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An Investigation into the Psychological Impact of Bladder Exstrophy

Christine Wilson

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University College London

Contents

(In final binding, appendices V and VI were removed for issues of confidentiality)

Abstract

Bladder exstrophy is a congenital urological disorder, which affects the development of the bladder, genitals and pelvis. Patients undergo a series of operations throughout childhood to construct a continent bladder, which functions normally or requires self-catheterisation. Patients with bladder exstrophy are often left with considerable abdominal scarring and genital abnormalities.

The literature suggests that psychosocial outcome for adults with bladder exstrophy is positive. Several studies report psychological difficulties associated with incontinence, self esteem, body image and sexuality in children and adolescents with bladder exstrophy. The literature related to these psychological constructs is considered with reference to normative ideas on adolescent developmental and discussed in relation to the current literature on psychosocial issues in bladder exstrophy.

Sixteen semi-structured interviews were conducted with young people (aged between 16 and 21) who have bladder exstrophy. These were analysed using Interpretative Phenomenological Analysis, (IPA) to assist in the systematic description of their accounts. Themes emerging from this analysis were described in terms of domains: "personal impact", "coping with bladder exstrophy" and "interpersonal relationships" and illustrated using quotes from interviews.

These results are discussed with reference to the previous literature and general adolescent issues. Methodological issues related to qualitative studies are considered and suggestions made for future research. Clinical implications of this research are discussed in some depth.

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Chapter 1: Introduction

Bladder exstrophy is a congenital abnormality where the bladder and other abdominal structures, including the genitals, do not form correctly in the developing foetus. Babies with bladder exstrophy are born with their bladder exposed outside their bodies and may suffer with a variety of complications. The abnormality can be treated successfully through a number of operations often throughout childhood but some differences in appearance and functioning of the bladder and genitals remain. There has been some research interest in the psychological aspects of living with these abnormalities but few have focused on their impact in adolescence. As a result of the nature of bladder exstrophy, its specific impact on appearance and sexual functioning, paired with the importance of these in the successful negotiation of transitions between childhood and adulthood, it would appear to be important to consider the impact of bladder exstrophy within a normal developmental framework.

Overview

This chapter will begin by describing in some detail the physical presentation and medical management of bladder exstrophy. Following from this, the literature on psychological adjustment of patients with bladder exstrophy will be explored firstly in relation to adults, then considering children and adolescents. Research findings will be discussed in chronological order within these categories and with reference both to methodological difficulties and the discrepancies between findings. Studies considering psychological adjustment are discussed first, followed by those investigating sexuality. The latter portion of the chapter will introduce the current study and briefly outline some of the psychological constructs identified by the previous research as relevant to adolescents with bladder exstrophy.

Physical Presentation

Bladder exstrophy is a congenital developmental disorder affecting the intra-uterine development of the bladder, genitals and pelvis in otherwise normal babies. The bladder of the developing foetus does not form into its usual shape and is flattened. At birth the front wall of the bladder is missing and the abdominal wall is open (Woodhouse, 1994). In children with bladder exstrophy the kidney and ureters are usually normal but connections to the outside world are defective. This results in the bladder being unable to store or control the release of urine. Boys and girls differ considerably in their presentation. Boys have a urethra that is often open throughout the length of the penis. Girls have a widening of the skin on either side of the genital area. Genital abnormality is generally described as less severe in females compared to males (Reiner *et al,* 1999). Several authors have observed considerable individual differences between children with the same diagnosis and describe a continuum of genital abnormality (e.g. Woodhouse, 1991).

The condition occurs in approximately 1 in 10 000 to 1 in 50 000 births, with boys being affected 2 to 3 times more often than girls. Reports indicate that it may be more likely to reoccur in families, with figures of 1 in 100 among siblings and a 1 in 70 chance of its appearance in offspring of bladder exstrophy patients (Gearhart & Jeffs, 1992). The precise aetiology of the condition is understood in terms of a defect of the closing of the mid-line in the abdomen of a developing foetus; however, the process of heritability is not really understood (Gearhart & Jeffs, 1992).

The condition may now be diagnosed during pregnancy with the help of ultrasound (Blane *et al,* 1983). Firm diagnosis is not made until birth when the exposed bladder is evident. There has been considerable debate in the literature about whether or not a diagnosis of bladder exstrophy pre-natally should give rise routinely to offers of termination of the pregnancy (Gearhart, 1999). As a result of this debate, the long-term quality of life of people with bladder exstrophy has been considered.

Most authors agree that early treatment of bladder exstrophy is essential mainly for cosmetic reasons, mostly because it is unacceptable in western society not to attempt treatment of this condition. Precise timing and technique of treatment varies between centres but in the developed world surgical intervention is usually attempted soon after birth, followed throughout childhood with a variety of surgical procedures to improve appearance and continence (Gearhart, 1999, Woodhouse, 1991).

The child may undergo a series of operations (staged reconstruction) early in life to divert urine to an external appliance or reconstruct the internal apparatus to close the abdomen, enable continence and produce a cosmetically satisfactory result. Several internal procedures have been developed, some utilising other bodily tissue (e.g. the appendix or part of the stomach, large bowel or intestine) to construct a reservoir to allow storage of urine, to join the urinary system with the colon or to divert urine from the bladder to an external stoma (hole) or appliance (e.g. Diseth, Emblem &Schultz 1999, Gearhart, 1999).

This may result in children undergoing many operations; one study of 15 adolescents with bladder exstrophy reported participants experiencing between 6 and 19 surgical procedures (median 12) during their childhood (Stjernqvist & Clementson- Kockum, 1999). These usually occur in tertiary care settings, which may be a great distance from the support systems centred around a family's home.

Considerable improvements in surgical technique have reduced the number of surgical interventions necessary in children born now with this condition. However, many adolescents and adults with the disorder may have had considerably different experiences to those of younger children, (Diseth, Emblem &Schultz, 1999).

Surgical Outcome

Whilst reported to be "successful" in 70% of cases, these operations may have considerable impact on a patient's ability to urinate in the same way as other children. They may have a bag outside their body, need to self-catheterise or use the toilet more frequently than others (Woodhouse, 1991). Depending on the type of diversion they have, they may excrete a mix of waste products. With the procedures connecting the urinary system with the bowel there is a significantly elevated risk (100-7000 times the risk of the general population over 20-30 years) of the development of bowel cancer. If the urinary system is separate, the risk of cancer remains inline with that of the general population (Woodhouse, 1991, Stein *et al*, 1994). Stockle *et al* (1990) reported complete continence in 92.3% in a series of 46 children with urological abnormalities, 40 of whom had bladder exstrophy

It is likely that there is some discrepancy between definitions of the success of operations. Surgically, a continent child may be the aim, but long-term follow-up appears to be essential for the monitoring of the development of secondary problems later. The definition of "success" may be different again if the cosmetic and sexually functional results are considered. Overall, it is necessary for all patients who have undergone this type of surgery to be monitored closely, attending appointments at least on an annual basis for most of their life. The actual appearance of the genitals, in terms of anatomical reconstruction and the size, particularly of penises, has been described as the most challenging aspect of reconstruction in bladder exstrophy (Diseth *et al,* 1999). This is a simplified fears as centering on a fear of ridicule by partners. Overall, these patients did not have "*retarded*" sexual adjustment when compared with age-matched controls but showed considerably more anxiety related to their sexuality. In comparison, male patients with bladder exstrophy struggle with similar difficulties with the appearance of their penis in addition to their issues related to continence, which may also impact on their sexual confidence.

Reiner *et al* (1999) used a combination of validated self-report questionnaires and semi-structured interviews to describe the sexual behaviour of a group of young men (aged 14-19) with bladder exstrophy and the attitudes of their families. They reported on the social isolation seen in many of this group of patients, who described having few friends and even fewer female friends. All of the participants met DSM-IV (American Psychiatric Association, 1994) criteria for an anxiety disorder secondary to a medical condition. Many were also described as suffering from severe anxiety in relation to social situations, the appearance and functionality of their penis and sexual activity. In addition, several (7 out of 14) were described as showing intermittent symptoms of severe depressive disorder. Eighty six percent had never undressed in front of other people and only two 19 year-olds had attempted to have sexual intercourse. Only 3 out of 14 had ever handled their genitals except for urinating and only 2 had ever masturbated and only over the age of 16 years. Although there is no comparison group used in this study, the authors suggest that this is considerably different from what might be expected in a "normal" group. Aside from these behavioural differences, Reiner *et* al (1999) described the anxieties expressed as being similar to those of typical adolescents, but the depth and intensity of this group's distress accentuated these "normal" worries. The authors attributed this at least in part to the chronic and consistent dysfunction of the reconstructed penis both to urinate and perform sexually. They also discussed the distress associated with body image as a result of this and as a possible cause of the apparent sexual dysfunction they had described.

The results of this study illustrate the profound difficulties with sexuality of their group of participants. They described more pronounced difficulties than any other study but many of the basic themes of psychological distress, general and sexually related anxiety and a wish to keep genitals hidden match the findings of several of the studies discussed above.

As a result of the relatively few studies and differences in methodology, it is difficult to draw general conclusions about the sexual adjustment of young people with bladder exstrophy. The majority of studies seem to focus more on older children and adolescents, presumably because similar methods can be used across all patients if the age range is smaller. It is clear, however, that difficulties do exist particularly during adolescence and that these appear to be accentuations of difficulties experienced by many adolescents. They seem to relate most to anxieties about the acceptability and functionality of the penis as a sexual organ. There is conflicting evidence as to whether or not this influences the time of sexual debut and preceding sexual behaviour in adolescents. It is striking that the majority of the studies have focused on the sexual experiences of male patients with bladder exstrophy and other genital abnormalities, and only one (Feitz *et* al 1994) has considered the experiences of female patients in detail. None of the studies investigating adolescent sexuality have included female participants.

Summary of the Literature on the Psychological Impact of Bladder Exstrophy

Overall, the studies into the impact of bladder exstrophy on children and adolescents indicate a constellation of difficulties, some of which are quite general whilst others appear to be more specific to the difficulties imposed by the nature of bladder exstrophy. These seem to relate to several areas of functioning and some studies report directly contrasting results. The key areas of difficulty reported in the literature include:

1. Those imposed by multiple hospitalisations
2. Dealing with incontinence
3. Internalising psychological problems such as anxiety and depression.
4. Externalising psychological problems such as impulse control.
5. Body image disturbances mostly regarding genital appearance.
6. Self esteem problems.
7. Sexual disturbance, mostly related to later sexual debut and increased anxiety related to sexuality.

The discrepancies between studies are difficult to evaluate. This is mostly due, as discussed above, to differences in the definition of populations, methodology and the age of the sample investigated. Differences in methodology could go some way to explaining the disparity between studies. It is possible that some difficulties may not have been detected by standard measures, or that many of the difficulties, whilst having significant impact on the lives and behaviour of the individuals, fell into a sub-diagnostic category. This might result in their non-detection by standard measures or through the questioning of participants by a researcher not trained in the assessment of mental health. The age range of samples is significant because it is likely that progressive developmental tasks in childhood and adolescence create vulnerabilities for particular difficulties at different ages. For example, whilst hiding the differences from peers may be the focus for younger children, concern with sexuality may be more likely to be an issue running up to and during adolescence. This highlights the need for individual psychological assessment and intervention and consideration of the developmental context of the child.

Whilst giving some description of the types of psychological difficulties experienced by children and adolescents with bladder exstrophy, the studies using mainly quantitative methodology give less of an indication of how these difficulties show themselves and affect the patients' daily lives. The earlier qualitative studies go some way to describing these difficulties, but have samples that appear to be less well defined and homogenous. Several of the studies did report the use of qualitative data from interviews and in several cases this appeared to hold the richest source of data. However, it was not clear in any study how the data were analysed and used to report trends and opinions of the participants, or how the data were recorded in the collection phase.

The literature suggests that there are psychological consequences associated with bladder exstrophy in children, but that long-term outcome into adulthood, appears to be more favourable. It would therefore appear that whilst children and adolescents with bladder exstrophy experience more psychological difficulties than their peers, these resolve by adulthood. Unfortunately there is no longitudinal data available, which could control for the effects of changes in medical and surgical management and cohort effects which would obviously impact on this conclusion. In addition, there is no indication of how this conclusion might come about or whether children with difficulties might turn into adults who function well, or whether the people with difficulties and those without remain as two separate groups throughout. This hypothesis would be difficult to test without the use of larger, possibly multi-centre studies to assess the progress of people with bladder exstrophy over time.

These factors all require further investigation. The distinct relationships between them can only be tentatively hypothesised at present. It would therefore appear important for these aspects of functioning to receive thorough attention and investigation. This would allow description of the specific problems encountered and resilience factors and highlight areas for potential psychological intervention to aid adjustment. A more detailed account of these difficulties would have significant impact on the clinical management of these patients and enlarge the literature for more detailed investigation of these difficulties.

Setting Bladder Exstrophy within a Developmental, Psychosocial Context

The issues identified by the circumscribed body of literature on bladder exstrophy overlap with several large bodies of literature in the field of psychology. These include: paediatric health psychology, specifically addressing issues for children growing up with a chronic illness; developmental theories; body image, self-esteem, sexuality, disclosure and coping. It is possible that, as with many areas of functioning, changes occur developmentally on an ongoing basis but that these are accelerated at adolescence. The literature relevant to each of these areas separately is substantial so will not be considered in depth for the purposes of this paper. Each area will be discussed briefly with reference to the areas of overlap with the bladder exstrophy literature detailed above, with a view to placing these difficulties within a broader developmental psycho-social perspective. The focus of the current study is on the experiences of adolescents with bladder exstrophy and salient aspects of psychological functioning highlighted by previous studies on the impact it has on young people.

General functioning in Children with a Chronic illness

Epidemiological (e.g. Cadman, Boyle, Szatmari & Offord, 1987) and clinical studies (e.g. Meijer *et al,* 2000) suggest that children with chronic illnesses are at increased risk of psychosocial problems. Lavigne & Faier-Routman (1992) conducted a meta-analytic study, which indicated that children with chronic medical conditions showed a two or three times greater risk of developing adjustment difficulties and internalising and externalising psychiatric symptoms compared to healthy children.

Several disease and individual factors appear to be important in the development and maintenance of these difficulties. Wallender and Thompson (1995) described several of these factors related to the type and severity of the condition, its duration and impact on functioning. They also reported on the impact of the gender of the child, age of onset of the condition interacting also with temperamental variables and individual coping strategies. Lavigne& Faier-Routman (1992) also found that socio-economic variables impact on the adjustment of children to their condition. The literature suggests that influences on the adjustment of children to chronic illness are interactional and multi dimensional, and therefore extremely complex.

The literature on bladder exstrophy has identified difficulties which appear to be consistent with these general findings (e.g. Diseth *et al*, 1998). Children with bladder exstrophy might also be more at risk of difficulties predicted by these models given the taboo and potentially embarrassing nature of some of the condition-specific problems discussed above. However, resilience factors that might be important could relate to the reduced impact of bladder exstrophy on general physical and intellectual functioning.

It is important to note that not all children who have a chronic health condition go on to develop psychosocial problems too (Pless & Pinkerton, 1975). Eiser (1996) goes on to argue for the unhelpfulness of these "deficit centred models" favouring instead one that takes account of, and maximises, strengths and resilience brought by individual families. In addition to considering the impact on, and resilience of, children with chronic health problems, attention has turned to a consideration of the effects of long-term illness, not only on the individual, but also on their siblings and parents (Eiser, 1996). It would appear that much of the previous research into the impact of bladder exstrophy has been focused on investigating the things that are potentially difficult and uncovering the problems that some develop. In the course of this, some strengths have been noted, such as the relatively normal sexual development of adolescents found by Mureau *et al* (1995). However, the underlying strengths and the process by which this resilience has assisted this normal development has not been discussed.

Adolescent Issues

Adolescence has traditionally been seen as a phase of development characterised by numerous changes, not only physically, but cognitively and emotionally as well (Coleman and Hendry, 1999). In the majority of patients with bladder exstrophy, intelligence and development follow a normal course, with most attending mainstream schools and functioning socially as would be expected for any other child, (Woodhouse *et al*, 1983). It would therefore be appropriate to view psychological issues demonstrated to be relevant to this group within a normal developmental framework. Key factors associated with adolescence appear to be particularly sensitive with people with bladder exstrophy. These are most often associated with physical and social change, in particular sexual development and changing of awareness of bodily appearance and attractiveness.

Physical Changes

Detailed discussion of puberty and its psychological impact are beyond the scope of this paper, but the physical changes of puberty provide an important backdrop to other developmental tasks of adolescence. The changes give a tangible physical indication of impending adulthood, and thus signal thoughts as to what this might mean in terms of the expectations held for an individual themselves and those of others around them. In ill children, it can also mean a change of medical team or hospital providing their care and a change in attitude over who should be responsible for ongoing care. This is often the case for children with bladder exstrophy. It would be reasonable to assume that the physical changes in puberty, particularly the development of secondary sexual characteristics, could potentially be a difficult time for children growing up with bladder exstrophy. This is likely because of the changes occurring in the genital region, were they already appear to have worries about their appearance (e.g. Feinberg *et al*, 1974, Mureau *et al,* 1995); but also because the growth of the penis in adolescents with bladder exstrophy is not always likely to follow a normal course. Pubic hair is also abnormally distributed in both girls and boys with bladder exstrophy (Woodhouse, 1998). It is possible that these differences hold even more relevance at puberty, particularly those related to physical appearance, because the pubertal changes in appearance signal the beginning of adulthood, which could be problematic if these do not occur at the same time or in the same way as peers.

Developmental tasks of Adolescence

Alongside the physical changes, cognitive and emotional changes also occur in adolescence accompanied by alterations in psychosocial functioning. Developmental theory indicates that, like every other stage of development, there are certain tasks that need to be negotiated by the individual in order for them to develop fully into adults. The key tasks of adolescence have been described by Chassin *et al* (1995) as being: firstly to define a sense of identity, secondly, to establish positive peer relationships, and finally, to establish independence and autonomy. Adolescence is often characterised by significant changes in psychosocial functioning. Significant dilemmas are often faced between dependence and independence and in the formation of an interpersonal identity. It is often a time of conflict between the individual, the influence of peer group and familial norms (Coleman and Hendry, 1999). These issues are discussed below with reference to the literature on normal adolescence and to the findings related to adolescents with bladder exstrophy.

Defining a Sense of Identity.

