of visible pubertal delay in accounting for psychological distress in this population of men, narratives associated with the experience of pubertal delay were prioritized as the point of analytic focus.

**Analytical method**

The basic strategy for analysis was the detailed decomposition of one interview text into themes that were then cross-referenced against close readings of subsequent texts. The analytical account linking all the texts was then (re)constructed during a sustained and cyclical process of (re)engagement and (re)interpret-

ation linking the analytical account with the interview material.

**Analysis**

The dominant theme of this analysis is the experience of *discreditation*. This concept, originally described by Goffman (1963), refers to the range of personal experiences that might arise when an individual possesses certain characteristics deemed *deviant* by a particular society at a certain socio-historical point. Goffman’s descriptions of the psychological impact of discreditation have been used to frame this analysis of the experience of sexually atypical development.

Discreditation can be divided into two sub-states: being *discredited* and being *discreditable*. An individual is *discredited* when their public identity is unavoidably marked by the clear visibility of their deviant characteristics. An individual is *discreditable* when their deviant characteristics, while apparent to themselves, are not immediately obvious to others. Thus it can be appreciated that the characteristics of social interactions available to the *discredited* and *discreditable* are likely to vary.

A state of discreditation was common to the accounts of social difficulties and psychological distress in all eight men. However, the way in which discreditation contributed to distress varied with the extent to which the men’s atypical sexual development was readily perceivable by others. Four of the men experienced delays to sexual development that were visibly obvious

to other people (i.e. absence of sexual hair, high voice, poorly developed musculature). These men, at this stage of development, are described as being in a discredited state. The other four men's experience of atypical development was one of possessing the visible characteristics of a sexually mature male while having genitalia that were under-developed or atypical for their sex (e.g. small size of penis and testes, absent testes, enlarged breasts). These men were described as being in a *discreditable* state. Through replacement testosterone treatment the four men with visibly delayed sexual development eventually developed the outward appearance of a sexually mature male although they still had to contend with having genitalia that were under-developed. This transition from a state of being discredited to discreditable is described as the *discreditation trajectory*.

This analysis gives an account of this trajectory and the positions that bookend it. It describes some of the emotional, psychological and social difficulties faced at various positions and offers explanations as to the possible contributions to distress at each stage. There are three sections to this analysis: Before Discreditation, Managing Discreditation and Becoming and Being Discredited as Men. Material from the four men who experienced sexual development that was visible to others forms the basis of the first two sections, while the final section draws upon material from all eight participants.

All identifiable details of the participants have been changed to ensure anonymity.

### ***Before-discreditation: benign bodily difference pre-puberty***

While aware of the way in which their bodies differed from those of other boys, most participants did not attribute negative meanings to the differences until the onset of puberty in other boys:

Mike: I always did enjoy swimming and then obviously with puberty and that I was more self-conscious of my body, so I didn't go swimming.

Philip: When I was seven, they discovered that I had undescended testes, and I remember other boys having similar operations and they would go to school and the teacher would say 'now children he's gone into hospi-

tal because some boys . . . So I knew it was common.

Puberty led to a shift in interpretation of bodily differences. Hitherto benign bodily differences became invested with negative meanings as they noticed their peers' changing physique:

Mike: The main difference that was very apparent was the voice. The fact that I still had a high voice when everybody else's had dropped. That was the obvious difference, and it's very difficult to know what's normal and not normal going through that stage of life anyway.

Philip: . . . when I was 15 or 16. When I noticed that I wasn't developing, sexually or physically, like my other classmates. They would have some kind of beard growth or stubble, their voices would break, they would be bigger, bulkier . . . but I stayed the same. I was very underweight, I was very skinny, my voice was quite high pitched, I had no beard growth at all.

John: I was finding increasing difficulty in accepting the fact that I looked different to other people. I had no facial hair normally associated with the male. I was weak, underweight, very pale complexion.

Unlike previous descriptions, the accounts given by these men of their own bodies start to become infiltrated with notions of normality and typicality. Notions of abnormality were based on evaluative comparisons with the bodily *appearance* of other men. Descriptions containing references to deviations from normal patterns of bodily functioning were noticeably absent. Thus descriptions of their body's 'abnormality' were couched in terms of deviations in its appearance and not in terms of the way it functioned.

### ***Becoming discredited***

All four men whose absence of sexual development was visible to others described the period of relative visible under-development as problematic. Three men reported feeling depressed while two reported suicidal ideation. The emotional difficulties arose from the men's increasing divergence in physical appearance compared to their peers. Distress arose from the

conflict between what the men felt themselves to be and what the appearance of their undeveloped body symbolized to others. The undeveloped body discredited them along a number of dimensions of 'normality' that they considered important. The experiences of these men suggested three potential sources of discreditment. These are described next.

*Being treated like a child while wanting to be an adult* The men's feelings of being abnormal were underlined by the way in which their developing peers responded negatively to their lack of bodily development:

Mike: I mean, at school it was, I think, the prejudice was a lot more obvious because people knew me and saw me and they obviously knew something wasn't quite right and they obviously and I suppose with school kids it's fairly easy to pick on somebody who's different.

The negative reactions of others constantly undermined the men's developing sense of themselves as an adult male. This challenge to a precariously maintained identity was further underscored by the structure of the social environment itself:

Phillip: . . . the people at college were much more developed than I was, and again I felt very apart from them. I was very much a loner, I never went out. Whenever I went to a pub I wouldn't get served whereas people younger than me would. Very embarrassing, night clubs, you get the taunts, teasings.

Joe: The major thing was like simple things like going to a pub and not being let in . . . 'cos the whole thing was that I was a late developer, physically I was a late developer. Socially that made me a late developer, because when you are 16 or 17 you should be going out to pubs and social life and I didn't.

The men became socially isolated because the structure of the social environment of their peers was dependent upon having the physical passport to an adult social identity that they clearly did not yet possess. The experience of these men was thus one of being largely dismissed from adult life. Although their physical body remained the same, the social value of

that body changed. The negative values associated with the undeveloped body in this new social context excluded them from the increasingly adult social life of their peers. They became discredited adults.

*Feeling male, looking female* Perhaps the most powerful source of discreditment was the way in which others could read the undeveloped body as being feminine:

John: I was walking around in this shell, which was a shop window if you like, it was a lie. Which is not what was in my head. Inside I would be very much male but outside I was just the opposite. And there's the conflict.

Mike: I suppose I thought, well, yeah, I knew that I was a bloke why shouldn't they know . . . because I suppose being upset by that meant that I didn't cope with that very well. But looking back on it I can understand why people would jump to that conclusion [that I was a female].

Phillip: I was about 17, 18 and one guy, I still remember . . . and he said 'stop taking female hormones' . . . And you know that was probably the most upsetting comment that anyone ever said to me.

Distress arose from a dislocation between the social identity advertised by their bodies and the personal and gendered identity that they 'knew' themselves to be. In these descriptions the dislocation is couched in terms of a difference between males and females. The experience of distress does not arise from being seen as less than a man but from the thought of being seen to be like a woman. Not only were they discredited as adults, but also as men.

*Feeling normal, looking like a weirdo* Some men felt that their undeveloped body advertised them as belonging to social categories that were already discredited:

John: And the fact that I was, gave the appearance of being weak and feminine was a fact. And I knew there was a conflict inside me growing up . . . My definition of a feminine man is Julian Clary and people like him. And I didn't want to be regarded in that way 'cos I knew I wasn't like that . . . I hate effeminate

men, I hate the idea of effeminate men, and to be regarded as one was the ultimate insult.

Philip: I wanted people to know that there was a physical explanation, something wrong and that I wasn't a weirdo taking drugs, it's just that my body wasn't working properly . . .

In both cases physical difference is associated with something that the men consider to be morally shameful. The image created by Philip has a Dickensian quality in the way it links physical imperfection with moral impecuniness. Both Philip and John felt powerless to control the way in which their bodies could be read by others to signify something shameful about their character. In the eyes of others, both felt tainted by the way in which their bodies advertised a morally dubious social identity.