Kroger (1996) describes identity as *" a balance between that which is taken to be self and that considered to be other"* (p 8). Several theories suggest that this is an ongoing process of development throughout the lifecycle with adolescence being a key time in an individual's formation of their own identity as being separate from other people. This process must be considered within the social context, as development of humans does not occur in a vacuum; cultural values, social roles and expectations form an important foundation to the development of individual's identity (Kroger, 1996).

One of the most prominent developmental theorists to describe the process of identity formation is Erik Erickson (1959, 1963, 1968). In his theories, Erickson described the process of identity formation using the word *epigenisis* implying that identity emerges as a developmental process over time with later stages building on the resolution of previous issues. In his description of the eight stages of development across the lifecycle, each stage is characterised by a bipolar conflict which must be addressed to enable progression to the next stage. Resolution of these conflicts occurs when the individual finds a balance between the two poles. Adolescence (the fifth stage) is said to be dominated by the dilemma between *"identity Vs. role confusion"* which requires the formation of a relatively stable identity enabling developmental progress. It also provides the basis for further personality development and has a powerful impact on subsequent reactions to life events. Further discussion of Erikson's work and the criticisms levelled at it (e.g. Marcia, 1980) are beyond the scope of this paper, but his concept of identity and its formation provides a backdrop to other research into development in adolescence.

Self-Esteem and Self-Concept

Various components play a part in the formation of identity; of particular relevance to the current study are the phenomena of self-esteem and self-concept, which overlap considerably. Both are irrevocably linked with a sense of identity, theorised to be prominent in development in adolescence (Coleman and Hendry, 1999). Harter (1990) describes a number of key changes in identity occurring during adolescence: she hypothesed that self-concept shifts from being concrete to abstract, in the developing ability of the young person to envisage how others might see them as opposed to how they might see themselves. Harter argued that this would make it more likely that views of self would be vulnerable to distortion and that they would be extremely reliant on social feedback for social verification. This process is evident in the shift from reliance on parental feedback to govern attitudes and behaviour to greater reliance on peer groups (Coleman and Hendry 1999).

Self-esteem has been studied extremely widely, both in relation to adolescence and as a barometer of coping and adaptation with numerous chronic health problems. It has also been measured in several studies of bladder exstrophy (Montagnino *et al*, 1998, Stjernqvist and Kockum, 1999). Low self-esteem has been shown to be related to depression and anxiety in young adults (Rosenberg, 1965). There are many problems with this body of research, most often as a result of the multidimensional nature of self-esteem and in unpicking causality where relationships have been found.

One of the key components to adolescents' self-esteem has been found to be satisfaction with physical appearance followed by social acceptance by peers (Harter, 1990). This takes on particular salience for young people with bladder exstrophy, who have indicated dissatisfaction with their physical, specifically genital appearance in adolescence (Diseth *et al,* 1998, Reiner *et al,* 1999). Children with bladder exstrophy have also been reported to be concerned about their acceptance by peers (e.g. Feinberg *et al*, 1974, Mureau *et al*, 1995). This seems to relate most to their concerns about their incontinence in addition to their body image.

In the case of the adolescent with bladder exstrophy, it is likely that their self-esteem may be compromised by the differences in their appearance, particularly due to the abdominal scaring and genital appearance. This is also likely to combine with and accentuate their anxieties related to their sexuality and the initiation of sexual activity. Several of the studies discussed above found difficulties in self-esteem of children and adolescents with bladder exstrophy (e.g. Reiner, 1995) whilst others measured high self esteem, (Stjernqvist and Kockum, 1999). The precise connections of body image issues, relationship difficulties and self-esteem were not explored, however, it is likely that there are some very specific connections between the nature of bladder exstrophy and particular aspects of self-esteem, which may not have been identified by general measures.

Establishing positive peer relationships

This second task of adolescence is likely to be influenced by and exert an influence on the previous and the third task. Varni *et al* (1994) cite good peer relationships as being an important protective factor in preventing poor adjustment among young people with chronic health problems. Adolescents with physical health problems have been found to be at greater risk of difficulties with peer relationships and are therefore more likely to experience difficulties with establishing positive peer relationships and thus with self-concept (Ungerer *et al*, 1988). As discussed above, this interaction may be mediated in some way by self-esteem, which although the direction of causality is unclear, is partially determined by acceptance by peers and vice versa.

Some authors, e.g. Savin-Williams and Berndt (1990) have illustrated the importance of adolescents spending considerable amounts of time with friends talking about themselves and their experiences, which creates loyalty and closeness in these relationships and in turn enables a sense of belonging. Being accepted or rejected by peers has been associated with mental health status (Parker and Asher 1987).

Whilst there is a diverse literature on the nature and function of adolescent relationships, their role in facilitating the negotiation of the tasks of adolescence is unclear. It is, however, evident that peer relationships play a significant role in psychosocial development. This area has not been studied widely within the realm of the psychological impact of bladder exstrophy. Some studies report social isolation (e.g. Reiner *et al* 1999), which might confer some vulnerability for poor adjustment during adolescence. In contrast, other studies report positive indications of social inclusion such as education (e.g. Woodhouse, 1994). In light of these discrepancies, and the importance of these issues to normal social development, the issue requires further investigation.

Sexual Relationships

Sexual development is a central part of development in adolescence and is, at least in part, initiated by the changes in hormonal activity around puberty. It is affected by a multitude of internal and social factors and has been described as an extremely complex process, which may evoke considerable anxiety in the adolescent and those around them (Coleman and Hendry, 1999). The timing and type of sexual behaviour engaged in by adolescents is largely determined by the cultures in which they live and is the subject of considerable study and debate, but it is apparent that more adolescents are engaging in sexual activities at a younger age than ever before (Coleman and Hendry, 1999). More detailed discussion of these issues is beyond the scope if this chapter, but it is of relevance, given the reports of normal sexual debut (Woodhouse 1994, 1998), or not, (Reiner *et al*, 1999), in the context of elevated anxiety about sexual relationships in adolescents with bladder exstrophy (Feinberg *et al* 1974, Diseth *et al*, 1998).

The impact of these issues on adolescents who have grown up with bladder exstrophy are therefore unclear, with considerable disagreement in the literature about sexual debut and the nature of the worries experienced by adolescents with bladder exstrophy about their sexuality.

Establishing independence and autonomy

This third task of adolescence is likely to follow resolution of previous tasks. As an adjunct to this, the development of personal and sexual identity is seen as an important transition associated with the struggle between dependence (as a child) to independence (as a young adult). The negotiation of these transitions, especially for adolescents with additional stressors (such as a chronic health condition) may well be confounded or assisted by their personal coping style and the type of stress imposed (e.g. Compass, 1995). The literature on coping per se is vast and therefore will not be reviewed, but the construct of coping would appear to be important in considering the development and adjustment of adolescents with any chronic health problem.

In addition to the influence of coping style, resilience factors are worthy of note in mediating the impact of stressors, like having a chronic health problem. Several factors that offer resilience to life stress in adolescence have been identified. These include: intelligence and problem solving skills (Furgusson & Lynskey, 1996), interests and attachments outside the home (Jenkins & Smith 1990), warm, supportive attachment with at least one parent (Jenkins & Smith 1990), having an "easy" temperament (Wyman *et al*, 1991) and having positive peer relationships, (Wyman *et al*, 1991). These will not be discussed in more depth, but these factors all appear to be important in providing resilience to stressors during adolescence.

These factors are worthy of consideration in the study of the psychological impact of bladder exstrophy, particularly given the number of reports of how normal and well-adjusted people (of all ages) with bladder exstrophy appear to be (e.g. Woodhouse 1994, 1998).

It is clear that there is considerable discussion about the experiences of "normal" adolescents in contemporary society. It is also apparent that the traditional view of adolescence as a time beset with conflict and stress should be challenged (Feldman and Elliott, 1990, Rutter, *et al* 1976). There is considerable evidence for the resilience and resourcefulness of adolescents (Coleman and Hendry 1999) enabling them to negotiate their developmental tasks with aplomb.

It is difficult to draw clear conclusions about how the difficulties faced by adolescents with bladder exstrophy are the same as those that challenge all adolescents, if they are accentuations of normal difficulties or if this group face an entirely different set of difficulties. It is possible that bladder exstrophy places an additional strain on normal coping mechanisms and resilience factors making the resolution of problems more difficult. It is also likely that these interact at an individual level, therefore making it difficult to detect group trends in small samples. Whilst some of these issues are indicated to some degree in the literature focusing on bladder exstrophy and other urological abnormalities, conclusions have been vague and conflicting.

Rationale and Aims of the Current Study

Themes emerging from the small number of previous studies of bladder exstrophy give the impression that whilst children and adolescents experience psychological difficulties, psychological outcome in adulthood is favourable. These problems have been reported to be both internalising and externalising in nature, although it is likely that any difficulties will present differently according to the child's chronological age and developmental stage. The developmental tasks for children at each stage are likely to underlie the difficulties experienced by children of different ages. The general themes that emerge include; anxiety, fear for the future, compensation, depression, secrecy, concealment, embarrassment, sexuality, body image and self esteem. These factors are likely to be particularly salient for adolescents within the context of their developmental stage.

Previous studies give little impression of what these difficulties mean to the lives of children and adolescents with bladder exstrophy. There is evidence for the existence of symptoms like anxiety but little evidence for how these may manifest themselves, what impact they have in the lives of the individual children or how they cope with them. Although a few previous studies have used qualitative data, none have reported a clear systematic approach to the analysis of this rich source of information.

Eiser (1996) argues that whilst standardised instruments and quantitative studies have their place in the investigation of the psychological impact of chronic illness in childhood, limitations of sample sizes and the lack of sensitivity of the standardised measures make qualitative approaches an important method of collecting information on the experiences of these children. Rich *et al* (2000) used a video based qualitative methodology to collect narratives about the adolescent experience of their illness, health and healthcare. Their study provided rich and informative data for systematic qualitative analysis under the assumption that:

> *"[I]f clinicians are made more aware of their patients daily experiences living with disease, they could provide medical care that was more responsive, sensitive and effective."* (Rich *et al*, 2000 p156).

This view was also shared by Giacomini and Cook, (2000) who set out in detail the value of qualitative research in assisting in the sensitive medical care of patients.

The current study uses qualitative methodology to describe in greater depth the experiences of young people with bladder exstrophy and how they manage any difficulties if they occur. It attempts to address some of the discrepancies and questions raised by the current literature about the psychological impact of bladder exstrophy on the daily experiences of young people. This study takes a phenomenological approach (Giorgi, 1995) using semi-structured interviews to gain a detailed picture of the experiences of individuals. This approach assumes that what is said in an interview has significance to the individual and is influenced by the beliefs of that person and the meanings they ascribe to their experiences. The current study focuses on the experiences of adolescents, and those at the older end of the adolescent range (up to the age of 21.) This enabled the recruitment of a large enough sample of participants in a similar age range and was restricted to those who were considered to be old enough (over the age of 16) to give their own consent. These were also the patients that had been transferred to adolescent services. It was assumed that this group would be subject to similar cohort effects in terms of their medical treatment and societal factors and that they would be at a comparable stage of development.

Research Questions

The main questions addressed by this study have arisen from the results of previous research into the impact of bladder exstrophy and from the overlap of these with issues relevant to adolescent development.

- What are the psychosocial experiences of adolescents with bladder exstrophy?
- What are the possible self-esteem, self-concept and body image problems associated with bladder exstrophy?
- How do these impact on the daily lives and relationships of adolescents with bladder exstrophy?
- What are the strategies adolescents have used to cope with the impact of bladder exstrophy on their lives?

Chapter 2: Method

Overview

Sixteen young people with bladder exstrophy participated in a semi structured interview focussing on their experiences of the impact of bladder exstrophy on their lives. The interview data were analysed using Interpretive Phenomenological Analysis (IPA; Smith, Jarman & Osborn, 1999). Quantitative measures of self-esteem and psychological symptoms were used to provide a context for the qualitative data.

Participants

Participants were selected from a group of patients with a diagnosis of bladder exstrophy currently being followed-up at a London teaching hospital. Approximately 10 patients with this condition, not compounded by other difficulties such as spina bifida, hypospadias and other complicating factors, are born each year and treated in two specialist centres within the United Kingdom.

Children with bladder exstrophy are treated initially in paediatric services (at another London teaching hospital) and transferred to specialist adolescent urology services when they are about 16 years old. A database of patients with a primary diagnosis of bladder exstrophy (being treated in both hospitals) was consulted, 54 patients fitting the extended adolescent age range (16 to 21 years) were identified. Of these 54 patients, addresses were available for 34 patients who were currently under review in the adolescent urology service. The remaining 20 patients within the target age range for whom addresses were not available are likely to have not been transferred from paediatric services, been discharged or live abroad.

Recruitment

In order to gain contact with patients, the hospital patient information system was used to obtain addresses and clinic appointment dates. Of the 34 patients for whom addresses were available, 30 were contacted. Eighteen patients with a clinic appointment scheduled between October 2000 and May 2001 were contacted. Twelve agreed to take part, five declined and one did not attend an appointment they had arranged. Due to the small number of patients with bladder exstrophy attending clinic during this period, a further 12 patients living in the Greater London area were contacted and invited to participate in the study. Four agreed to take part in the study, seven declined and one did not attend an appointment. Four patients were not contacted because they did not have scheduled clinic appointments during the data collection period or lived outside the Greater London area.

A total of 16 individuals were interviewed as part of the study. The final sample represents 29% of the population of young people aged between 16 and 21 years who were treated for bladder exstrophy in the two London hospitals and 46% of those whose addresses were available.

The mean age of participants was 19 years (range from 16 to 21 years). Eleven participants (69%) were male and five (31%) were female. These proportions reflect the general ratios of people with bladder exstrophy (cf Chapter 1).

The majority of the sample were students at the time of the interview; one studying for GCSE's, three studying for A-Levels, and seven undertaking further qualifications after leaving school. Two participants were in full time employment after finishing a degree, the remaining three were in full time employment and one was seeking employment. Generally, subjects or vocational aspirations of the participants varied, however, worthy of note was that five (29%) of the sample were studying some kind of dramatic art with the aim of becoming an actor or musician. Further description of the sample regarding medical background will be presented in Chapter 3.

Procedure

Two weeks prior to their clinic appointment, each patient was sent a pack, containing an introduction letter (appendix I), patient information sheet (appendix II) and consent form (appendix III). Those who were invited to participate in the study when they did not have a clinic appointment were also sent an information pack, with a slightly amended introductory letter (appendix IV). They were asked to fill out and return the consent form if they were interested in taking part in the study and available for an interview. They were informed that the researcher would contact them by telephone to answer any questions and arrange an appointment. It was emphasised that their participation would be confidential and have no impact on their medical treatment.

On the day of the interview, consent was again sought and participants were asked to re-read the information form, ask questions and complete the consent form. Each participant then took part in a semi-structured interview. Following the interview, participants were invited to complete some self-report scales to provide further contextual information. Participants completed the Culture Free Self-Esteem Inventory-2 (CFSEI-2, Battle, J. 1981, 1992) and the Brief Symptom Inventory (BSI, Derogatis, L. 1993).

Each interview was conducted by the researcher and recorded onto audiocassette for transcribing purposes. Interviews were transcribed verbatim by the researcher and analysed using IPA. A sample Interview transcript can be found in appendix VIII.

Measures

Semi Structured Interview

The interview was designed to follow a protocol suggested by Smith (1995). Each interview varied somewhat in response to what was brought by each participant (see appendix VII for interview schedule). All interviews were conducted in a room in the child and adolescent psychological services area of the hospital, away from the main clinic area. This provided greater confidentiality for the participants.

The interview lasted an hour to an hour and a half. It began with an introduction and gathering of factual information relating to the participants' current status regarding their bladder exstrophy and progressed to open questions relating to their experiences and expectations for the future. Initial questions relating to medical status and asking for a brief history allowed the interviewer to orient herself to the status of the participant, their understanding of bladder exstrophy and an indication of the most salient issues for each individual. This provided the basis for the direction of further questioning as certain issues were mentioned.

Previous studies have indicated difficulties with body-image, self-esteem and relationships, which formed the basis of the opening questions. Other issues targeted for follow-up enquiries related to participants' experiences of disclosure related to their condition, continence and sexuality. Participants were asked general questions initially which were then followed by questions focused in response to the information given. In the same way, more sensitive issues such as those relating to sexuality and sexual relationships were asked later in the interview, once participants had had an opportunity to relax and speak about their primary concerns. Often target subjects were raised by individuals themselves and were followed up as appropriate, where possible using the participants' own words rather than those specified in the interview schedule. This allowed the researcher to engage the interviewee as effectively as possible.

Quantitative Measures

Culture Free Self-Esteem Inventory-2 (CFSEI-2, Battle, J. 1981, 1992)

The CFSEI-2 has been standardised on adults aged between 16 and 65 years and is used widely in clinical and research settings (e.g. Battle J. 1990). It is a 40-item scale, which contains four subtests. Sixteen items measure general self-esteem defined as "the aspect of self-esteem that refers to individuals' overall perceptions of their worth". Eight items measure social/ peer related self-esteem, or "the aspect of self-esteem that refers to individuals' perceptions of the quality of their relationships with peers". Eight items measure personal self-esteem, which "refers to individuals' most intimate perceptions of self-worth", and 8 items form the lie scale, which is designed to indicate defensiveness. Items are divided into two types, those related to high self-esteem and those indicating low self-esteem. Participants were asked to indicate "yes" or "no" to whether the statement described how they usually felt. Scores were calculated for each sub-scale and summed to compute a total self-esteem score. Possible scores range from 0 to 32, with a high score indicating high self-esteem.

Battle (1992) reports good reliability for the subtests, which make up the total score. Alpha co-efficients range from .78 on the general scale to .57 on the social scale. Test-retest reliability of the total scale was .81. The CFSEI-2 correlates highly with the Beck Depression Inventory (Beck and Beamesderfer, 1974) with correlations of -.55 reported, with low self-esteem indicating higher scores for depression.

The Brief Symptom Inventory (BSI, Derogatis, L. 1993)

The BSI is a 53 item self-report scale, which measures psychological symptoms in a range of psychiatric patient and non-patient respondents. Normative information is available for both psychiatric patients and non-patient groups in two age groups, adolescents aged 13-19 years and adults over the age of 19. The scale consists of nine subtests each measuring a different type of psychological symptom: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation and Psychoticism.

Participants were asked to rate each item on a five point likert scale of distress (0-4) ranging from "not at all" (0) to "extremely" (4). They were asked to indicate on the scale "how much that problem had distressed or bothered them during the past 7 days including today".