#### *Distress through discreditment: a summary*

The experience of looking non-sexual in the eyes of the public appears to have been fraught with difficulties. Distress arose from the experience of conflict between what the under-developed male body was felt to represent to others and how the men would have wished to be thought of. The men felt powerless in preventing others from evaluating them as abnormal, childlike and feminine.

The under-developed male body seems to take on the significance of a stigmata—a mark that is taken by others to denote something that is unacceptable about the individual who bears it. The stigmata of the sexually undeveloped adult body is something that is very much within the public domain and, as such, plays a crucial role in structuring social interactions. These men thus have the unenviable task of having to manage social and psychological consequences of their discreditment. The next section describes how they achieved this.

#### *Managing discreditment*

The men's main response to managing their discredited social identity was one of withdrawal and isolation. This strategy could be total or partial. A strategy of partial isolation was described by both John and Mike:

Mike: I suppose it was easier to hide behind the 'what I don't know wouldn't hurt me' sort of thing, so you don't actively, well I didn't

anyway, go out and find how I was different and so on. And looking back on it it seems fairly easy in some ways to isolate yourself . . . every now and again, I suppose . . . You met someone new and it would make you think that 'I am different because people see me as being different'.

John: I buried myself in my work. I worked in a factory for 28 years and I've always had interests, hobbies and things like that, . . . I used to work seven days a week sometimes, shifts, days, and nights. And I got through that way. I didn't think too deeply about it. I had hobbies; gardening, handicrafts, whatever took my fancy . . . so my life was taken up with that in a way.

Partial isolation was a strategy for avoiding thoughts and feelings relating to their bodily appearance. John and Mike insulated themselves from information and situations in which they could potentially be confronted with their discredited identity. Their isolation strategies allowed them to achieve a productive life in spite of their bodily appearance.

A strategy of total isolation was described by Joe who became consumed by his lack of development and withdrew from all social contact. Preoccupations about 'not growing up' became so extreme that it partly accounted for failing most of his secondary level exams:

Joe: I was starting to get really depressed about it and stuff and my schoolwork really suffered and this was like coming up to GCSE and stuff. Yeah, I fucked 'em up 'cos I wasn't growing up properly. All my attention was on that . . . It's just that I was hoping that things would kick start and that I would just grow up . . . and I just decided to, well basically, I just slept through two years, I just slept. And that was the way I dealt with it. I could have gone mental or whatever but I just went in my shell and . . .

For Joe, lack of bodily development became the organizing factor around which his life was built. He did not feel that he could progress with life until his body had developed. In retrospect he described his behaviour at this stage as 'killing' himself. Other men used words such as 'surviving' and 'existing'. Such phrases connoting a diminished self and life were commonly used to

communicate the distress felt by all four men during this stage of discreditment.

The way out of this situation for all of the men came only with actual bodily development. Secondary sexual development had to be artificially induced with testosterone therapy. For three of the men, however, seeking medical help was itself a challenge.

### *The difficulties of seeking help*

Only one of the men in this study, Joe, sought a medical opinion as a teenager about his delayed sexual development. Philip, Mike and John delayed seeking help until the ages of 23, 25 and 34 respectively. The difficulties experienced by men in seeking help with their condition can be organized into two themes: *when does normal become abnormal* and *avoidance of a discredited identity*.

#### *When does normal become abnormal?*

Given the wide variations in bodily development in pubertal transition during adolescence and young adulthood, it is unsurprising that participants reported having experienced considerable confusion in knowing whether their bodies were developing normally:

Mike: it's very difficult to know what's normal and not normal going through that stage of life anyway . . .

Philip: Because up until then [the point of seeking treatment age 23] I thought it will happen, my father apparently was a late developer, but there's various definitions of late developer . . .

The men experienced their own bodies as abnormal because of comparisons with others and not because of any change in bodily function. This seemed to make it more difficult for the men to determine when normal development became abnormal. This is illustrated by the comparison of the following descriptions offered by Joe (who had an identical twin brother) and John:

Joe: And yeah, having someone there who is like the spitting image of you and you're identical but you don't look alike, it was just the clearest indication that there was something wrong . . . and so I saw that something was not happening and I just went to the doctor.

John: [in the context of a long conversation about why he didn't seek treatment earlier] Well [sighs] it's like it's always been there. Perhaps if I had had a normal life I'd at some point I would have found it impossible to bear, but because I'd never had anything else it was just, I think you just . . .

Joe's expectation that his development should be synchronous with that of his twin helped him to identify that something was wrong. Joe had a model of his own development that gave a reliable indication that things were not proceeding as they should. This was not available to the other men. John described his experience of his body as something that he was unable to stand apart from and evaluate objectively. His 'abnormality' was, in embodied terms, phenomenologically normal; he had never known 'anything else'. This made it difficult to state with certainty that his development was abnormal. John compares his situation with a hypothetical one: a 'normal' life that becomes abnormal. The hypothetical situation is one that permits a contrast between normal and abnormal that could have helped him to make the decision about when to seek treatment. Without this he, like the other men, was stranded with regard to what to think and what to do about his body.

*Avoiding a discredited identity* The difficulties in distinguishing between abnormal and normal development might explain the delay in seeking professional advice. However, it cannot explain the men's failure to seek help even when their under-development was clear by a wide margin. One possible explanation is that these men withdrew from information and situations that highlighted their differences, thus potentially preventing them from comprehending the extent of their abnormality. As a complete explanation however, this was not easily supported by the men's descriptions of their failure to seek advice. These accounts suggested that these men were not unaware of their difference, but were afraid of what this difference could mean:

Mike: It's a big risk I suppose. If you are fairly ignorant you can actually comfort yourself with the thought that nothing can be done and you know you were doing the right thing. But the other side of that is that something can be

done and you know. So it's: do you hide behind the not knowing as comfort sort of thing, or do you go and find out and then the risk is being told nothing can be done, so . . .

John: I felt like there was something missing. I never admitted that to myself when I was younger but as I said till the age of 34. That was the first time that I talked about it to anyone . . .

Philip: I had a heart with (my dad) and said that 'I'm worried that something's wrong' and he made an appointment to see an endocrinologist . . . but I cancelled it. Because I was scared. I was scared about what I would hear. And this was about a year before I had the guts to do it.

These men were clearly in constant negotiation with themselves about what to do about their undeveloped body. Seeking help was not a simple matter of knowing that something was wrong and looking for assistance to deal with it. There appeared to be risks attached to the seeking of advice about their condition and what might have resulted from that. The language used creates an image of hiding from knowledge that is perceived to be potentially threatening. In phenomenological terms it was clear that the men could not, or were reluctant to, articulate what they were afraid of discovering. However it seems clear that the avoidance of seeking medical advice served the function of preventing the men from having to confront what their physical difference might mean about themselves and their prospects. The strategies of isolation and withdrawal described earlier can also be seen as being functional in a similar way.

#### *The difficulties of seeking help: a summary*

The men experienced their development as being abnormal in social rather than embodied terms. This was dependent upon the constant comparison of their own body with that of their peers. However, since the criteria against which this social comparison is made is itself highly unstable, the perception of abnormality was not clear-cut. It became difficult to tell when normal became abnormal. Seeking help involved taking risks that could threaten the emotional status quo. The contents of these risks were not readily available for phenomenological reflection but

were characterized by fear. Not seeking examination and advice may have served the powerful function of helping the men to avoid fears associated with what their under-developed body might mean.

#### *Becoming and being discreditable as men*

Through treatment, all four men reached a stage where they felt generally satisfied with their visible sexual characteristics. However, the development of a normative adult male appearance also saw the transition from being discredited to being discreditable. While treatment had led to genital development this did not have a major impact upon the men's feelings about the appearance of their genitalia. The perceived unsatisfactory genital appearance could undermine their newly minted social identities as sexually mature men. Thus despite the appearance of outward 'normality' these men still felt far from normal in the areas of sexual potency and reproduction. All four men described their experience during this phase in terms of 'milestones' along the 'road to normality'. Psychological difficulties were often experienced as hurdles to be got over with in order to achieve this end point. This section describes three such hurdles to 'normality'.