Scores can be calculated for each subscale. Three global index scores can also be computed to provide overall assessment of a participant's levels of severity (Global Severity Index, GSI), positive symptoms (Positive Symptom Total, PST) and distress at those symptoms (Positive Symptom Distress Index, PSDI).

Derogatis (1993) reports good reliability for the nine symptom dimensions, alpha coefficients range from .71 on the psychoticism scale to .85 on depression. Test-retest reliability for the three global indices was reported to be .90 for the GSI, .80 for the PST and .87 for the PSDI.

Researcher Context

It has been suggested by some researchers e.g. Stiles (1993) and Elliott *et al* (1999) that the researcher should disclose their preconceptions and expectations to provide an anchor for the reader, in order for the position of the researcher to be understood. It has been recommended that researchers make some statement about their position relating to the study and relevant personal and professional positions.

The researcher was a Trainee Clinical Psychologist on placement at one of the teaching hospitals whilst conducting the study. She had worked with children and adolescents for some years prior to training but was not experienced in working with urology patients. In general, the researcher held a broad theoretical orientation, most often using systemic and cognitive-behavioural frameworks in her clinical work.

Ethical Approval

The researcher obtained ethical approval for the study from the Joint University College London/University College London Hospitals NHS Trust committee on the ethics of human research. A copy of the approval letter can be found in appendix IX.

Analysis of Qualitative Data

Interpretive Phenomenological Analysis (IPA, Smith, Jarman and Osborn, 1999) is a technique which offers a method of detailed exploration of participants' view a specific topic under discussion. In this study the impact of bladder exstrophy on the lives of a group of young people was considered. The aim of the analysis was to capture the detailed content of the interviews and the complexity of meanings for each individual participant as well as across the sample of participants. IPA acknowledges that the research process is a dynamic one, which is, to some extent influenced by the interests of the researcher.

While transcribing each interview, the researcher noted broad themes that characterised each interview; this provided an overview of possible themes and sub-themes, which might emerge in more detail through the subsequent analysis.

Transcripts were each read several times and parts highlighted which appeared to hold particular relevance to the interviewee. These included any comment that appeared to the researcher to be significant or where the participant had made associations between different facets of their experience. The researcher also noted connections, associations and reoccurring themes that could be made within and between transcripts. Initially, anything commented on with emotion or particular examples of general experiences were noted in one of the margins. This stage of analysis also allowed consideration of the variety of experiences of different participants and began to illustrate variation as well as similarities between transcripts. This enabled the interviewer to draw out themes that emerged during the interviews and attempt to make some interpretation of their meaning. The aim of the process was to capture the essential qualities of the content of the text of individual and the full set of interviews. An attempt was made to read each interview with an open mind. However, due to the sequential nature of this type of analysis certain themes or comments may have already been bought to the attention of the researcher, which may then have primed her to notice them more readily in later transcripts.

As themes were identified, notes were made in the other margin of the transcript with reference to other transcripts where the theme had also occurred. A separate sheet of these themes and instances of them across all transcripts was kept in conjunction with the annotations on the transcripts. This allowed the process of organisation of themes to begin. Themes were arranged tentatively in clusters of similar issues. The process of clustering also enabled the explanation of ideas expressed in one theme to be explained by another. For example, in this study, considerable material in the "reasons not to tell" theme was explained by issues revealed in the "bullying" theme. In this way, themes were arranged under larger organisational categories, referred to as domains. Each time a cluster was noted, the original transcript was consulted to ensure that the ideas expressed by that participant within the context of the interview did indeed fit with that method of organisation.

The process of the clustering of themes occurred in conjunction with collection and analysis of new data. New themes were either integrated into the master list, or new themes or headings constructed allowing ongoing reorganisation of the data. This also involved constant reference to previously analysed transcripts.

The connections between the themes were further examined in order to enable the construction of a coherent list of domains, themes and sub-themes. Each theme and sub-theme was based on a set of statements from the text, and illustrated using selected quotes from interviews. This ensured a clear link between observations from the interviews and the researcher's interpretation. This process was completed for each interview in turn, with frequent re-assessment of earlier interviews until a list encompassing themes from all the interviews was constructed.

Finally, themes were translated into a narrative account with the data organised to make consistent and meaningful statements about (the researchers' observation of) the participants' experiences. This was rooted in the words of the participants through the use of illustrative quotes.

Credibility Checks

Several authors have discussed issues of validity of qualitative research (e.g. Stiles 1993, Elliot *et al* 1999) and have suggested strategies to address these issues. Credibility checks are procedures by which a researcher is able to verify the "trustworthiness" (Stiles, 1993) of their categories and themes. The methods used in this study are described below and discussed further in Chapter 4.

Annotated transcripts were reviewed several times by the researcher to ensure that the list of themes and sub-themes was as exhaustive as possible. Several annotated transcripts were reviewed by another researcher experienced in qualitative analysis (a supervisor) to ensure agreement on the categorisation of particular parts of the interview, the emergent themes and the coherence of the illustrations for each theme. Any discrepancy was discussed until it was resolved, and the choice of illustration either amended or explained more fully.

The table of themes and sub themes, plus illustrative quotes were reviewed by two other (peer) researchers to ensure the face validity of the process. This was particularly important in cases where a quote could illustrate more than one theme. It also allowed discussion of overlap between themes and their organisation. This was resolved as above.

The same two peer researchers conducted a final auditing of the organisation of themes, sub-themes and quotes used to illustrate these. This enabled fine-tuning of the presentation of themes and choices of the most illustrative quotes and another check on the "paper trail" of the analysis (see Smith, Jarmin and Osborn, 1996). It also facilitated further discussion of the overlap between themes and how they could most logically be arranged and presented in the narrative account.

Chapter 3: Results

Overview

The results will be presented in two main sections. In the first section, the participants will be described, including some detail of the practical implications that bladder exstrophy has had in their lives. This section encompasses the quantitative data from questionnaires, demographic and some medical information relevant to placing the qualitative data in context.

The second section forms the bulk of the chapter. It presents the analysis of the qualitative data gained through the interviews. Quotes from interviews have been used throughout to illustrate the account. These have been highlighted using italic script and are labelled with the participant's research identification number. Occasionally quotes from an interview are interrupted for the sake of brevity, this is indicated using a short dotted line. Normal print within quotes indicates the interviewer's words.

Section 1: Contextual Data

Practical Implications of Bladder Exstrophy

As a result of the bladder exstrophy all of the participants had undergone numerous operations, mostly as very young children, to close the hole in the abdominal wall, reconstruct the bladder and enable it to hold urine. Some of the participants had been affected in-utero in the formation of their pelvis and hips, which meant they needed to have orthopaedic work to correct this. These participants frequently described difficulties walking, and some had walked with a limp for some of their childhood. These procedures usually involved several long stays in hospital with reconstructive surgery to improve cosmetic appearance following later into childhood. Many females born with bladder exstrophy need to undergo an operation (vaginoplasty) to enable them to have penetrative sexual intercourse. Most patients had this operation in their mid to late teens. The number and scale of these operations had left many of the participants with many scars on their abdomens and genitals and frequently with weakened abdominal muscles. All participants were required to attend hospital regularly, at least annually for constant monitoring of their status. Several participants commented on the inconvenience of these visits and their desire to avoid further need for hospitalisation:

> *"When I have to come up for tests and things, you just think 'I just want to left alone, I've had my operation, I'm fine, I haven't got any infections, well I don't feel like I have' and I do get a little, ' God I've got to come up here, have more people stick [things in me]'. " (P11)*

Precise details of participants' experiences of continence aids were unclear; at least six participants had used an indwelling[2] catheter prior to learning to self-catheterise and at least five of the participants wore incontinence pads until their bladder was made continent enough to allow self-catheterisation[3]. Not all participants could recall when they had either become continent or learned to self-catheterise. Of the five who did recall when they had stopped using pads, the mean age quoted was 8.4 years (range 5-13 years). Of the six participants who recalled the age they had changed from an indwelling catheter to intermittent self-catheterisation, mean age quoted was 9.8 years (range 4-17 years). Most participants made some comment about their difficulties switching between methods of catheterising or in learning to self-catheterise.

> *"It was, well it was a bit sort of strange putting something into your body to make yourself go rather than go naturally, it was a bit sort of strange, um but obviously it took a bit of training and perseverance" (P10)*

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[2] An indwelling catheter is one that is permanently in place running from the bladder, via the urethra to the outside. A supra-pubic catheter is one that has been inserted surgically to run from the bladder to the external abdominal wall, leaving a tube from a stoma (hole) to enable urination.

[3] Self-catheterisation involves using a small tube (the catheter) inserted through the urethra into the bladder to enable the drainage of urine.

> *"I think that was a psychological thing of I can't put a tube in because its going to hurt." (P2)*

At the time of the interview all of the participants except for one had to self-catheterise. Nine of the participants had a mitrofanoff[4] through which they catheterised, six catheterised urethrally and one could urinate normally but needed to apply pressure to the bladder externally.

As a direct consequence of these methods of urinating, all participants commented that it took them considerably longer than other people to use the toilet. It also meant that most had to carry around extra items whenever they went out. These included several catheters and lubricating jelly (to assist in the insertion of catheters). Several spoke about the importance of finding a toilet at least every three to four hours and how difficult this could be in certain circumstances such as when out on a hiking trip for example. All the male participants highlighted their unwillingness to use urinals in men's public toilets.

Quantitative Data

Culture-Free Self-Esteem Inventory

Participants' scores for Total Self-Esteem were compared with the normative data. The normative data had a mean of 23.8 and a standard deviation of 6.67. Male and female participant's scores were considered together to give a larger sample; this had a mean of 23.8 and a standard deviation of 6.11. The current data were compared with the normative information using an independent samples t-test (t 598) = 0, p NS). The t-test indicates that there are no significant differences between the participant's scores and the general adult norms for total self-esteem.

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[4] Many of the participants had undergone an operation to connect the bladder to the outside through a tube running from the bladder to a stoma on the abdomen. The stoma is usually in the tummy button or on the side of the abdomen, midway between the waist and the genital area. This allows self-catheterisation through this stoma rather than urethrally. The bladder neck is closed so no fluid can leak urethrally. (For more detail see Chapter 1)

Brief Symptom Inventory

Participants' scores for the Global Severity Index[5] were compared with the non-patient adolescent norms. Normative data had a mean of 0.69 and a standard deviation of 0.59. Participant scores had a mean of 0.68 and a standard deviation of 0.71. These were compared to the normative scores using an independent samples t-test to compare the means (t (2421) = 2.50. p NS). This result indicates that there are no significant differences between participant's scores and the non-patient adolescent norms on this global measure of psychological and psychiatric symptomatology.

Section 2: Qualitative Data

The organisation of the qualitative data is summarised in Table 4 (page 57). The data were divided into three broad areas, or domains. The domains relate to the questions asked in the interview, but also reflect topics spontaneously raised by the participants. Domains were labelled "personal impact", "coping with bladder exstrophy" and "interpersonal relationships" which encompass particular groups of themes.

Themes label the key aspects of living with bladder exstrophy commented on by participants and sub-themes encompass specific aspects of each theme. Inevitably there was considerable overlap between themes and sub-themes, with several (such as "understanding") playing a role in many areas. Other themes are closely related but have an impact within different areas of functioning. Themes have been illustrated using quotes from interviews. As a result of the open nature of the questioning, many quotes illustrate more than one theme. Participants' experiences span most of their lifespan; as a result some descriptions of

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[5] The GSI is calculated by dividing the sum of all items endorsed by the total number of responses; possible score range from 0-4.

experiences are retrospective, others are current or represent an ongoing process and some are thoughts for the future. This sense of time span emerges in all domains and is commented on as relevant.

Table 4: Domains, Themes and Sub-themes

Personal Impact

- **Normal but not normal**
    - "Everyone else is normal and then there's me"
    - Being and feeling different
    - Missing out
- **"It's made me who I am"**
- **Confidence**
- **Physical Appearance**
    - Scars
    - Self-consciousness

Coping with Bladder Exstrophy

- **Who is in Control?**
- **Searching for Solutions**
    - Getting on with it
    - Practical solutions and support
    - Joking and Covering up
- **Cognitive and Emotional Reactions**
    - Withdrawal
    - Feeling depressed
    - Rationalising

Interpersonal Relationships

- **Telling**
    - Who's in charge of telling?
    - Reasons not to tell
    - Reasons to tell
    - When and who to tell
    - What to say
- **Bullying**
    - Experiences
    - Dealing with bullying
- **Sexual Relationships**
    - Trusting and Insecurity
    - Sex and Fertility
- **Family Relationships**

Personal Impact

This domain encompasses themes relating to the impact of bladder exstrophy on the participants' view of themselves and other people, often about how they thought other people evaluated them. The themes relate to some underlying psychological processes that affect other key areas that emerged in the interviews, in particular, the way people coped with having bladder exstrophy and their approach to interpersonal relationships.

Normal But Not Normal

A major theme that emerged in all the interviews was a sense that participants felt that they were essentially "normal" but also that they were "not normal" in some ways too. Although participants frequently described feeling "not normal", they were not always able to say what "normal" might be.

"Everyone else is normal and then there's me"

Many of the participants communicated a belief that they were not normal and that they felt that other people were. There was a sense that participants often felt different in comparison to other people and that this had been the case in the past as well as in the present. They also clearly indicated that the differences they saw between themselves and others were usually not positive.

> *" I don't feel normal, I sort of feel different to other people. If I was taken to one side I would feel different. If I was in a group of 20 people I feel I would be able to be picked out as different. Its not that I've got antennae and all that I just feel different in myself" (P10)*

> *"I just feel like everyone's, not better than me but normal really... there's something wrong with me there's nothing wrong with them, so the way I look at it, they're alright I'm not." (P13)*

Many participants expressed a wish to be more normal, indicating that they were becoming more normal as time went on, through surgery or strategies to deal with the ways in which they did not feel normal.

> *"You have then got to then have reconstructive surgery to make you sort of normal kind of thing or to function properly in everyday life."(P* 2)

Several participants had aspirations that further surgery might help in their quest to be more normal. Other people spoke with ambivalence about operations. Several indicated that they wanted more operations to "make them normal" but at the same time wanted to be left alone. There was a considerable sense of hope that at some point it might be fixed and then "normality" might be reached. Several participants spoke not only of their hopes for what surgery might give them physically but also ideas about the possible impact of feeling more normal:

> *"I don't want anything to be done in a way I just want to be me.....but I realise if something does happen, all right it looks normal, cos if it doesn't I'll be really annoyed, if all looks really normal and stuff suddenly I'd have all my confidence back" (P7)*

Others spoke of the conflicting emotions associated with getting closer to being normal:

> *"There was one night when [name of surgeon] gave me like a belly button cos he cut out one and he basically gave me a belly button back. And it was so nice to be able to have a belly button. But I thought of it completely differently. I was in shock I was crying and stuff all evening and I was like, suddenly I was becoming normal and I was really happy and but I wasn't, it was all weird. It suddenly all really hit home what had happened to me. And I was just sitting there one night and basically I just cried myself to sleep that night" (P7)*

Conflicting emotions and beliefs characterised several of the discussions about how bladder exstrophy had affected participants' lives. In addition to the hopes and concerns related to surgery there also appeared to be considerable tension between acting and wanting to be seen as normal whilst at the same time feeling different to other people.

> *"I looked normal apart from the scar. I've got a normal physique, there's some people who have got a limp or their legs are very wide, ...[I'm] not that different at all... But I suppose I feel different. It does sometimes depress me, just a touch. I look at people and I think, silly things. I just wish just for a week I could be normal, just for one week."*
> "What would be different if you were normal?"
> *"Things like going to the toilet, peeing in the ...urinal. And stuff like that and um, just seeing what it's like to be normal. Not so much seeing what it's like to be normal because I regard myself as normal but everything normal down there [genitally]" (P1)*

Most participants also reported that, despite their wishes to be normal, the way things were and what they did were actually normal to them, and that they did not really know any different.

> *"Yeah, I've known no different. I've not known normality as far as I'm concerned I'm normal." (P9)*

Being and Feeling Different

> *" I felt like I had antennas, or you know, 15 fingers...came from the planet Zog, and you know it wasn't like that." (P10)*

Another facet of being "normal but not normal" was illustrated by the experiences of participant's when they felt different to other people, and that they were treated differently to other people. Being treated differently was one of the reasons given for not feeling normal; there was a sense that it was the reactions of other people that made them feel different to others, in contrast to the more internal sense of not being "normal".

> *"I just want to be normal. And they don't make me feel normal, they make me feel different and basically like an outcast, and that's not nice....I get treated abnormally so they obviously think I'm not normal so I can't do that ....I've got to cross this to get treated normally." (P7)*

Other participants described how bullying by other children when they were at school had also made them feel different

> *"[Bullying] made me feel different. Um which is, I've always said to my mum all along what I want to try and avoid, you know OK I was unfortunate with what I've got, but I don't want to feel different to anybody else. You know if I'm in a crowd of people, it's not just, you know, put him to one side and you know, this is this lot and you know... I'm just the same, I'm the same as everyone else in sort of every other way its just unfortunate." (P10)*

All of the participants talked about how the physical and practical differences that were apparent were picked up on by peers and reacted to in ways that accentuated these differences. Almost all had some current difficulty with this or had past experiences that they could remember as being significant. Some examples of situations are included below. The most frequent comments related to the use of incontinence aids such as pads or permanent catheters as a child, comments and questions about scars, not using urinals and about the length of time participants spent in the lavatory.

> *"Because I was still incontinent when I went to primary school it was a case of not being a big girl and not being able to wear big girls pants because I was still in incontinence nappies... I went to school thinking everyone wore nappies which was a big mistake then blabbed to everyone else, oh I need my nappy changed now and everyone just looks at you and goes, you're not a big girl." (P2)*

> *" You get the occasional person who once he's had a few [beers] sort of just says 'eh you spent so long in the loo last time what's going on?' and then carries on about something else but it kind of puts it in the air and other people are there going 'oh yeah, So?' .." (P3)*

Several of the participants recalled experiences at school as being the most uncomfortable. Participants' experiences of being bullied were one of the major factors contributing to their feelings of being different; this will be discussed in more detail later.

Often, it was measures intended as a support for the individual in school that also made them feel different. Many participants had an ancillary or nursing assistant who shadowed them in school and helped them if they encountered difficulties catheterising. Nearly all gave the impression of this being both *"a blessing and a hindrance"* in that it was reassuring but also a cause of bullying or feeling excluded.