*Having the right equipment* The men described how they felt sex to be impossible for them before treatment. This feeling centred upon the view that their genitals were structurally inadequate to sustain the mechanics of heterosexual penetrative intercourse:

Philip: I just didn't think that I was capable of having sex.

Joe: I didn't know that I could have sex, 'cos I thought physically I really can't.

Mike: I suppose that I did wish that things would work out and I was normal and would have a normal life, which included a perfectly normal sexual relationship. I remember thinking that. But then you think, well, is it possible? And I didn't know that at the time . . . because of the physical things.

Pre-treatment, the delayed men placed a great deal of emphasis upon their genital characteristics as the major barrier to having sexual

relationships. Post-treatment, they were generally surprised to learn that having the right equipment was only part of the story:

John: But it didn't change my life that much, other than physically, because I was still left psychologically with inhibitions, towards girls and women. Although I fancied them like hell, I was unable to make the approaches, so I found that frustrating . . .

Mike: Yeah, 'cos I was aware that things weren't right. But when things were sort of put right you think, right, it's just a psychological thing now. Eh, 'cos physically you're fine.

I: Knowing that it was psychological, did that help? Or was it the case that the sex drive in itself made you more willing to overcome . . .?

Mike: It did, because, but psychological is more difficult, I think, because physical stuff you go along a set process and there's things that can be done or can't be done but psychological, you know, there's big hurdles to jump . . .

Joe: Yeah, in some ways it's a real physical problem but it's always, it's more internal than anything else . . .

Psychological barriers to getting a sex life were experienced to be at least as great as the physical ones. Having the right equipment seemed to be a necessary, but not sufficient, condition for sexual activity (defined by implication to be penile penetration). The majority of the 'hurdles' faced by these men related to their feeling that their atypical genitalia could cast doubt on their claim to be a normal adult male in the eyes of others:

John: To me it was always something that I kept a secret. And if I was to have sexual relations with a woman the secret would get out. My cover would be blown. Mixed up with 'what's she gonna think of me, am I gonna be the object of tomorrow's gossip?' And so forth. And I found that thought unbearable. That alone would be enough to put me off.

Philip: I suppose there was a little bit of fear there. I kept thinking that they would burst out laughing. But it never happened. Never happened.

Joe: [In the context of a long conversation about how the condition affected his view of being a man] Being capable of having sex. Was a lot of it. And yeah because you think that if you've got small genitals sort of thing you can't. One you think you can't and don't even think of yourself in that position . . . basically, you think 'oh they're gonna find out and that will be it'. You lose all confidence, any shred of confidence that you had is shattered.

The sexual encounter is described as a situation in which their inadequacies as men are potentially laid bare for everyone to see. The stakes are high. The men imagine that others would consider the appearance of their genitals to be at best a joke and at worst the subject of public humiliation.

The cost of being found out to be a less than proper man was imagined to be high. Several men were fearful that being seen by potential partners as not a normal man could be used against them in hurtful ways. This was evident in the fantasies of humiliation that attended the descriptions of sex. Fears arising from such fantasies were powerful determinants of the structure of the men's sexual behaviour:

Mike: I think that it is probably a defence mechanism. Ehm . . . Because if you trust somebody you are less likely, if someone does notice that something is wrong or different in some way, then you know, if you trust them you don't feel so vulnerable. But no, I've never had sex with anyone I haven't trusted (laughs).

Joe: Even the first time I had sex and stuff I was wary and I told the girl this first of all that this is what I have got (concerns about size of his penis) and stuff. Yeah I always used to say that I have testosterone then I used to say the diagnosis and stuff and there's always. I'd always planned to do it like that anyway.

These men only have sex with 'good people' and make 'good choices' (Mike) about who to become sexually involved with. This is done with the implicit aim of minimizing the psychological damage that they feel might result from someone who might react negatively to their genital difference. Trust in a partner who would not ridicule their perceived genital abnormality

was an essential prerequisite for all sexual activity.

*Being able to perform* The men described the act of having sex as a major milestone on their road to normality:

Mike: It was quite nice to have sex for the first time, you think 'right I'm on the road to normality now'. Although it meant more to me than that. That was a step to being normal in a way.

Joe: Yeah, I think like everyone else it was like 'Is that it?' And the best thing to come out of the whole thing was 'yeah, I can actually do it'.

I: Did getting involved in a sexual relationship actually improve the way you felt about your body in sexual terms?

Phillip: Yes. Yes it did. Even though I don't have a sperm count I still felt that 'it's working' and ehm that made me feel like I was almost normal. I'm almost normal . . .

Having the right equipment and being able to perform were especially important to these men. The acts of penetration and orgasm with a partner gave them permission to enter the category of 'normal' men who are grouped by their ability to engage in penetrative intercourse. This is illustrated by the way in which Joe referenced his experience with the 'everyone else' that found the first time something of a deflating experience. Knowing he can 'do it' finally establishes him as belonging to the category of normal sexually active men.

*Being experienced* The next milestone on the road to normality was that of having sufficient amounts of sexual experience. The notion of what was sufficient was closely influenced by the idea of the normal male as being naturally sexually promiscuous. The following extract from the interview with Phillip illustrates several passages found in the interviews with other men in this study:

Phillip: The first time I had sex was when I was 23, prior to that, no desire to. I had a couple of girlfriends. I've had very few girlfriends. I've had four my whole life. One prior to diagnosis and three since. So far as sexual experi-

ence is concerned I've got very little. I should say quite a lot because that's what men are supposed to say isn't it?

I: Well, you feel you've got little.

Phillip: Yeah.

I: And how do you define little, is it by number of partners?

Phillip: Number of partners. Promiscuity.

Having sex allowed Philip to feel 'almost normal'. He clearly indexed the notion of normality to the concept of the promiscuous male. His perceived lack of sexual experience led Philip to feel that he fell short of this norm.

The idealized norm that men are constantly acting out their lustful urges was evident in the participants' speculation on how things might have been had they received treatment for or come to terms with their condition sooner:

Phillip: Ehm well, if I was completely healthy normal and everything else . . . I would have been quite different if I hadn't had that embarrassment earlier in life. I would probably have gone to night-clubs and picked up a girl or two in the disco. It's just not me at all.

Joe: The main thing [not having the condition] is that it would have changed the way I am, I mean I could have gone well, gone about and shagged whoever I liked, and yeah, fine.

The men expressed regret and sadness at the loss of potential sexual opportunities during the teenage years. For most of the men the loss was articulated in quantity rather than quality terms. It is possible that these descriptions represented an over-estimation of both the quality and quantity of sexual experience available to the average male adolescent. The previous experience of being marginal to the sexual arena may have contributed to this somewhat unrealistic estimation.

*(Not) being a father* The final arena in which these men felt discredited as normal adult males related to whether or not they would be able to have children. The experiences of the men in this area were very diverse. Two men, John and Mike, were completely infertile. Mike had known about this since he was 12 while John never wanted to have children. Phillip had

undergone fertility treatment that had failed. Joe was aware of his potential infertility but had yet to seek treatment. Because of the diversity of the men's experience it was difficult to make generalizations. However all participants, apart from John, expressed feelings of sadness and loss at their inability to conceive:

Phillip: Perhaps the most upsetting thing about the diagnosis was the fact that I wouldn't be able to have children. That was the most upsetting thing.

Joe: When someone says to you 'you can't have kids' you just have it. It's just something that if you think it's not gonna happen, although it's one thing that I really didn't want to accept, but on top of everything else I just did.