> *"I had a lady who came with me which was a bit of a bind....So that kind of stood out as a sore thumb to the whole school that this lady was following me all around school and everything. ....A lot of friends or some girls didn't trust me in that if they were bunking off school or something I'd just be completely deleted out of that from the circle of friends in case this lady*

> *found out.... It was having like a detrimental effect on me socially at school, because I would rely on her a lot for stuff ....I wasn't seen as normal and the whole point of me having her was for me to have an easier school life, and it was actually being detrimental and going the opposite way." (P3)*

Many participants were also allocated separate toilets to other children in the school. This, while intended as a support, was another point of difference. This was often the disabled facility, which provided more privacy and potentially cleaner surroundings and eliminated the need for them to carry all their specialist equipment around. It also seemed to some to underline their differences.

> *"I had my own toilet at school which was a blessing and a hindrance, in that I had a separate toilet and that was fine coz I kept all my catheters and syringes and what-not in there and it was locked but then people became curious and it was right in the middle of the school, people became curious about what was in this cupboard, what was in this room and why they couldn't go in there" (P2)*

In some cases, it was not just the provision of these facilities that accentuated the differences, but also a lack of understanding about the underlying problem. This appeared at times to fuel ideas about potential threats and worries.

> *"School actually didn't want me...they thought I might pass or someone else might catch something from me, that shocked me. That they were so, that they weren't willing to find out that I wasn't going to give someone anything." (P2)*

Missing Out

> *"I can't do something that maybe everyone else could do." (P6)*

Nearly all participants expressed the feeling that there were things that they had missed out on as a result of having bladder exstrophy. Many of these things were related to missing out on things in the past as children but some were also experiencing this currently. Participants gave several reasons for their non-participation in certain activities. These were often associated with self - consciousness about their scars, general appearance or anxiety related to aspects of an activity.

> *" I don't swim very much now cos I'm paranoid taking my top off cos of the scars" (P5)*

> *"Going out and getting drunk is quite a problem. (laugh) If you think about it coz each time I go to the loo I have to go, I have to use a tube basically. Most pub toilets are pretty foul, especially student ones, no running water generally half the time or not that you'd really want to trust" (P4)*

Many participants spoke of missing out on both day trips and longer holidays. Again, this was often related to worries that *"something might happen"* that the young person could not deal with without assistance.

> *"I didn't want to do it [go on a school holiday] because I was too worried about not having anywhere to go. So it stopped me doing something like that cos I was just too worried...I guess overall I'm just worried about something going dramatically wrong and having to go back to hospital" (P6)*

> *"I always had the operations in the summer holidays, so everyone was off enjoying themselves and I was sat in hospital" (P11)*

Often they had been told not to participate in contact sports by doctors. Aside from missing out on these activities, many participants also described the difficulties associated with other people noticing their non-participation.

> *"[Name of surgeon] says be careful, don't do anything you're going to split all your scars open, I can't do it all again. So you weren't allowed to play football all this that and the other and he used to say think about what you do before you do it" (P9)*

> *"I wouldn't be playing rugby and everyone else would be playing.... I think and someone had said are you – you know asked me which one I was – and he said are you the like, bladder person something along those lines, and I kind of thought oh perhaps I will try and hide it a bit more." (P 15)*

There was, however, a sense that these experiences would lessen as time progressed. This seemed to link with hopes of becoming more normal and that as a result they would have less reason to miss out on things. Many participants gave the impression that these things were missed in part because of their parents being more protective of them as a result of their experiences with bladder exstrophy. The issues related to threats and worries (in theme of "Who's in control?") appeared to overlap somewhat with both of these issues, and may provide some explanation for the protectiveness of the parents of adolescents with bladder exstrophy.

> *"They wouldn't let us go out, like all the lads went out to [town] of a night and that was where they hung about and mum and dad wouldn't let us go*

> *up there. As a kid used to curse them like hell cos all your school friends were up there I think that was because there was like fights and that if I'm not there I'm not getting involved in the fights" (P9)*

Many participants talked about how difficult it was for them missing school because of time spent in hospital having operations, for out-patient appointments or because of illness. Often they described feeling that they had not only missed out academically but socially as well.

> *"I was found to have dyslexia and they wondered why it wasn't detected before and one of they things they said was that if you missed all this time off – probably they just thought you were a bit behind" (P14)*

> *"I'd missed so much time off school, I got through all my GCSEs and passed them all, but I just didn't like it." (P5)*

> *"I wasn't really very popular at school. Probably cos I was away so much. It bothered me when I was at school, like bullying and everything." (P14)*

The overall message from many of the participants was that having bladder exstrophy had made them miss out on many of the things that their siblings and peers were able to do. Several of them continued to express some regret at the things they felt they currently missed out on and that they might miss out on in the future. As one participant put it, *"I'm still not doing what I should be doing at 17".*

"It's made me who I am"

Several of the participants thought that having bladder exstrophy had not been a solely negative experience for them. They spoke of how spending much of their early childhood in hospital surrounded by often unfamiliar adults, meant that they had developed confidence and maturity. They felt that the whole experience of coping with daily life had made them stronger generally as people.

> *"It's quite a positive thing, its made me quite self assured, quite confident, quite good at talking to people and things" (P2)*

> *"I would say perhaps it's made me more, slightly more mature...Because I've had to take on board quite a big responsibility of looking after myself." (P1)*

Several of the participants also felt that coping with bladder exstrophy had helped them to choose their career, in particular, two of the participants were training as nurses which they said was directly related to their childhood experiences.

> *"I always wanted to be a nurse... I wanted to be like [name of nurse] when I was little" (P12)*

Other participants said that their decision to go into dramatic arts had been influenced by their experiences, specifically that they had learned from an early age to cover things up and that they were able to use their experiences in their work.

> *"I've learnt to lie quite convincingly as well. I think on the spot which is probably why I went into drama in the first place. I love improvisation, where you think of things on the spot." (P1)*

This particular strategy is discussed in more depth below as most of the participants felt they needed to "cover up" for the daily differences regularly. Despite all of the difficulties, the vast majority of participants said that they felt that they had gained a considerable amount from their experiences, both as general experiences of being a child in hospital and specifically related to bladder exstrophy.

Confidence

Whilst many of the participants stated that they thought having to cope with bladder exstrophy had helped to develop self-confidence, many also described how various aspects of it had also reduced their confidence in themselves.

> *"The one bit of me that makes me different to everybody else, which is the only bit really that I feel that I am different to everybody else, it's just confidence." (P5)*

Occasionally, they cited a particular episode that they felt was significant in this lack of confidence.

> *"It [bullying] kind of shot my confidence, cos I used to be really outgoing ..It was annoying. And it just really for me went through the window. And if anyone ever said anything I'd just shrug away go into like a little ball." (P7)*

> *"Done my confidence a bit when I was younger. It's done it a bit now, I'd like to have a bit more confidence about myself now. But I suppose that's just getting on with it. I've got to get on with that." (P8)*

Almost all of the participants that had suffered from bullying in some form felt that this was a contributory factor in their general lack of confidence.

> *"I guess it makes me a little bit more cautious sometime... during my teens sometimes it verged on paranoid but now just occasionally." (P3)*

The theme of confidence ran through many other areas of discussion. In particular it seemed to relate strongly to participants' confidence in interacting with potential intimate partners and in their attitude to and experience of telling other people about their bladder exstrophy. This is discussed further below. However, as participants had positive experiences of talking to and interacting with other people, their confidence grew. A similar process appeared to occur in participants' perception of their own ability to manage difficult or unexpected circumstances, which seemed to increase with age. It is possible that this process interacted with parental protectiveness (specifically in their parents' confidence in the participants' ability to cope) and the participants' determination to lead a "normal" life.

Physical Appearance

Inevitably, because of the nature of bladder exstrophy, issues related to participants' physical appearance, in addition to its impact on sexual relationships formed an important area of concern for the participants. All participants spoke about issues relating to perceptions of the attractiveness or acceptability of their body, often spontaneously. It was an area of variable concern; some gave fleeting consideration to how others might see and judge their bodies whilst others appeared to become quite preoccupied with it. This issue is discussed below within the theme relating specifically to sexual relationships per se. Aside from sexual relationships, issues about physical appearance fell into two further sub-themes: one relating to the appearance of scars, the other relating specifically to general self-consciousness.

Scars

> *"My stomach looks like a patchwork quilt." (P 8)*
>
> *"Being a bit of a Frankenstein is what it sort of feels like. Being fixed and made and stuff, kind of weird." (P14)*

All of the participants commented on their scars at some point in the interview. As a result of the numerous operations all participants had scars on their abdomen, back and in some cases, genitals. The scarring appeared to be an issue of concern in two main areas, one relating to sexual contact and the other, a more general wish to keep scars hidden.

> *"One thing I don't like about my body is scars, its left a lot of scars so.. I just prefer them covered up... that's I suppose an embarrassment if you want to put it like that, I'd rather people not see that side of me." (P13)*
>
> *"It is purely image....I do get days when I think I really wish I could just flit around in little jeans or wear a bikini, yeah the little crop tops my friends used to wear in the summer, I used to think I wish I could do things like that." (P 11)*

For many of the female participants in particular, the scarring meant that there were certain types of clothing that they were not comfortable wearing, especially things like bikinis. However, several thought that their need to hide their scars had diminished as they got older.

> *"I have got my scars... I never used to wear a bikini, but I did last year (laugh).. cos I didn't like anyone to see... I dunno I just wanted to be like everyone else I suppose, I'd got to like 18 and, didn't care any more, didn't bother me." (P12)*
>
> *"I'm not sort of ready to go hey everyone look at my scars, I'm not, I'm getting better and better, I mean my friends have seen my scars, you know, and [name of boyfriend] does, but I won't wander round butt naked, sort of thing, well I will but not with, you know I'll always make sure he can't see everything, its like my arm is carefully positioned" (P11)*

Self-Consciousness

Many of the participants encountered occasional difficulties with leaking urine, either from their stoma or urethra. They spoke of their worries about leakages happening and measures they took to avoid embarrassment.

> *"If I was leaking quite a lot at that time I would suddenly think what if I'm going to leak when I go out. What can I do? Um and there are times when, I never did, but I nearly wore two pairs of underpants just thinking that oh OK that will help. And so there it just made me feel a little bit more cautious" (P3)*

> *"The sphincter muscle isn't tight um I sometimes leak, its really quite a bit so whenever I leave the house or go out anywhere I just wear a sanitary towel, which gives me a bit of confidence as well... seeing someone with a long wet patch on the back of them, its quite a horrible thing to have to be faced with, If I wear a pad all the time I'm not so worried about that any more." (P6)*

Several of the participants also spoke of their self-consciousness when using toilets and their wish for them to sound as normal as possible when urinating.

> *"Very self- conscious if you go to the loo, and you can hear other people go the loo and if you've got this little trickle coming out sometimes you really try and push it out to make it sound like you've got a normal, you know... Basically, you stand there with your back, get the stance, whip it round, make it look like you're... from behind, you hear the sound, see the stance... you don't make a point of looking, it's the bloke toilet thing, straight ahead, no side glances"(P4)*

> *"I'm very self-conscious about people hearing me take the catheter out of the packet and things like that, especially at work. So I tend to hold on a lot and make sure no-ones in the toilet, I'm very self-conscious and I don't wash it, I don't go up to the sink and wash it." (P11)*

Others spoke of their self-consciousness both currently and in the past when changing in communal changing rooms. In particular, many of the male participants seemed to find this particularly distressing when changing for sports activities in school.

> *"You go and have a shower in big communal showers which is difficult so I had to....it gets a bit tricky sometimes trying to figure out the gap between everybody in there else etc. trying to find a space when no-one's in there...It's like something on your mind about the whole evening but its not an upsetting worry – got to do this." (P15)*

> *"I used to not be able to do much swimming and if I did get changed there I'd have to go into my own private cubicle and stuff and everyone was taking the Mickey out of me constantly about that." (P7)*

One participant vocalised the issue that appeared to underpin at least some of the self-consciousness:

> *"I just think its unattractive and its sort of a medical thing and its not. I'm not bothered about the scars, I'm quite happy for him to see my scars, but having a little hole in your side is a bit urgh." (P11)*

Coping with Bladder Exstrophy

Inevitably, because of the physical differences and personal impact of bladder exstrophy, participants described the strategies they and others had developed over time to help them deal with these issues and make it possible for them to lead the kind of life they wanted to. In general, participants described two main types of coping; strategies aimed at finding practical solutions for the difficulties they faced, and the cognitive and emotional processes they went through whilst coping with bladder exstrophy. These processes are included as part of coping as they appeared for many to represent part of the process they had been through in finding solutions for their difficulties and in coming to terms with their bladder exstrophy. Many participants also spoke about issues of control, relating to who was in charge of coping with the implications of bladder exstrophy.

Who is in control?

Several participants' commented on issues of control related to who was in charge of dealing with the bladder exstrophy; them or the doctors. Many implied that, although they appreciated the expertise of the hospital staff, they preferred to be self sufficient, to cope with things alone, rather than enlist the help of others. Other participants described their anxieties related to not being in control when in hospital and during procedures, which was one of the difficult things about their hospital experiences.

> *"Just not being in control. Cos suddenly I go to sleep kind of but I don't have any control of, kind of subconsciously. I mean I suppose I do of my heart but not of like my breathing.... [it's] quite scary to think that someone else is controlling me, keeping me alive, its like not nice...The thought of being out of control, not being awake, having someone inside you, its like, its not good." (P7)*

Another participant spoke of how difficult it was for him that the doctors knew more about his body than he did, and that it made him feel *"a bit small"*. This was not an isolated experience. Another participant described an incident when he had felt very exposed by the actions of a doctor showing pictures of his genitals to his mother.

> *"Once [the doctor] examined me and there were all these trainee doctors around and he invited them all in behind the curtains, like seven people. That must have been when I was about 14. That wasn't pleasant. And then he got his digital camera out.... I didn't have anything against it because I thought well if you just kind of say no then it's not a constructive thing to do. This is a doctor – he is obviously a useful person so I wouldn't have said no but I would have if I wanted to. And then the thing is ... while I was doing myself up he went and showed my mum because you get the little thing [picture on the screen] – I didn't like that." (P15)*

In this case, the participant implied that he did not feel that he had much control of this situation, and although clear on the doctors' intentions, it still appeared to feel uncomfortable. Other participants found it difficult to understand what the medical team were saying to them and as a result felt out of control of their situation.

> *"I feel like I've got no say in what happens..... They tell me this is wrong, this is what we're going to do.....I dunno, they know what they're chatting about, my mum might know what they're on about cos she's read books but when it comes to me, they're chatting to me and they're explaining this that and the other, this is what were going to do this is where its going this is how were going to do it and... I just look at diagrams, I can't really understand what they're saying I'm just looking at the diagrams trying to understand myself what they're on about." (P13)*

Other participants described being very much part of the decision making process. This bought with it difficulties about how to make decisions and concern over the impact of these decisions once made.

> *"They just said look either we can try and straighten your urethra again or we can try this alternative operation and have a mitrofanoff, which was a new thing then. Erm and being a kid I was like 'I don't want to be in hospital any more, just go for the alternative' but at that age you don't sort of think about consequences- i.e. having a hole there, you don't think about boyfriends and what blokes are going to think of you when you are older and your sex life and things, its like 'oh no'. " (P11)*

Several of the participants reflected that it might have been useful for them to have had the opportunity to talk to someone at times during their treatment or while they were growing up. Some had made use of the support group or of contacts with others with similar difficulties on the ward, but most expressed a need for a professional person to talk to.

> *"I think it would have been nice if someone was there, when I was in hospital and going through the big patch, it would have been nice for somebody to sit down along my bed just talk about anything and try to understand how you are feeling at the time." (P1)*

In addition to control exerted by themselves and other people, several participants spoke of times when it felt like their condition was exerting some control over their lives. They communicated a sense that they lived much of the time under the impression that there was always a threat of " something happening", that they might become ill or that complications might set in that would interfere with their life.

> *"I do know that bladder exstrophy goes in cycles of you'll have 7 years of good health and then things will start to go wrong and you'll have another 7 years of health problems...I'm cautious that I might get ill soon....You notice absolutely everything yes, yes, yes definitely, every twinge I get in the lower part of my body this is it the start of bad health" (P2)*

> *"I think the fear, maybe to a strange level if I get a small pain anywhere in me I don't tell anyone...try and forget about the pain and carry on cos I think I'm scared that if I tell anyone I had something I'd have to go and see a nurse and then go back to hospital." (P6)*

In support of these worries, most participants had some experiences of ill health or difficulties related to catheterising that had resulted in their hospitalisation. These had, without exception, happened during their early or middle childhood when they were learning to catheterise, but they still appeared to represent some threat for many of the participants. This also seemed to provide a reason for the protectiveness of some of the parents, who appeared to worry about their children developing complications or getting into a situation they couldn't manage without having help nearby.

In contrast with this, several participants appeared to take control themselves through taking a relaxed attitude to medical advice. Some admitted that they did not use the toilet as often as they had been advised to, did not drink enough water, did indulge in alcoholic drinks and were not as scrupulous about cleanliness of catheters as they should be. Others also admitted that they had often participated in sports or activities they had been specifically advised not to.

> *"I get told you want to watch what you drink, this that and the other but the way I see it, no, not that I don't give a shit, that's not the word I should look for, if I don't live my life as I want to now and I stick by rules, I might live that extra couple of years longer but I really don't care about that. I just get on with what I am now and you know" (P5)*

One participant explained his relaxed attitude in terms of wanting to live as much of a normal life as he could. He communicated a feeling that the doctors might be over-cautious in their advice and that adhering too much to it would keep you away from normal activity and the positive benefits that being normal brings.

> *"If they had it their way they'd keep you locked up, and I think that's pointless, because what are you going to do? You going to sit indoors feeling sorry for yourself all the time, it's not worth it." (P8)*

These issues of control span many of the themes and domains that emerged through the interviews. In particular, they were associated with anxieties about not being in control of telling other people about bladder exstrophy and their reactions (see below) and the issues related to the bladder exstrophy itself and its medical treatment.

Searching for Solutions

Participants all appeared to have developed their own ways of coping with the daily hassles afforded by the bladder exstrophy. Many of the solutions described appeared to have the aim of "*covering up*" any differences that might be apparent to other people and enlisting the help of trusted friends and family to collude with this and make these strategies more effective.

Getting on with it

One of the most frequent comments made by most participants related to their determination not to let bladder exstrophy *"stop them doing anything"* or let it affect them in any way. Many said that it had never really had much of an impact on their lives.

> *"Its kind of made me more determined as a person to just lead a normal life." (P1)*
>
> *"It's never held me back in any way no, just it shouldn't and it doesn't. It doesn't affect the way I think or the way I act or the things I do." (P6)*

It was interesting that even those who made this type of statement also described some of their worries about "feeling normal but not normal" and their difficulties with some of the differences they perceived between themselves and other people. Some participants commented that if you thought of yourself as normal then so would everyone else, thus implying that there might be differences that may need to be hidden.