*Possessing or achieving normalcy* The sexual development of four of the eight men interviewed did not include a period of substantial pubertal delay. For the most part these men described the challenges of atypical sexual development in much the same way as their delayed counterparts: atypical genital appearance was experienced as a deviant characteristic that conferred the status of being a discreditable man. Common to the accounts of both groups was the narrative of passing milestones, mostly relating to sexual experience, on the road to 'normality'. The one notable divergence between the groups was apparent only in the men's talk about the challenge of infertility and its impact on their sense of being masculine. Those men who did not experience pubertal delay talked as if masculinity was something that they possessed which being infertile had 'chipped' or 'taken' away, while the men whose puberty had been delayed saw the ability to have children as a step towards the achievement of masculinity:

I: Has having Kallman's affected your sense of being masculine?

Phillip (delayed puberty): I certainly think yes prior to diagnosis. Post diagnosis, no. But the inability to have children is that one thing that I needed in order to be a man if you like. But essentially I feel completely male, completely male.

Bill (undelayed puberty): I don't think I've ever questioned it [masculinity] ... But I

think the bit about being told that you may not be able to conceive children, that's certainly chipped away a bit, that's not helped.

Geoff (undelayed puberty) (in context of a long conversation about his fertility): That's a big issue to come back, the answer coming back, it's the bloke that's the problem, 'cos that's your masculinity taken away from you. And then it's sort of like more a publicized thing that you're told that we're trying for kids but nothing's happened.

The way 'normality' was experienced differed between the men who had delayed puberty and those whose sexual development was on time. Men who had been discredited defined normality in terms of milestones that needed to be made in order to become a 'normal' male. Men whose puberty had not been delayed seemed to experience normality as something that could be taken away from them. Put another way: both groups of men compared themselves to a normative notion of manhood, but differed with respect to the direction of comparison. Non-delayed men experienced a fall from a state of grace, being masculine, for which the delayed men strove. This might explain why infertility appeared to be a much more emotive issue for those men who had not experienced pubertal delay.

*Being discreditable: a summary* The main psychological challenges faced by all eight men during the discreditable phase are best described by using the notion of risk. In making the transition from an 'abnormal' to a 'normal' man these men faced a difficult paradox. In order to become more like 'the normal man' they had to expose a hitherto hidden aspect of their problem thereby risking having their deviance confirmed. Finding ways to resolve this paradox was the main psychological challenge of the discreditable phase. There was some evidence to suggest that previous experiences of being discredited might confer psychological advantages for men coping with the challenges of the discreditable phase. Men who experienced delayed puberty have already faced and coped with the consequences of that which non-delayed men fear most: being 'found out'.

## Discussion

The experience of sexual development that is atypical for one's sex and gender has long been recognized as being a difficult experience (Rekers, 1992). Understandings of why this may be so are less well developed. Insights into the origins and structure of distress in this population have been hijacked by agendas marginalizing their experience in pursuit of answers to the highly politicized debate about intersex management. This study aimed to develop an empirical account of some of the experiences associated with atypical genital development as defined by the men who live it.

Accounts based upon phenomenological method are well placed to investigate the multiple aspects of personal experience. The present analysis generated important insights that simultaneously confirmed, contradicted and extended those offered by previous research. Two features of the present analysis, its focus on developmental and social contributions to experience, distinguish it from accounts generated by previous research and warrant further discussion.

### *Developmental aspects of distress*

Previous research has suggested high levels of psychological disturbance in men experiencing atypical genital development (Huisman, Bosch, Delemarre, & Waal, 1996; Keselman, Martinez, Pantano, Bergada, & Heinrich, 2000; Money & Clopper, 1975; Money et al., 1980, 1985). However such studies have tended to present this distress as a form of steady state personality pathology; a disordered psychological development arising from a state of arrested bodily, and principally genital, development. The myopic focus upon penis size as central to the experience of distress may reflect the operation of several sources of bias in previous research. As a key proponent of surgical reassignment of infants presenting with genital anomalies the work of Money et al. may be viewed as having an implicit bias towards presentation of poor outcomes for men with genital anomalies. Methodological factors may operate to make such a bias less open to potentially disconfirming data. By focusing on the experience of very young men, mostly in their late teens and many

still in contact with mental health services, it is likely that the narratives of distress presented in Money's series of articles represent the more extreme end of the spectrum of experience.