> *"I mean I've found my way, you think logically, you bat it all off and consider yourself normal…. You consider yourself normal. As far as I'm concerned there's nothing wrong" (P9)*

Others indicated that over time it became possible for them to get on with things. Some participants described this as a learning process that has to be gone through.

> *"I've always learnt that I can deal with it, never suddenly got worried about one thing." (P3)*

Several participants described feeling quite alone at times, and *"left to cope"* which meant that they had to *"get on with it".*

> *"Well you were sort of just to cope... Well you've got to go through it. You can't like not go through it, you haven't got any say in it you might as well do it... You can't like not go through it, you haven't got any say in it you might as well do it." (P4)*

Although not necessarily articulated directly, it was often hinted that these struggles were part of the process of reaching a point of acceptance about the implications of having bladder exstrophy.

> *"Something that I'm learning to accept as sort of part of me part of life and just get on with it really". (P3)*

> *"It doesn't really affect me at all any more its just every day life. I don't think of it as a burden or anything I just think of it as. part of life " (P6)*

Practical solutions and support

Participants described the practical solutions and support, which had assisted them in their quest to *"get on with it".* Several described how they would be careful in their choice of clothes, in case their bladder leaked or to cover up their scars

> *"[I] Wore a lot of dark so if anything did happen it wouldn't show" (P3)*

> *"And I never wear anything short any more. Just cos, I'm not wanting everyone to see." (P6)*

Others spoke of having to plan what they would wear or carry with them to make it possible for them to carry their catheters and other paraphernalia as discreetly as possible.

> *"I used to wear big jackets like this when I went out and have the bag in my pocket" (P3)*

Many participants spoke of they help they had gained from friends and family in constructing these solutions and providing assistance in keeping them hidden. In the example below, one participant described his discussions with his family to find a way for him to carry his catheters etc rather than having a large bag.

> *"One day we were sitting round the table at home and had a bit of a brain-wave and thought well actually if you get one of these travel belts you get for holidays [to put catheters etc in]" (P3)*

Family relationships are discussed in detail later, but many participants, as above spoke of their reliance on their family for help and support in coping with their difficulties.

> *"We talk within the family. We're all there for each other" (P8)*

Although supportive, at times there appeared to be a fine line between help from families being seen as supportive or as parental over- protectiveness.

> *"In some ways, I'm being treated with kid gloves and I've said to my mum and dad, stop smothering me basically, you know if I'm going to make a mistake, let me make the mistake rather than you saying well I don't think you should do that." (P10)*

The majority of participants said that their friends had become a vital source of support for them. They appeared to be particularly important in helping them deal with bullying and teasing at school and assisting them in "*covering up*" as it was necessary

> *"Until I was 10 I had to wear a nappy, so like I say I had a good set of mates then, so I was all, they made it easier for me... People know about it and everyone that knows about it always say to me 'if you ever get any problems let me know'." (P8)*
>
> *"If I disappear he knows where I'm going he'll lie to someone like 'oh he's just gone to get a drink or something', or he'll make up something." (P13)*

Joking and Covering up

Many participants described their use of humour to cover up difficulties or differences that may have been noticed and in response to questions that they did not want to answer.

> *"I just constantly wind people up. And I suppose that's my way of just getting over it really, it just joking about it...And yeah when I'm changing or when I'm sunbathing and there's loads of my friends around 'what's that scar'. I just say 'oh don't want to talk about it, its a shark attack'. Or something like that or 'Nam, I got that in Nam'...." (P1)*
>
> *"We all used to take the piss out of each other so...'It's where me belly split open, its where I had it sewn back up.' 'Oh right oh!' And because it's all wiggly they used to call me cobra [name]". (P9)*

This often appeared to be in response to questions about scars as well as when the participant was conscious that they had been a long time in the toilet.

> *"It's the timing most people notice when I go to the toilet. Normal people go for a pee and they'll be about 30 seconds, as I will probably be about 2 minutes, minute and a half if I'm quick. And I will come out and I will say 'ah just washed my face' I have to make an excuse every time." (P 1)*

Some of the participants described it as joking whilst others felt that it was " *a set load of excuses*" to avoid giving detailed explanations.

> *"A few comedy ones like, it [belly button] fell off in a car crash and how I didn't like it so had it sewn over that sort of thing and then eventually I often just say" (P3)*

> *"We were in the swimming pool once and one of the boys said, because he noticed my mitrofanoff 'what's that?' I said 'oh its an apple', again cracking jokes. And they just didn't ask any more questions, obviously it wasn't. But they just, I dunno, I think it's a [country] sense of humour thing. If you ask a question and you get a silly answer you just leave it at that." (P1)*

This appeared to be connected with participants' desire to keep their bladder exstrophy to themselves or at least have some control about when and whom they might tell.

> *"You don't let on what you're doing, you watch what you're doing, you don't let yourself play football and that won't happen. Like when you go swimming if you knew you had swimming that day, it was easier to get changed into your swimming trunks at home and I used to tuck the tube up right round my waist so you couldn't see it all" (P9)*

> *"If you make it obvious that you are doing something for a reason then people will notice it, but if you have a go at it then people will say, you can try it or they wouldn't even notice." (P1)*

As part of the desire expressed by some participant's to cover up for any difficulties, many appeared to feel a need to do things that everyone else did, (which also related to their feelings of "missing out") even if the doctors had advised them not to. In many cases, this involved playing sport.

> *"I shouldn't have but I participated in football, I was not allowed to do any contact sports" (P1)*

One participant explained another reason for his joking and other behaviour:

> *"If I couldn't show then that I was a normal lad by not playing football or rugby on a Saturday or Sunday then I'd just push it more when I was with*

> *them, jokes like, make them laugh, make them think 'ah he's great he is.'..." (P 1)*

The need felt by many of the participants to cover up their differences appeared to relate strongly to their feelings of being different and wanting to be normal, or at least appear to be. This also appeared to serve a protective function so that they could remain in control of who knew what about them and to prevent teasing and bullying as much as possible.

Cognitive and Emotional Reactions

Participants described a range of emotional reactions to their bladder exstrophy. They appeared to form some kind of process to enable the generation of new strategies when previous ones were no longer effective and allow processing of the impact of the bladder exstrophy on their lives.

Withdrawal

These reactions were sometimes spoken of in response to a particular event, particularly incidents of bullying and they often appeared to serve a protective function. Several participants described how they had withdrawn themselves from social contact to avoid any further bullying or hurtful teasing.

> *"I just stopped being as open as I was about it. I just kept my head down, wouldn't speak to anyone, do nothing...I was just not talking to anyone about anything cos I'd be afraid, like the question would pop up and that would be it, so, I just kept myself to myself." (P13)*

> *"I will not talk to anybody, I won't even talk to mum and dad, will not talk to them at all.... my thing always used to be, if I had a bad day at school, I'd disappear with a rifle get out of it that way." (P 9)*

Other participants described another type of withdrawal, cognitive avoidance.

> *"I can put it away and then I just could put something away that's actually important out of my mind." (P6)*

Unfortunately, although somewhat protective, withdrawal from other people as well as avoiding thoughts cognitively did not appear to work all the time for the participants. Several participants described periods of feeling quite down and depressed because of the bladder exstrophy.

Feeling depressed

Many participants described periods in the past when they had felt *"sorry for"* themselves because of all the difficult things they had to deal with in comparison to their peers.

> *"First of all I was self pitying, then I felt bad with myself for being self pitying... I just felt this is horrible why do I have to go through this type thing and I was feeling really unfortunate. And really quite depressed with my situation...I've been told that it won't change but I know I'm always going to have this and I was like why have I got this for the whole of my life why have I always going to have this and it was just pure kind of burden on me kind of thing and so it was a hard thing to deal with" (P6)*

Several participants described their comparison with other people and their feelings related to the differences they perceived, in association with a wish to be normal.

> *"I still get it occasionally, and I find that all of a sudden I'm gutted, I'm really disappointed that the fact that I was born with this only very rarely, but I still get it. Perhaps once every 4 months when I get a spell or a day where I'm like or 2 days where you're like ugh.....Just looking at people, knowing that they're 100% normal and they're like, I wish, sometimes I do wish I was born normal...I wish I could pee normally, I wish I didn't have to worry about infections why did I have to be born with this why can't somebody else... that persons' all right, bastard." (P1)*

Again, these emotional reactions often were described in association with a certain event, which had underlined the impact of having bladder exstrophy. The following quote was from a young man describing his distress at his lack of confidence when trying to get to know women, and admitting that he sometimes took his angry feelings out on those close to him.

> *"I sit in my room and think what a fucked up life.... and if I have an argument with my mum or something, and I've done it so many times and I turn round and say well its your fault I was born and.. and that's really hard and I shouldn't do that but its just anger and it comes out. I think I just use it as an excuse... I sit at home and think what a shit life. Or or if coming back to the sexual thing again, if I've met a girl, I come home and think if I had that courage, know what I mean.....There has been people that I've liked*

> *but I've never had the courage to go up to them because of the sexual side of things again." (P5)*

Other participants saw this as part of a process, again towards acceptance of their difficulties

> *"Um at first I felt why me, why does it have to be me? But then it doesn't really affect me at all any more its just every day life. I don't think of it as a burden or anything I just think of it as, part of life" (P10)*

Rationalising

Many of the participants described thought processes that they used when they were feeling depressed to try and make themselves feel better. Many of them said these ideas might have also originated from other people, most often their parents. This process appeared to take different form for different people, however, the majority described what sounded like a process of "rationalising" their thoughts and feelings, where they tried to adopt a logical, rational way of thinking.

Many of the participants viewed their bladder exstrophy as a kind of disability, and that it sometimes helped to consider it in the context of other types of disability.

> *"[It is] to a degree a disability of some sort and these people wouldn't go in the street and making fun of people in wheelchairs or well they might, these people I don't think, they were just school boys mucking around and I don't think, there was another guy in the class below me who only had one arm and he went through school fine because it was an obvious disability, people made allowances for him um but I think because this is a hidden one...." (P3)*

The idea of bladder exstrophy being a hidden disability was recounted by other participants, they seemed to think this had its advantages in that it wasn't immediately obvious, but had disadvantages too.

> *"Not to sound cruel but like being in a wheel chair probably is very complicated but when they see you they know. When I'm out clubbing, .. every time I get chatted up it's like 'you can buy me a drink but that's as far as it goes'... just fear of... cos they just do accept you as normal and you know being called gorgeous and all that kind of stuff when you're out you think yeah but when they find out they're just going to think urgh," (P14)*

In the face of these difficulties, and in a similar fashion to the "joking and covering up", many participants said they felt they should "*look on the bright side*" and appreciate the things they did have.

> *"My mum always used to say to me, just look at it, you're not in a wheel chair, you haven't lost a limb, you're still walking round being able to do all the things that everyone else can do, its not that much of a disability... And looking at magazines and that bit is a bit depressing, you think oh god. But then I think, I'm not overweight I'm not disabled, I haven't, I've got all my limbs and there is worse, it could be on my face, I could have scars on my face, and I don't think I'm that unfortunate." (P11)*

In a similar vein, one young woman spoke of her attempts to keep her thoughts and feelings in a wider perspective, which helped her with the process of accepting her difficulties.

> *"I went through a stage in the summer where I was really uneasy with myself and I was really upset that I had this and no-one else did but then I suppose I started thinking about it in a sort of global perspective and I thought I have absolutely nothing compared to anyone else and it effects my life in a minimal way and I don't think, I think I've got over the whole 'oh my god why me?' kind of thing." (P6)*

Many participants spoke of how helpful talking to other people was in shifting their thoughts and feelings away from the depressed to the more "rational". One person who had not spoken to anyone about her bladder exstrophy used a diary as a substitute for talking, but described the process very articulately.

> *"I keep a diary, I always write everything down and that normally just helps me think things through. I normally get, I normally manage to think things through and reach a logical conclusion to it. But at the end of the day instead of talking to someone, clearing up my own head. " (P6)*

Another facet of "rationalising" was the way in which some of the participants spoke of their anxieties and difficulties as being the same as everyone else's, particularly during adolescence.

> *"Everyone, they're conscious about everything, I'm sure you've got something you don't like about yourself, obviously you look to that and your mind thinks you've got to change this change that but other people like wouldn't even notice." (P4)*

Of particular note was the way all participants felt that their coping with the impact of bladder exstrophy had improved with time and that they had found strategies that worked for them. This mirrored their descriptions of dealing with telling other people and with the physical implications of bladder exstrophy.

> *"I thought this was a terrible thing, up to about 8 I didn't think about it at all then I sort of, I think someone pointed out one day and I thought 'oh yeah, oh no!' I was a freak, what's going on! And up to about 13 I hated it and didn't mention it at all and then when I was about 13 or 14 I realised it was a talking point and people went 'oh wow look' and it got me attention." (P3)*

Interpersonal Relationships

Participants spoke at considerable length not only about the impact that bladder exstrophy had on them personally but also its impact on their interpersonal relationships. It appeared that the personal implications of bladder exstrophy, in particular the emotional impact of these and their effect on behaviour, also led to a subsequent impact on several aspects of the way participants related with other people. Four main themes emerged: "telling", "bullying", "sexual relationships" and "family relationships".

The theme of "telling" was one that was raised in all interviews and appeared to hold great significance in many of the participants' stories. There was variation in participants' attitudes towards and experiences of telling other people about their condition. However, the vast majority appeared to spend considerable time thinking about the issues related to disclosing this information about themselves which in itself was a source of considerable concern.

The remaining three themes are directly associated with relationships in different areas of life. They detail the struggles and successes that many of the participants had in their relationships with others. For each individual participant there appeared to be considerable overlap in the domain of interpersonal relationships. Individuals appeared to have particular strategies that permeated all types of relationships; which also appeared to reflect their approach to more general coping. While several participants felt that their supportive relationships had helped them to deal with difficulties, many had experiences of relationships that had caused them anxiety or pain. The two most common sources of difficulty expressed by the majority of participants were firstly; in dealing with bullying, mostly during their childhood, and secondly; their anxieties related to current and future sexual relationships. Family relationships were also spoken about, but in comparatively little detail and mostly retrospectively.

Telling

Many of the participants spoke at length about their dilemmas related to whether or not to tell people about their difficulties. There were two main groups of participants. For one group, talking to people about their bladder exstrophy was not difficult and many of their friends knew about it. Often participants had disclosed in some degree of detail and had made judgements about who needed to know and who didn't. Another group of participants were considerably more uncomfortable with talking about these issues with people outside their immediate family. Many communicated a sense that they felt that this was a private issue, or one that they hoped might remain hidden.

Who's in charge of telling?

A number of participants talked about how their decisions to tell people had been influenced by advice from health professionals and parents. Several participants had been advised by medical staff and their parents not to talk to other people about it.

> *"[Name of doctor] my initial doctor said it would be best, it would be easier on you if you didn't tell anyone around you. And it was right cos it was easier to cope when just you know." (P 6)*

> *"When I was younger it was always, you are always told look don't speak about it.... it was just recommended, Mum and also the nurses like recommended stuff like, look don't make it open sort of like, just sort of cope with it." (P4)*

Participants were not able to articulate what the impact of this advice might have been, but implicit in their accounts was a sense that disclosure was risky and that other people might not understand. One participant did comment that he thought advice was different now and that younger families were now advised to be more open with friends and family and that this would be easier. The type of early advice may also have had an impact on family views of talking about bladder exstrophy, which in turn appeared to have some impact on whether participants found it easy to talk about or not.

Several participants spoke of experiences of having someone else take control of telling people about bladder exstrophy. In the quote below, one young man described his relief when his mother spoke to his class about his difficulties:

> *"I felt uncomfortable being there... cos no-one knew and they were like looking at me in funny ways and they were talking about me and I just wanted it to be put straight..... She* [the participants' mother] *thought it would be better to tell them and get it out of the way." (P13)*

In circumstances like this disclosure appeared to achieve its aim of helping other people understand some of the differences they might have noticed. However, some participants had experiences whereby someone (usually a teacher) made a decision to tell other people about the bladder exstrophy, often with consequences that were the opposite to what was hoped for.

> *"The head teacher just walked into the class and said 'oh [participants' name] has got such and such and he's had more operations than hot dinners' and it was hell as soon as I got back, it was awful."*
> "So she walked in and told everybody? Did she tell them exactly what happened?"
> *"Oh yeah, yeah, I just sat there and I thought why? And they said 'oh they won't pick on you now' I thought, they'll pick on me even more now, thank you, you know it was just awful when someone went in and did that and I*

> *said 'why?' And they said 'well at least it's out in the open' but I said you didn't ask me you just went off and did it." (P 10)*

This experience appeared to make the participants' feel like they had little control over the process of including others. It made them more vulnerable to bullying and was another way that they felt that they were treated differently. In the case quoted above, like several others, the disclosure by teachers gave the bullies more ammunition.

Most participants had both positive and negative experiences of telling people which appeared to result in them having a relatively clear policy about whether or not to be open about the bladder exstrophy and to what degree. They connected their opinions about the necessity (or not) of disclosing with what they saw as the potential consequences of people knowing. Some thought others knowing might have a positive outcome, however, many participants feared different treatment, bullying or rejection if they disclosed. Often, participants indicated a specific experience, good or bad, which had impacted on their position of secrecy (or not) in relation to their bladder exstrophy. These experiences seemed to dictate what their expectations of the outcome of telling might be and in many cases a single or rare "bad" reaction held more significance than many positive experiences of telling. Participants' perceived outcomes of disclosure appeared to impact on their approach, not only to talking about bladder exstrophy but also in the way they coped with questions from others. It is therefore likely that whether or not a participant wanted the bladder exstrophy to be a secret was also related strongly to some of the coping strategies detailed above. It appeared to relate most to those involving avoiding drawing attention to differences and covering up potentially noticeable differences.

Reasons not to tell.

All participants expressed some level of anxiety about possible reactions from other people and all thought that a bad reaction was likely to happen at some point. The fears expressed by the participants seemed to be very real to them and appeared to play a large part in decisions not to talk about bladder exstrophy

Unfortunately, many participants did have some bad experiences with reactions to their disclosures. It would be fair to assume that it would be unlikely that anyone would disclose if they had no hope of a positive reaction. However, almost all participants harboured fears of negative reactions even if they had never had one themselves.