The present study sampled men with a much wider age range who had a relatively successful response to hormone replacement therapy. From this analysis we can appreciate that distress needs to be understood as a function of the interplay between the various bodily states and social positions that contribute to the experience of discreditment. By taking a perspective that prioritized men's own accounts of their experience we are better placed to see that both genital and non-genital aspects of sexual under-development contribute to distress in different ways and at different times. For the men who had experienced delayed puberty, genital concerns crystallized into real threats only when their external appearance enabled them to pass as normal. Before this, concerns about genitalia were comparatively latent with regards to their contribution to distress. The importance of temporal-developmental factors to the distress associated with atypical genital development has also been highlighted for women with vaginal agenesis (Holt & Slade, 2003).

### *Social aspects of embodiment*

Previous research has described a high level of social isolation in this population of men (Huisman et al., 1996; Keselman et al., 2000). It has been suggested that this lack of social support might account for the high levels of depression seen, especially in younger men. The descriptions of social isolation during the discredited period partially corroborate this hypothesis. However the present analysis also suggests that the contribution of social processes to the experience of atypical sexual development may extend far beyond the role of social support. It was the predominantly social processes of comparison and stigma that contributed to the men's experience of bodily dissatisfaction, discreditment and diagnosis. But it was social processes, particularly the intimate social act of intercourse, which also certified the authenticity of their claim to be 'proper men'. In essence, it was the social currency of the sexually atypical male body and the transactions it permitted which drove the experiences associated with

visible sexual under-development. This suggests that, in helping such men, we should be concerned to enquire about the organization of their social worlds and helping them (and those around them) to develop skills to negotiate within an environment that is generally ill equipped to deal with sexual and reproductive diversity.

### *Methodological issues*

Part of the appeal of phenomenological investigation for health psychology is its commitment to a relatively realist epistemology. That objects are allowed to exist outside of their perceptions of them affords obvious advantages for the study of the meanings surrounding bodily events (Yardley, 1997). While phenomenological approaches are concerned with individual meaning they have relatively little to say about the origins of the concepts used by participants to construct their experience (Willig, 2001). This is particularly evident in the case of concepts that might have taken-for-granted status within a society at a particular point in time. Concepts associated with gender, sex and sexuality are particularly good examples of constructions, which, while relevant in today's society, none the less may be considered ideological practices particular to a certain socio-historical context (Foucault, 1979). The 'hegemonic masculinity' against which these men found themselves to be lacking is one example of such an ideological practice: an aspirational ideal of masculinity which few males attain but most remain complicit with because the concept affords them tangible social, psychological and economic benefits (Connell, 1995). Previous research within social psychology has identified how those men who fall short of the hegemonic ideal (e.g. those with disabilities) nevertheless construct masculine identities by drawing attention to experiences that demonstrate values that are implicitly embodied within the hegemonic project. Typical examples of such building blocks of masculine identity formation include narratives of: overcoming adversity, tolerating discomfort and the triumph of reason over emotion (Sabo & Gordon, 1995). All of these elements are readily apparent within the present analysis. Using the framework of discursive psychology Wetherell and Edley (1999) demonstrate how research interviews them-

selves can be sites where masculine identities are produced by those who feel the bite of hegemonic standards. By viewing the research interview as a site for the production of identity we can better appreciate the opportunities and risks that taking part in qualitative research affords potential participants. The present account is based upon interviews with men who had been largely successful in completing the masculine project; all participants were clearly and unambiguously identifiable as sexually mature males. However, several potential participants declined to take part in the study, stating that they felt it would be too upsetting. Questionnaire data on such men indicated that they were likely to be younger and less virilized (Chadwick, 2001). It is possible that for such men the prospect of taking part in a research interview presented opportunities that they anticipate would challenge their already difficult project of engagement with hegemonic masculinity. Thus one needs to be wary of what this account can say about the experience of those men whose lack of sexual development is more pronounced. This issue clearly warrants further empirical attention.

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