Many of the participants communicated a sense that often they would prefer nobody to know about their bladder exstrophy. Several thought that how they used the toilet (which they saw as the key consequence of bladder exstrophy on a day-to-day basis) was not a topic relevant to most people they knew.

> *"It's like telling everybody how you go to the toilet, its, you don't really share that with people." (P14)*
>
> *"I think it's more that people don't need to know about it. I find it quite personal. I never really thought about telling anyone." (P16)*

Several others appeared to think that there was little point in sharing information about their condition, as it wouldn't serve any useful purpose. The issue of who needs to know is discussed in detail below, but most participants felt that disclosure was on "*a need to know basis*".

> *"Its not something which concerns me enough to need someone else to know and need someone else to worry about me. I don't want any sympathy of any kind. Cos I just don't like sympathy. [Laugh]. It just makes me feel like everyone's pampering over you and I don't like that... it won't make any difference to me or to them if I tell them and it won't make life easier for me, someone else knowing. It might it a bit harder even. (P7)*

Several participants described their concerns about employers' perceptions of their ability to perform certain jobs and how they had or might change if they knew about the bladder exstrophy.

> *"I explained about my bladder and that and he said 'bloody hell' and I said 'as you can see it doesn't affect my work', 'no, no' he said, 'I've seen that', he said 'I wish you'd told me that before, I wouldn't have taken you on', I said 'but why?' And he said 'well you're a bloody liability you are'." (P9)*

> *"I just like refuse to tell them that I've got a problem so I just like keep that to myself and I try and get on with the job like, but I obviously disappear now and then to the toilet and they actually pick up on that and they start asking questions. Cos I won't tell them what the problem is they end up saying we're sorry we're going to have to let you go." (P13)*

Several of the participants said that their decision to be less open with other people about their bladder exstrophy was strongly influenced by a bad experience of telling someone else.

Some participants described responses such as *"caring"*, *"sympathy"* and people *"feeling sorry for them"* as being difficult to deal with, even though they were among the commonest reactions to disclosure.

> *"People go on sympathy acts when they do find out and I don't like that whatsoever." (P7)*

> *"The worst thing I hate is that sometimes people feel sorry and I don't want people to feel sorry, you know, look I was unfortunate, don't feel sorry for me, let me get on with it and you get on with what you.. but people tend to say 'ohhh, poor [participants' name]' and its like 'No!'.." (P10)*

Several had also felt that people rejected them after they had talked about bladder exstrophy. Some people were afraid that others would be put off by the nature of the problem being in a socially taboo area.

> *"I've come to terms with the fact that it happens and I'm secure about it and I'm not secure about what other people would think of me, I think even though I'd try to say that, yeah well your opinion doesn't matter to me, but then I think if people see me as quite a yuck unhygienic kind of person that would bother me a bit"(P 6)*

> *"I have had experiences where people have just been grossed out because its something to do with urine and its like ohh go away, I don't want to hear about it kind of thing" (P2)*

Other participants described blatant rejection:

> *"The one [girl] ran a mile obviously that still imprints in you mind…I felt awful, I felt tiny you know, so what, you know… I mean you either take me as I am or you don't basically, this is me." (P10)*

Participant's recounted their fears that people would not respect their confidentiality and that, like the experiences of some, everyone would find out.

> *Um maybe them just going back to their friends and saying 'oh my god you'll never guess what she does' or something. I think just the gossip of it." (P6)*

Many participants had more experiences of broken confidences, a bit similar to those experienced when teachers had inadvertently "*blown the cover*".

> *"It's a bit hit and miss….sometimes its like the jungle telegraph…at times, tell the one person and its oh God, (laugh).. everybody knows. " (P10)*

> *"I've had an occasion where I've told someone that I thought was a friend but wasn't and it got around if you want to say that and that's when all the problems started" (P13)*

Participants were concerned that a disclosure might mean that people treated them differently. This appeared to be associated both with thinking they would not be seen as normal, resulting in different treatment from people who knew.

> *"[I] suppose some of the feeling different and how people look at me. As an actual person when they get to know me its, one of the things I worry about once I've told people" (P 10)*

Some participants connected their reluctance to tell with these bad experiences and the worry that those sorts of reactions might happen again.

> *"Having that experience of just going into primary school and telling everyone absolutely everything I then went into secondary school feeling fairly guarded about it um. And I waited a year before I became really good friends with one girl and I said look this is the situation, and she was fine about it." (P2)*

Despite all of these fears and their experiences of less positive reactions, the majority of participants did not hold rigid views about whether or not to tell. Most had talked to friends and romantic partners about the bladder exstrophy. There were only two exceptions who had not spoken to anyone else about it apart from medical staff and their families. Both of these participants felt that they had no need to talk to anyone else about it and would prefer to keep it private. They did, however think that at some point they may talk to an intimate partner, but that had not yet been an issue. Other participants described phases of cautiousness or thinking about these issues in the process of deciding whether and who to tell on a case-by-case basis.

Reasons to tell

The majority of participants held relatively flexible beliefs about disclosing their bladder exstrophy. They spoke about several advantages to being at least partially open about it. Their openness seemed to relate to what participant's hoped to gain by telling people which was weighed up against their fears about possible consequences of talking about it.

Several participants expressed the hope that by telling people about what had happened to them, or explaining some of the differences they might have noticed, people might understand about some of their difficulties and offer support.

> *"People look after me a bit more, if I tell people they're like, you know what I mean, but if I didn't tell people they'd never know." (P8)*

They also felt that it might be helpful if there was ever a problem.

> *"I don't think they need to know but its good for them to know. So if I ever go out with them and something happens they wont think what the...hell is going on here, I didn't know about that." (P8)*

Most participants had mainly good experiences of people understanding following disclosure. Occasionally it brought about respect in terms of the courage it was seen to take to come forward with that kind of disclosure.

> *"I think he admired me more then for having the courage to tell him. I think he was chuffed that I'd chatted to him about it, to let him know."(P 1)*

The most common response reported by the participants was curiosity and questioning about the impact of bladder exstrophy.

> *"In a nice way kind off really curious about it and just want to know all the in's and out's about it and I get fed up with telling them I think its not relevant," (P2)*
>
> *"I just get irritated when they start asking questions" (P13)*

Participants varied in their reaction to questioning by others; several found it comfortable to answer these questions and reassure the other person about the consequences of bladder exstrophy, whilst others described becoming irritated with the questioning and the feeling that it was inappropriate.

> *"It can feel like I'm on Mastermind you know and sat there being bombarded, and its, and I sit there and I think why do I have to answer to you? Who are you to question me?" (P10)*

There was also a sense from many of the participants that some people needed to know, primarily so they could understand. These mostly included teachers, employers and potential intimate partners. This appeared to be both stressful as well as helpful. In this, as well as the sense of being "normal but not normal", participants seemed to fluctuate between two positions, each of which appeared to be appropriate at different times.

When and who to tell

It became apparent that talking to people about the bladder exstrophy seemed to happen at a time when participants felt comfortable with the people around them or when there came a point when it seemed to be necessary to give some information, mostly in explanation for the differences. This links in some ways with the coping strategies, particularly "joking and covering up" that participants seemed to employ when they first knew people or were not that close to them so felt that they had no need to know anything.

For many of the participants telling other people occurred when they felt that the reasons to tell them out-weighed the fears about possible bad reactions. This seemed to be the case most with teachers and employers

> *"I don't even want to tell anyone. But I have to tell a few people...You might as well be straight cos like sometimes they just find out and then they get a bit annoyed." (P7)*

Overall, participants' seemed to feel that this, like so many of the things to do with bladder exstrophy, got easier as they got older.

> *"If I'd started telling my friends at school when I was 13 about the intimate details of it then I would have been a laughing stock" (P3)*

In part this was because they had found a way of telling people that worked for them and thus had developed a strategy.

The majority of participants spoke of how important it was to them that they knew people well before telling them anything about bladder exstrophy.

> *"Once I'm fairly good friends with someone and I know that I'm not just going to, that they're not just a passing acquaintance Um I'll normally let them know that I have this condition or a condition, I don't necessarily even say what...... Generally there came a point when I thought I had to mention something, and actually as time goes on its much more free for me to mention it rather than I feel that oh I really have to say something." (P3)*

Participants said this was mostly to enable them to know people better and enable them to gauge how people might react.

> *"I tend to focus more on peoples minds and, people just sort of say something and I'm thinking how would your mind react to what I'm telling you" (P10)*

What to Say

All participants who had talked to people about their condition appeared to have a clear idea of the level of knowledge people needed to know. The majority of people told others in stages.

> *"I sort of tell it in stages, I sort of say well I was born with this problem and I've had a few operations, I don't sort of tell them I catheterise, and them slowly after, over the months and say, have a few drinks and say 'oh my*

> *God I've got this wrong with me' and they're all like 'what were you worrying about it doesn't matter' so.." (P11)*

There was a split between people who told others in detail about their condition:

> *"Generally the thing is, I usually say I was born with the bladder on the outside of my stomach, that's been put back in, my hips were out of their sockets they're wired in er and I have to go to the toilet using a tube, I generally say I stick it in a hole in my stomach and its like 'oh Christ, bye then'. " (P9)*

And those who were more cautious about giving details:

> *"I don't give all the grotty details people aren't going to want to hear that."* (P 3)

They also spoke of avoiding certain words, in particular bladder or medical words that might not be easy for non- medical staff or friends to understand

> *I don't really talk about it because it's not exactly the most, oh I've got something wrong with my bladder and things, people are like urgh... I try to skirt around the bladder bit, I tend to say its more kidney s and things cos that sounds a bit more.. I don't say 'well I was incontinent as a child' or anything like that and I don't tend to go 'oh I have to catheterise' or 'I've got a hole on my stomach' or anything like that. I'd say things like 'when I was born I had such and such wrong with me and I had operations over time and I have to go for check-ups over time but I wouldn't go majority in depth'..." (P11)*

> *"Its just a bit, its too much, you've got to be, the terms, I only know the medical terms which you, or me, or my mother, or the doctors would know, but I don't know any other way of saying it." (P1)*

It became apparent that sometimes talking to people about the condition was painful for participants, not only in terms of what they said and to whom, but also in terms of their own emotional reaction. It is likely that this evokes feelings of difference and amplifies insecurities that many people would have in social or emotional situations within relationships, particularly sexual relationships.

> *"Cos, I don't know, people nowadays its just, you can't explain things like that cos they just sit there, they've got a grin on their face and you just think I'm going to smack you in the face whatever. And I get agitated speaking about it as it is so.. I just don't, I just keep it to myself...Sometimes I can't explain why I get upset and I start fighting. Its hard to explain some things, I just don't want to explain it cos its too hard to explain." (P13)*

Issues about disclosure raised by participants with specific reference to sexual partners is discussed below, but many of these appear to be similar to those raised above. In general, these concerns appeared to relate most to personal friends and acquaintances as well as to those perceived to be in authority such as teachers, lecturers and employers. The majority of participants, in particular the older ones, said that whilst it was difficult in the earlier years of adolescence, their struggles around issues of telling others about it had culminated in the resolution of these difficulties. This meant that talking about bladder exstrophy and its impact on them had become easier with age and presumably with more good experiences of telling people. It is also possible that with maturity, participants' peers became more understanding of information received and therefore more likely to receive it sympathetically.

> *"When you tell an adult something, you don't expect them to get all giggly, and...various bits, but when you tell a younger person you know what they're like, they go off and tell their friends" (P10)*

Bullying

Several of the participants described some experiences of bullying from other children. This was almost exclusively (except in one case) spoken of as something that had occurred in the past and was not anticipated to continue.

Experiences

The way incidents and experiences were described they appeared to fit along some kind of continuum between no bullying reported at all (four participants), through some minor incidents of bullying, mostly mild name calling or a few isolated incidents (reported by nine participants), to a few cases of persistent and potentially severe bullying (reported by three participants).

Many participants were bullied during their earlier years at school. Quite often, this seemed to be dealt with successfully, so was described as a more minor, distant memory.

> *"I remember getting picked on when I was younger because I still had to wear nappies to school." (P4)*

> *"There were odd children that used to pick on me about that, but that was at first school, I haven't had an incident like that since." (P11)*

> *"Um name calling in the playground. But that was always sorted out, someone used to do it, they used to get a clout for it." (P8)*

For others, the bullying appeared to be a more accessible, vivid memory. This was sometimes of a specific incident, but often participant's recounted stories of more protracted bullying, lasting for a considerable period of their schooling.

> *"There were a couple of horrible nicknames... someone called me 'tube' which was a bizarre name but the best they could think of, I was called 'Plastic [name of participant]' for a while, which because they weren't quite sure what it was with me and they thought that it was something to do with plastic surgery or something or some part of me or something.... I think they thought that I wasn't completely human or not ......It was upsetting, particularly as it's a private thing that they say in the corridor to you I sort of can deal with it a bit better, but occasionally if they say it in the classroom or across a crowded thing then it's a little bit embarrassing." (P3)*

> *"I was in the shower so I'd come out and some chap see the top of my catheter little hole and he said to me what's that, so I showed him and he pulled it [an indwelling catheter] out. Yeah and I had to go to hospital". (P5)*

Unfortunately, for a few participants, the bullying they described was still occurring:

> *"People have got an advantage on me if they know, cos there was an incident one time, I think it was in the beginning of year 7 after I'd started fighting with people I had to use the toilet in the new school, and two people that knew actually, I had to put a catheter in my side to go to the loo and one of them like they were in a group and they dared to do it they actually came in, pulled the tube out of my side and ran out.... it was just the fact that they pulled it out and things" (P13)*

Many participants described how awful the bullying had made them feel, both at the time and in retrospect. Several participants, particularly those who suffered protracted and severe bullying said that it had resulted in them withdrawing from contact with their peers and hoping that it would "*go away*".

> *"Just knocking me down so much that I don't want to be with people basically, um its like with anything, if people continually being horrible, you tend to keep away from it and avoid it um, and that was my defence mechanism.... to stick my head in the sand and hope it will go away, but it won't... they made me feel so tiny." (P10)*

Participants came up with different explanations for why the bullying had occurred. Many felt that it was part of the normal course, that everyone gets picked on for something and that for them bladder exstrophy was the thing that was picked on by others.

> *"Whether you've got something wrong with you or whether you haven't people will find something to pick on you for and if they haven't they'll make something up" (P3)*

Other participants identified that the bladder exstrophy was the thing that made them different and this was why it was picked up on by other children.

> *"I tend to find… they like pick on bits of it and you know, 'oh you're different to the rest of them', oh and its like, you don't need it, I mean people can be really nasty if they want to be nasty." (P 10)*

Another participant described this difference as a weakness and began to talk about strategies he used to combat the bullying, in his case, fighting back.

> *"To me having bladder exstrophy is like a weakness, and for someone to pick up on that weakness and make fun of me, that's the weakness I've got so that's their main target for me. I'd rather something to be able to back that up which is basically my temper, which is covering that weakness." (P13)*

Dealing with bullying

Participants described strategies they employed to deal with bullying. Inevitably these varied with the type and duration of bullying encountered. Participants own coping strategies as discussed above bore similarities with the methods used to deal with bullying. It is possible that experiences of bullying assisted in the development of the coping strategies that might have generalised to other areas.

Several participants said that they reacted angrily to bullying by others and that this had proven to be an effective strategy

> *"I started firing back at people, I used to be really quiet and if someone took the piss I used to run off and hide in the corner, but towards the end of the first year I got big and I realised I was getting big and I thought sod it…..a couple of people started taunting me and you just push them, and with your anger you push them harder than you realise and they go further back than you think" (P9)*

> *" I get angry cos I'm agitated and paranoid that people are talking about me, looking at me, laughing at me and things like that... I don't mind if they say it behind my back cos then they're not going to say it to my face, its not going to upset me and I can go about my own way. But if they keep coming up to my face then that is when to me it's easier to solve it with my fists. " (P13)*

Some participants had told teachers about the bullying in an attempt to gain their help in making it stop. This appeared to work in some, but not all circumstances.

> *"I actually just told the teacher. And I was really lucky that the teacher took it seriously and sort of like was 'well this has got to stop' whereas some teachers may have said 'that's just playground tittle tattle it'll go away'.." (P2)*

> *"Teachers all say oh come to us if you're getting bullied so you go to them, they go to see him [the bully] and it comes back and say 'why are you telling the teacher on me? You can have some more now'..." (P9)*

Others enlisted the help of friends which in many cases appeared to provide " *a hard hat and shield"* from the bullies.

> *"I had friends at school who were fine about it and just thought well they're idiots as well so don't worry about it. And that was fine. I think it was mainly just me knowing that actually what do they know? They're making up they know that oh he's got something wrong with him lets pretend its something to do with plastic surgery and I knew that they didn't know anything about it" (P4)*

Several participants shared the view of people around them that if people understood some of the reasons behind the differences they might have noticed, the bullying might stop.

> *"I just kept thinking if you knew the truth you'd shut up. If you stopped listening to your mates if you come and ask me you'd actually know the truth." (P9)*

All participants, with one exception, described the bullying as in the past and as having been dealt with. Most felt that they had used their strategies and gained assistance from others and that it had either made the bullying stop or that they had been able to fight back for as long as necessary until it stopped.

> *"I just hardened up, I just managed to repel it away but then after a while everyone stopped and I got loads of respect" (P7)*

whilst others had been advised to ignore it, which some found very difficult:

> *"I remember my mum and my sister always saying, 'just ignore them, just forget about them' but when you're trying to be a part of something and fit in, you don't want to ignore them, you still want to be a part of something but being a part of something you've got to get flack coming to you, people mouthing off calling you names and stuff." (P14)*

The participant for whom the bullying had not stopped was one of the younger interviewees and was still in full-time education. The majority of bullying had occurred in school settings. Several of the participants implied that increased understanding by their peers of their differences, as well as an increased tolerance for difference which appeared to come with maturity, contributed most to the cessation of bullying.

Sexual Relationships

One of the major concerns raised by all participants related to intimate, potentially sexual relationships with other people. All participants indicated they were heterosexual and all except one had experiences of girlfriends or boyfriends, most indicated that they were not virgins. Despite this, many spoke spontaneously about the difficulties they faced in intimate relationships and many felt that this was one of the major areas of impact of bladder exstrophy on their lives. Several said that they had felt pressurised by their peer group to be interested in, and want an intimate partner. Many felt that they would rather " *change the subject*" or " *ignore it*" whilst others felt pressurised into lying or entering sexual relationships so they would not be left behind.

> *"There was a group of about ten of us and it did get, got to about 15, 16 and everyone was like, oh I slept with so and so last night and I was like 'oh God this is never going to happen to me'.....all my friends are losing their virginity at 16, 17 and I'm going to be like 25 before its time, I did, you do, sort of make up stories, and say oh yeah I slept with so and so" (P11)*

Others felt this pressure and a sense of their own differences when they compared themselves and their physical abilities to those reported in the media. This man was talking about his thoughts about his own difficulties in sustaining sex for a long period.

> *"You hear things and you read things in a magazine, you read two hour sessions and you think 'oh no way, um, this that and the other'. As I say, you just think about it for a while, you think well... you wonder what its like to be like that." (P9)*

These issues were reminiscent of those talked about in relation to physical appearence and where ideas of what might be "normal" may have come from. It is likely that in the area of sexual relationships this would be particularly powerful as they often highlight areas of general insecurity experienced by many people, particularly during adolescence even those not struggling with the implications of bladder exstrophy. Several participants spoke of this directly and their wish that they could be the same as others as they saw them.

> *"Its easy for them, they can just go full whack into a relationship and not have to worry whereas I can't help but worry if everything's, if its going to affect them or not." (P1)*

Many participants referred to their own lack of confidence when talking to members of the opposite sex or in taking a relationship into the realms of sexuality.

> *"Pulling girls now that is a big problem.... I don't really have the confidence in case anything goes too far...I can talk to a girl and she's really nice and suddenly there comes a point when I think yeah she's really nice then I stop, I suddenly become like a little tiny, like a really scared person, and she'll say something to me and I'm like ah she's spoken to me, then I walk away, and I'm like yeah she had a chat with me that was good. And then I'm like really confident as soon as I'm like six feet away from her." (P7)*

> *" There has been people that I've liked but I've never had the courage to go up to them because of the sexual side of things again. If I didn't have this, then I'd have the courage to go in. (P 5)*

This appeared to relate most to fears of rejection if they knew about the bladder exstrophy and its implications and the sexual side of relationships.

> *" [I lack] Confidence when talking to females and that. I mean I've got a lot of girl mates but I don't have many relationships cos that's always an issue. I think like should I tell them or should I leave it...I'm always thinking oh, the worst, basically...'Oh, you're a freak get out'...." (P8)*

> *But it does worry me that um, some very shallow guy is going to come along and say, 'no I cant do this because your stomach is so twisted and mutilated and disgusting'.." (P2)*

Other participants reflected that having bladder exstrophy and worrying about its implications for sexual relationships had made them "*more cautious*" about entering relationships.

> *"I need to find someone I want to stay with, I want to take it slower then I can break it to them in my own time" (P7)*

Several participants felt that it had made them more "*fussy*" about potential partners and several said they made choices of people who they thought would be more likely to understand. In several cases the partners of choice were connected to the medical profession like nurses or children of nurses or doctors.

> *"I felt more comfortable cos she was a nurse. I thought excellent she's not going to go urgh. And she never asked anything, and I thought ah good, no explaining to do here" (P9)*

> *"My current boyfriend, his mums a nurse so he's used to all things like that, he's like 'oh its not a problem, doesn't bother me at all'..." (P11)*

Trusting and Insecurity

The key issue overarching these concerns appeared to be in difficulties trusting potential intimate partners. For young people growing up with bladder exstrophy, this appeared to go beyond the usual insecurities evoked when entering intimate relationships. It seemed also to include elevated concerns of rejection because of physical, specifically genital appearance and trusting them to not "*run a mile*" when the difficulties were exposed.

> *"I've always been really conscious about girlfriends and things like that...I suppose it was when I, when you start getting into a sexual manner and all my scars on my stomach and I still had a catheter up to two years ago" (P5)*

> *"I thought 'oh no she wants someone who's normal down there, she wants a normal boy' and that's always been a big worry for me is like they want a boy who's straightforward not someone who's got to explain some thing and lots of stuff like that. I don't know I was frightened that, yeah, that I wasn't quite your normal boy. Not quite. You know I say I am but its black and white that I'm not really that normal, ish. Um and that's always a biggest concern for me, is what they really were thinking or were they putting on a front or did they really think 'oh why have I got myself involved in someone like this' but I dunno." (P1)*

Most of the participants spoke openly of their insecurity related to their sexual prowess and their inexperience because of their difficulties in starting relationships and their fears about the possible reactions of other people.

> *"Everyone else is going to be experienced and there's going to be me, never have done this before, never have done that before, its going to be, quite scary…all the girls are going to go back to their friends and go oh my God he was disgraceful." (P7)*

Many described their difficulties in "*going beyond a certain point*" in terms of their physical intimacy with other people and the sense that they were concerned about "*going too far*".

> *"All I've done is really kissed someone, before I get scared…. I just get kind of nervous…. I don't want to go any further, that just makes me feel good for a day or something and that's enough, I don't want to go any further cos I get kind of scared. " (P7)*
>
> *"It was really difficult for me because I did pull a lot of men, but I tended to back away from them whenever they wanted to get intimate, cos I thought I'm going to blow this I'm totally going to blow this" (P 11)*

These fears prevented some participants engaging in casual relationships, which they felt was different from their friends.

> *"You know a lot of your friends go out on a Saturday night and meet a girl you go home and… I can't do that" (P5)*
>
> *"If you get a bit tipsy and you meet someone, and you think like what the hell and so I've never actually done a one night stand, the full hog, never. It, you have a bit of a fumble maybe but you never.." (P4)*

Participants made a clear distinction between their friendships and sexual relationships, most felt comfortable with friends but considerably more insecure with intimate partners. This was mostly attributed to their difficulties with trust and their insecurities.

> *"It's the trust thing…. Just trusting, somebody, I mean my best friends, I mean I knew that I could trust them cos we've grown up for years and years and years and that's different, that doesn't tend to happen with a girlfriend, you go out and you meet on, you know its different." (P5)*

The other area of trusting others that raised considerable insecurity for all participants was related to telling boy/girlfriends about the bladder exstrophy. This was also connected with issues related to telling, as discussed above but seemed to raise even more anxiety and fears of rejection particularly because bladder exstrophy can cause deformity of genitals and have an impact on some areas of sexual performance.

> *"Its tentative, I sort of am a bit cautious with it, the problem is the thing is with friends is friends are there forever as far as I'm concerned so I feel I can tell them and that's fine. The girlfriend thing I often think well, OK, chances are we're going to break up at some point so hopefully it will be an OK break-up, if it isn't I've got to be thinking how much do I trust them with what I want them to know and you know, you hear stories about how girlfriends go and rip up someone's shirts and tell them all these bad things about them. And I'm thinking of what can I risk this person telling all of her friends about me. So that's always put me off that sort of thing." (P3)*

Many participants described their feelings of concern at the possible reactions of potential partners and worries about what they might think as well as what might happen at the end of a relationship.

> *"Its more their reaction what's their reaction going to be rather than....It's like, you know, 'frankendick' or something like that." (P4)*

> *"how they'll think of me afterwards, yes I suppose if they'll reject me." (P1)*

Many participants described a strong sense that they should tell sexual partners, even more so than other people. This presumably related most to the sexual nature of these relationships and the impact of bladder exstrophy on the genitals and sexual organs. One person described herself as *"damaged goods"* and as such those who were going to be with her might have a *"right to know"*. This articulated the feelings expressed or implied by several participants.

> *"I used to think if you don't tell him at the start then he'll just hate me forever" (P14)*

As a result of the fears of rejection and difficulties in trusting others, many described the process of telling as "*traumatic* " and a *"horrible horrible thing to do"*.

Other participants described how they would avoid telling people about the bladder exstrophy, sometimes by finishing the relationship before they got to the point that they would need to tell or just by not telling them anything.

> *"I never used to tell them....Um, just cos its going to frighten them off, what I'd had done. Never used to show your belly to anybody" (P9)*

> *"No a lot of them I'd just end it because I was too scared to.....I always used to back off or end it, cops as soon as they wanted to go that last step it was just like " no I don't want to" (P11)*

Sex and Fertility

In addition to the general issues related to physical appearance discussed above, this issue also held particular salience to participants' fears about sexual relationships. For the men in the study, the appearance of their penis was a regularly cited source of distress.

> *"Because it's got scars all over it, its horrible looking, its short it looks angry.... Well its red, urgh, you know what I mean, that's why really. That and the numerous transport network of scars around it."(P4)*

In addition to the general appearance, penis size was an area of considerable concern, particularly the fear of ridicule or rejection as a result of this.

> *"What the doctors are happy with I'm not" (P13)*

> *"You hear about, you get those jokes. Mmm I don't know you get all these size jokes...And you are sitting there and you are just talking and blatantly you've got a small dick. Its like you're sitting there and you're like ah, are they joking or do they know? Its like shit." (P7)*

> *"You always think that because you're not as well endowed as other people obviously you don't go the distance and you think will they find someone else who is like Mr Stud." (P4)*

All participants expressed concern that the unattractive appearance of their scars would also lead to rejection sexually.

> *"I'd be really nervous that if she saw my scars she'd freak out." (P7)*

Several of the participants described themselves as not being "*comfortable*" with sex whilst others said that when they were comfortable with the partner, mostly through being with them for some time, then it was fine. This was often assisted by alcohol, which helped several participants to relax and enjoy their sexual relationships.

> *"It is really difficult and also because you're tensed and worried about it it makes intercourse more painful as well cos you're not sort of relaxed, its just 'oh my God oh my God'.. I was very comfortable with him and he was*

> *very understanding and wasn't interested in what I looked like and I think since then I've become more and more confident..... I still have more fun if I've had a few drinks cos I'm quite happy to get going. Whereas if I'm sober its still a little bit difficult cos I just think, he's sober so he's still going to notice I'm still a bit conscious with [boyfriend]. Its just like, if he's had a few drinks then I know there's nothing to worry about." (P11)*

Some participants described the limits placed on their sex lives by their physical condition.

> *"Physically, it's limiting in what you can do, you can't do all the positions you want to."*
> "Has it stopped you trying?
> *No way. Curiosity drives you on basically. Emotionally at first you thought what the hell's, what's the reaction going to be and that was quite a buzz"*
> "A buzz?"
> *"A buzz because you're crapping yourself at the same time as thinking wehey." (P4)*

Several of the female participants had needed a vaginoplasty to enlarge their vagina to enable them to have penetrative sex. This appeared to make telling sexual partners difficult, particularly if they had attempted to have sexual relationships prior to the operation.

> *"I was about 17 and we tried to have sex and it wouldn't go in....I had a feeling it might not but I wasn't sure and I just, I was just so humiliated" (P14)*

It also raised anxieties about painful sex but at the same time, all wanted the operation and were frustrated by being told they couldn't "*be like everybody else*".

> *"I couldn't have sex to start with because I had to have the vaginoplasty at 18 cos everything was kind of messed up down there....I did worry but not, because we never really talked about sex and things when you're younger and so I didn't really know what I could and couldn't do anyway, until I was about 17 or 18 and they said well you'd have to have that done. But I didn't really think about it... just, wanting to do it, just because I couldn't I suppose....just wanting to be normal, and I though that I'd ruin it with my boyfriend. But it didn't." (P12)*

As described above, bladder exstrophy can also have implications for later fertility in men and the monitoring of women during pregnancy. The majority of participants had some idea about the impact of bladder exstrophy for their fertility and many had thought about solutions of adopting children or using other methods of assisted fertilisation.

> *"I would be gutted if I couldn't have my own children. Um but I, I'll probably cross that bridge when I come to it, I doubt that I'd mind I doubt I'd mind, obviously I'd be gutted but I'd understand. As long as my wife would understand I think that would be fine." (P1)*

> *"Things that do work and things that don't and that sort of thing um but however it happens, even if I have to adopt if need be I'd, that's fine by me." (P3)*

Other participants shared their concerns about the possibility of passing bladder exstrophy onto their children or of the possibility of its transmission within the family

> *"I think one of the worrying things is, obviously I was unlucky with it but its whether its hereditary or, you know anything like that. And part of it is if we have kids are they going to get it? One in a 2 million chance and they got it, its like with anything, if you know it can be passed on you avoid it.... when my sister had her first one they said oh my brothers got bladder exstrophy, is there any chance this child could have it? And I thought well why? You know this is me, nothing to do with you its me, um but again because the chances of getting it are one in... very minute, its still a worry." (P10)*

In general, it appeared to be the combined effects of factors related to physical appearance, confidence and the insecurities that accompanied these which exerted the clearest effects on participants' sexual relationships. These influenced other relationships and areas of life, but exerted a more pronounced effect on these types of relationships mostly by accentuating the difficulties experienced by others when faced with sexual relationships as adolescents.

From their descriptions, it was apparent that most participants had been sexually active at some time in the past. They thought that they had started to explore their sexuality with other people at the same time or only a little it later than their peers. The few who had not begun to have sexual relationships were the younger participants all of whom had experimented with dating and anticipated a progression of these activities. It was striking that all participants were extremely positive in their expectations for future relationships. They expected that they would get married and have children at some point, when it was the "right time".

Family Relationships

The majority of participants still lived in the parental home or were at university and lived there, returning home to their parents during college vacations. Unless asked directly, few participants spoke at length about their relationships with their parents or about how their parents had dealt with the bladder exstrophy throughout their childhood. Some mentioned them in passing as important in supporting them in the early years and helping them to learn how to look after themselves or learn to catheterise. At times, participants described their parents support for some of the more distressing aspects of bladder exstrophy, such as being there whilst in hospital, attending appointments with them or helping them to follow the advice of the doctors. It was, perhaps, surprising that little mention was made of emotional support gained from parents. The main issue where parental support was seen as vital was in dealing with the more protracted bullying and assisting in contact with school to gain their support in making it stop. It became apparent that many families did not discuss bladder exstrophy much at all, and that participant's often did not really know much about what it had been like for their parents to have a child with bladder exstrophy. Some reported that they had got the impression that *"it was harder for them than me"* and others had vague memories of how difficult it was for their parents in the early years of hospitals and operations.

> *"I remember actually seeing her having a mental breakdown about twice in hospital.... Obviously she was at her wits end ....she just snapped and that, snapped, cried, proper sat on the floor and just sobbed. Right in the middle of a hospital corridor." (P4)*

> *"It was the world's end when I was born ...It was a scary moment where there's a silence, because they didn't know if I was a boy or a girl when I was born because I was so sort of deformed, so that was, for my mum the words end that she couldn't tell parents, relatives and friends that she had a boy or a girl, so she had a rough time of it as well. I grew up with bladder exstrophy so I know no different, whereas mum knew life before bladder exstrophy." (P2)*

Some participants spoke of their own feelings about the impact their condition had on their parents, both currently and in the past.

> *"The other thing I worry about is my mum and dad have to take time off work and its horrible cos obviously they've got their own lives to lead and I feel like I'm, can you take a day off to come up to London for sort of moral support." (P10)*

Others noted the impact of the bladder exstrophy on their siblings:

> *"To my sister it [bladder exstrophy] means I'm getting special treatment ... because she's the younger sister she's never known any different, and obviously when I was in hospital Mum stayed with me, so she was cast off to relatives and things so to her, it's a very negative thing... it has a detrimental effect on her" (P2)*

The main area of comment in relation to family relationships was in relation to participant's feelings of missing out and their perception that their parents were sometimes rather overprotective, thus making it difficult to engage in some activities that they would have liked to.

> *"Because of what's wrong with me my mum worries too much and she's well you can't go there, how many of you're going? No that's not enough of you" (P13)*

> *"Mam and Dad wouldn't let me play for a side [rugby], they wouldn't let me. As much as they knew I would have loved to and that everything probably would be fine, but they just didn't want to take the gamble." (P1)*

In some cases, the receipt of the letter inviting participation in the study had prompted some discussion and for many this was one of the first times they could remember talking about what had happened. Many of the participants' medical status was stable and had been for several years, so they didn't think that it needed to be talked about. In addition, as adolescents, most were independent in their own care and had taken over responsibility for looking after themselves some years prior to the interview. On some occasions, as part of arranging suitable interview times, the interviewer had conversations with some participant's mothers, all of whom were extremely enthusiastic about the research. Many of these parents asked to be interviewed themselves so they could have some time to talk over their own issues related to bladder exstrophy.

Overall, this lack of comment was not really as expected, but it is possible that it is at least partially as a result of the life-stage of the participant's as adolescents, beginning to separate as individuals from their parents.

Summary

Overall, the participants described their wide ranging of experiences of the impact of bladder exstrophy on their lives. They also described their resourceful coping with these situations. The researcher was left with the impression that the majority of the participants had used their determination to be normal to minimise the impact of the difficulties they had experienced. One of the young men interviewed, commented on the nature of bladder exstrophy and its impact:

> *"That's the thing with bladder exstrophy, its not necessarily one big thing, its made up of little tiny bits"* (P10)

This was certainly the impression of the overall impact of bladder exstrophy which was given by many of the participants.

Chapter 4: Discussion

This study has investigated in detail the psychological impact of bladder exstrophy as described by a group of 16 young people. The small existing literature on the long-term outcome in people born with bladder exstrophy describes adults as generally well-adjusted and integrated into society. In contrast, children and adolescents are portrayed as being vulnerable to a number of difficulties including internalising and externalising psychological problems, poor self-esteem and body-image and sexual difficulties. Given the nature and medical consequences of bladder exstrophy, it is probable that this may be a group of people at greater risk of psychosocial difficulties than their peers.

The current study aimed to investigate these issues further and in greater depth with a focus on the reported experiences of young people with bladder exstrophy viewed within a normative developmental perspective. Participants took part in a semi-structured interview designed to give them an opportunity to talk openly about their experiences. Qualitative data from these interviews were analysed using a systematic procedure (Interpretive Phenomenological Analysis; IPA). This yielded a set of themes and sub-themes, which described the content of the interviews. The analysis indicated that the key concerns of this group of adolescents with bladder exstrophy fell into three organisational domains, relating to: personal impact, coping with bladder exstrophy and interpersonal relationships. The themes and sub-themes clustered within these categories.

The findings of this study describe in depth the nature of some of the difficulties described in previous studies, in addition to providing evidence for the way the particular concerns of this group of adolescents might be understood within a psychological perspective. In this way, the findings provide support for the conclusions from some studies as well as an additional perspective on their conclusions.

This chapter will discuss the results of the study in terms of the psychosocial experiences of the young people with bladder exstrophy who were interviewed and how they relate to those described in the literature. It will explore the impact of these on their daily lives and the strategies they have devised to cope with them. Firstly, the psychological issues will be discussed and related to issues of physical appearance, sexuality, disclosure, bullying and "normality" as described by the participants. Following from this, their coping strategies and resilience are explored and the results considered within a developmental framework. Issues related to the methodology used in the study are discussed with reference to the literature on the use of qualitative methodology. Finally, suggestions for future research to follow this study and its clinical implications are considered.

Psychological Difficulties

The results of this study give some indications that the young people who were interviewed did experience periods of psychological distress. These were mostly described as discrete periods of what sounded like anxiety and depression, mostly in response to specific circumstances.

Previous studies have reported a high prevalence of depressive disorders in adolescents with bladder exstrophy (Diseth *et al,* 1998, Reiner *et a,l* 1999). Whilst this study lends some support to this conclusion, the descriptions of the participants were of times when they felt very low and upset about what was happening to them; they attributed these times to their bladder exstrophy. They thought that they recovered from these incidents within a few days and did not describe protracted periods of depression.

The results therefore suggest sub-clinical or periodic episodes of depression as opposed to a depressive syndrome. It is possible that the discrepancies between the current and past studies could be attributable to the differences in measurement used; with diagnostic interviews and questionnaires being used in the past (Vandvik and Storhaug, 1985 and Diseth *et al,* 1998) as opposed to the qualitative analysis used in the current study. These differences aside, the majority of studies indicate some psychological distress, which is supported by the current study.

Other general difficulties reported in young people with bladder exstrophy such as anxiety, low self-esteem and poor body-image (e.g. Diesth *et al*, 1998) were also described by participants in the current study. It is difficult to comment on the intensity of these but they were not detected by the measures of psychological symptomatology (the BSI) and self-esteem (the CFESEI) used in this study. This does not imply, however, that they do not cause significant distress. The comments made by participants in this study indicate significant distress in several of these areas at different times.

Physical Appearance

The majority of participants described feeling dissatisfied about their "physical appearance", mostly relating to their embarrassment about scars, other physical features of bladder exstrophy and their resulting self-consciousness. In accordance with other studies, (e.g. Mureau *et al* 1995), this was seen extensively in both the young men and women in the current sample. All participants described considerable anxiety over the reactions they might get from others as a result of their appearance. This theme and the comments made by participants relating to their concerns about their physical appearance seemed to relate to the psychological construct of "body-image" which is discussed in other studies.

The majority of previous studies have identified difficulties with body-image in groups of patients with bladder exstrophy, but these have focused mainly on boys and reported primarily dissatisfaction with genital appearance and functionality. The current study indicates that for this mixed group of young people, their unhappiness with their bodies was not limited to their genitals, but included concern about the scars on their abdomens. They described the ways in which these concerns limited their activities, for example: swimming, feeling uncomfortable in communal changing rooms, being unable to go on holidays with friends and to some extent limiting the way they dressed. In accordance with other studies, the participants also felt that these issues with their physical appearance impacted on their sexuality.

Sexuality

Sexuality has been a major focus of previous investigations into the psychosocial outcome for patients with bladder exstrophy. One of the primary concerns reported by many researchers (Fietz *et al,* 1997, Diseth *et al,* 1998 and Mureau *et al,* 1995) relates to the association between dissatisfaction with genital appearance and functionality, and anxiety over sexual relationships. The participants in this study shared these concerns. All spoke at length about their anxieties related to even initiating social contact with members of the opposite sex (all participants in this study said that they were heterosexual) with a view to flirting and possibly entering into an intimate relationship. Most located the origin of their concern in the reaction that they anticipated when their partner discovered their difficulties. They expected revulsion and rejection, at least at some level, and most described times when they had avoided any potential liaison for fear of these results. In addition to this, most participants experienced difficulties disclosing their condition to potentially intimate partners due to similar fears of ridicule or rejection. These concerns appeared to show themselves most in the participants' lack of confidence in moving a relationship towards greater sexual intimacy, but at the same time they had experiences of romantic relationships and sexual experimentation. In many ways it was impressive that such normal sexuality was possible, given the depth of the participants' concerns about it. Participants felt that this had been possible because of the amount of support they got from friends and partners and possibly by their determination to be "normal".

In spite of these issues, the majority of participants were sexually active and felt that they had progressed into these relationships at the same time as their peers. This is in direct contrast to the reports from Reiner *et al* (1999) of severely retarded sexual development in boys with bladder exstrophy, but supports the conclusions drawn by Reily and Woodhouse (1989) of the normal sexual development of boys with bladder exstrophy. It also provides some evidence for the impact of bladder exstrophy on female sexuality.

Unfortunately, due to the size of the sample and method of analysis, it was not possible to explore in depth the gender differences in sexuality or to compare and contrast the attitudes of the young men and women in this study. Although not evident in the current analysis, it is possible that themes relating to gender identity might be important, given the abnormality of the sexual organs, arguably at the core of gender identity.

Telling

Previous studies have given vague indications of issues of disclosure that are relevant to groups of children with bladder exstrophy. Participants in the Feitz *et al* (1994) study retrospectively related their loneliness in adolescence to their inability to talk to friends about their condition. Feinberg *et al* (1974) and Vandvik and Storhaug (1985) reported similar findings in younger children. Results from the current study indicate that this remains an important concern for young adults. Issues related to telling to other people about bladder exstrophy were central to the stories of many of the participants. This was not expected, given the lack of indications of this in the literature. Even without prompting, all participants spoke in depth about their concerns about talking to others about the bladder exstrophy and how they had resolved them.

Underlying the worries about talking to other people, participants spoke at length about their experiences and fears of rejection because of the nature of their difficulties. These were expressed in connection with employers, friendships and romantic relationships. They also appeared to relate to episodes of bullying by other children, either in response to knowing or through ignorance of the true nature of their difficulties.

It was not clear, however, if these anxieties were purely a result of the bladder exstrophy or elevations of the insecurities and fears normally seen in adolescents. Harter's (1990) hypotheses that during adolescence, children begin to be able to envisage how others might see them, could go some way to clarifying this issue. In the case of a child with bladder exstrophy this could have two functions. In earlier adolescence they may experience fears of rejection due to their peers reactions to them; that is, they can envisage bad reactions. Later in adolescence they may believe in the maturity of their peers and their ability to view them as an individual.

This brings discussion of normative development into the exploration of the impact of bladder exstrophy, for in many aspects, these are essentially "normal" young people with a very specific difficulty. In terms of development and progress over time, many participants spoke about changes over time especially related to their confidence in telling people about their condition and in the reactions they received. It is possible that this corresponds with the point at which peer pressure and the difficulties with being different recede, as each individual becomes more comfortable with their own identity.

Bullying

Teasing and bullying of children with bladder exstrophy has been mentioned briefly in one paper (Vandvik and Storhaug, 1985), but nowhere near the level of bullying described by some participants in the current study. Although it does depend to some extent on how "bullying" and "teasing" are defined, there were several worrying accounts given by participants of the bullying they were subjected to because of their bladder exstrophy. This is a clinically important finding as professionals working to support these children have a responsibility to be aware of the sorts of bullying that occur, in order for them to ask about it effectively and take steps to deal with it. Some of the bullying seemed to be based on the ignorance of the bully and a lack of coping strategies (apart from violence) available to the victim.

On a more positive note, most participants had eventually been successful in dealing with the bullies, through reliance on support from friends and teachers or physical intervention themselves. This was another area where the resilience and resourcefulness of the participants in the study were apparent, and their mobilisation of these to deal with challenging situations.

Being Normal But Missing Out

Differences in physical appearance and worries about possible complications were associated by many of the participants in this study with the sadness and frustration expressed about the things they felt that they had missed out on as a result of the impact of bladder exstrophy. Similar feelings of shame and regrets at a "loss of normality" were reported by Stjernvist and Kockum (1999), but not by any other studies. This is interesting, as it was one of the strongest themes, in conjunction with the related themes of feeling "normal but not normal" to emerge from all interviews. Participants spoke at length about the ways in which they felt that they were the same as their peers, whilst at the same time feeling limited and different because of their difficulties. This almost appears to be an analogy of the physical presentation of bladder exstrophy: in most respects, the child is normal, with one, primarily hidden flaw. This is similar to the way these young people present: "normal" but with difficulties that they work hard to keep hidden.

However, the level of concern and the way in which these participants managed these difficulties raises the question of whether these are signs of psychological problems or part of a normal reaction to difficult circumstances. It is possible that these difficulties might form part of a process necessary to facilitate the development of effective coping strategies. This was certainly the impression given by several of the participants, who spoke of these issues as being part of normal life when you live with a health condition.

Many of the researchers exploring the impact of bladder exstrophy have commented on the apparent "normality" (Reily and Woodhouse, 1983 and Feitz *et al, 1994*) of children and adults who have grown up with the condition. However, there does appear to be a discrepancy in the literature between the appearance of normality as an adult and findings of psychological distress in children, reported in some studies (e.g. Diseth *et al*, 1998, Montaginino *et al,* 1998, Reiner *et al,* 1999). In the current study, participants communicated a sense that they felt that they were both "normal" and "not normal"; that they were in some ways different to other people and that this was not a good difference. They appeared to spend considerable time and energy covering these differences up. Many of the comments related to this also appeared to overlap with constructs important in self-esteem, like body image and acceptability to others, but quantitative measures did not detect any difficulties in self-esteem, in spite of these difficulties.

In reference to the past literature, it could be suggested that while children and adolescents with bladder exstrophy experience some difficulties, they develop into well functioning adjusted adults. If this were so, it would be appropriate to propose that a developmental process might be at work in the resolution of earlier difficulties. It is also possible that they have struggled towards and achieve this normality. This study possibly illustrates some parts of this struggle. For example, a substantial proportion of the participants in this study were involved with performing arts, when asked about this, some made a connection between their acting abilities and their need to cover up their difficulties in order to appear to be normal. Others thought this was a result of subject choices in school (for many there was a choice between Drama and P.E) when anything related to sport and the use of changing rooms was avoided where possible, again as a strategy to avoid the discovery of their differences.

Resilience and Coping

Given the evidence presented from this and earlier studies, it would appear that the adolescents interviewed had become very skilled at covering up their difficulties in order for them to lead a "normal" life, and had developed effective coping strategies for managing these difficulties. What has helped them to do this? They seem to have had some clear resilience factors such as intact intellectual functioning, good peer relationships and minimal impact on their immediately obvious physical appearance or physical functioning. These aspects, and the positive outcome for children with bladder exstrophy have not been considered in depth to date.

Varni *et al* (1994) cite good peer relationships as an important protective factor against the development of adjustment difficulties. The vast majority of the participants in the current study spoke about their peer relationships with satisfaction, and connected their successful management of many difficulties, especially relating to bullying, with the support they had gained from their friends. A few had felt isolated at school, but nurtured outside interests which provided them with an alternative social network and social support. This is likely to have fostered their resilience and developmental progress. However, some did describe isolation at school, due to their withdrawal for fear of bullying; it was not possible to test the hypothesis that these were the ones who were more disturbed but it would be an interesting topic of investigation.

Other resilience factors noted in Chapter 1, which have been illustrated by the participants in this study, relate to their level of intellectual functioning (at least generally at an average level). Although not measured, the level of educational attainment in this and previous studies indicates that the presence of bladder exstrophy does not compromise cognitive functioning, therefore offering resilience to the development of adjustment difficulties. This could be another factor assisting this group to maintain the normality of their lives.

It is therefore clear, that although participants did experience difficulties, they managed to cope with them to some degree and seemed to attain satisfying lives. It is perhaps concerning how much psychological energy might be necessary to achieve this and how helpful it is in the long term to hide such difficulties. It was also not clear how much this concealment might interfere with social activities and relationships.

One further question presents itself in considering participants' desire to be seen as "normal". To what extent does this desire overlap with the desire to be the same as everyone else, typically seen in adolescence? An answer to this is not clear, but is an issue worthy of note when considering the results of this study and is discussed in more depth below.

In terms of the strategies employed to maintain at least the appearance of normality, the ease or difficulty in devising and employing these strategies was not discussed in the interviews, but would be an interesting focus of further investigation. It is possible that one of the factors driving the development and maintenance of coping is the self-perpetuating cycle of success and confidence; experiences of successful coping may build confidence in coping abilities and thus set up a positive cycle of coping, in turn boosting resilience. This seems to be what participants were referring to in their accounts of how positive bladder exstrophy had been for them as people and how they had developed coping strategies over time. The sense of things getting better pervaded many of the participants' accounts; it is possible that this occurs in conjunction with a process of adjustment between childhood and adulthood.

Developmental Issues

These results can also be understood within a developmental context. Chapter 1 of this thesis described in some detail the developmental tasks of adolescence (Chassin *et al* 1995): physical change, the definition of a sense of identity, the establishment of positive peer relationships and establishing independence and autonomy.

In terms of physical change, many of the young people who participated in the study made little comment on their progress through puberty, except in their comments related to their dissatisfaction with the size of their penises. In addition, although not referred to directly, the distribution of pubic hair in adults with bladder exstrophy is unusual; it is likely that this contributed to their general difficulties with their physical appearance and insecurity in establishing sexual relationships.

The themes of feeling "normal but not normal", "its made me who I am" and to a lesser extent other themes in the "personal impact" domain can be understood in the context of the process of identity formation. These themes relate to the way in which these young people understood themselves in relation to other people, and how having bladder exstrophy fitted within themselves and in the beliefs of others. Their descriptions alluded to their beliefs that there was something different about them, not normal, by which they implied that "normality" existed. However, they also appeared to have a clear sense that in many ways they were normal too, implying that they had also negotiated a fit between themselves and their expectations of normality. Several finally reached the conclusion that bladder exstrophy was normal for them and this was good enough. Through their descriptions of their academic and social achievements it became apparent that these young people held a strong sense of themselves as individuals and had incorporated the impact of bladder exstrophy into that.

Of relevance to this were the scores of participants on the Self-Esteem Inventory, which were in the normal range. This suggested that, despite their difficulties, their global self-esteem was intact. This is perhaps surprising given the difficulties spoken about relating to physical appearance and the link between this and self esteem in adolescence. What is not clear, however, is whether the distress caused by dissatisfaction with physical appearance in this group of young people differs from that commonly seen in adolescents. Whilst it is clear that this particular group are likely to have a more tangible reason for feeling dissatisfied, the level of distress and functional difficulties caused by it may be more significant than for other adolescents. It was clear that the young people with bladder exstrophy worked hard to limit the impact of these difficulties through their determination to be normal. Of particular note was their ability to embark on sexual relationships despite these difficulties and at a time, which, they felt, was in line with their friends' sexual debut.

All of the participants described positive peer relationships, and the importance of these in coping with any difficulties. This appeared to come to the fore whilst at school and dealing with bullies. However, one interpersonal difficulty described by most was in their struggles with telling others about their difficulties. Despite their problems with this, most had progressed to a stage where they felt able to share their difficulties with their friends and elicit their support. In addition, they were also able to form intimate relationships and allow these to progress into sexually satisfying relationships too. Their anxieties appeared to be elevations of those described in the literature on adolescent sexuality (Coleman and Hendry 1999) and seemed to relate most, understandably, to their physical abnormalities. The ability of this group to form positive relationships is likely to have operated as a buffer against several difficulties, in particular isolation and depression (Parker and Asher 1987).

In the descriptions of their activities, the young people in the study implied their transition between dependence and independence in several ways. They appeared to have taken on the task of their own self-care relatively young, in terms of managing their own catheterisation from around the age of nine years. Of particular note was their movement form home to university, mostly away from home, and several of the participants lived with their partners. These all provide clear evidence of the ability of these young people to take on independence, in what appears to be an appropriate way, in spite of all their difficulties. This is likely to have been facilitated by their successful negotiation of other developmental phases and resilience and coping factors described above.

Overall, it was striking how these young people had apparently successfully negotiated the tasks of adolescence. Their key difficulties, in the main, appeared to be elevations of what can be considered to be normal issues of adolescence, the majority of which seemed to be extremely successfully resolved. It is likely that their success in negotiating these transitions will act as a resilience factor in their continued development through adulthood.

Methodological Issues

Whilst several studies in the literature on the psychological impact of bladder exstrophy make use of qualitative data (e.g. Vandvik and Storhaug, 1985), none, to the author's knowledge has used a systematic mode of analysis of this data. The current study used a recognised method of data analysis in order to provide a systematic and detailed account of the difficulties of a group of young people. In contrast with most previous studies, the findings were considered within a normal developmental context. Whilst the study makes some contribution to the literature, the findings must be considered in light of several methodological issues.

Analysis and interpretation of the data.

There has been considerable discussion in the literature regarding the evaluation of qualitative research (e.g. Stiles, 1993, Smith, 1996, Elliott *et al,* 1999 and Yardley, 2000.). To this end, these authors present sets of guidelines for quality control, to ensure that qualitative research is carried out and evaluated systematically and that conclusions drawn can be considered representative of the data. Throughout the current study, from planning to writing up, these guidelines have been adhered to where relevant.

Elliott *et al* (1999) suggest that researchers engaged in qualitative research make their personal context and biases clear in order to orient the reader to their position. In accordance with this, the researcher's context was stated in Chapter 2. The guidelines also recommend that samples be clearly defined, as in Chapters 2 and 3.

Several authors (e.g. Smith 1996), along with Elliott *et al* (1999) discuss the importance of grounding the analytic procedures and the understanding and explanation of data in examples taken directly from the data. This allows appraisal by the reader of the fit between the raw data and the researchers' interpretations. To this end, all interpretations and comments made in the analysis and the emerging themes were grounded in quotations from participants' accounts of their experiences. Attempts were made to illustrate how each theme and category was derived, with several quotes presented for each to allow the reader to appraise the interpretations of the researcher. Following from this, the issue of the coherence of the organisation of the outcomes of analysis has also been addressed in this study in the organisation of themes and sub-themes into domains, higher organisational categories which assisted in the integration of the data and its analysis into a clear narrative account.

Finally, in accordance with the guidelines suggested by Elliott *et al (*1999), credibility checks were implemented at two stages of the analysis. This involved another experienced researcher checking that a coherent chain was apparent from the initial raw data to the final narrative account of findings. This process was repeated with another group of two peer researchers attempting to follow the "paper trail" (Smith 1996) from annotated transcripts to final write-up. Precise details of these procedures are given in Chapter 2. However, whilst these procedures do provide a check on the reliability of the interpretations, they do not address the validity of these interpretations as, despite attempts to place biases aside, all members of the group of researchers may have held similar biases and preconceptions. The reader should hold these in mind when considering the extent to which these may have influenced the interpretations.

Triangulation (Stiles 1993) refers to the process of gathering information from a variety of sources in order to gain multiple perspectives and increase the validity of conclusions. In this study, participants completed two widely used questionnaires to provide overall assessment of their self-esteem and psychological symptoms. These were chosen in light of findings from previous studies and provided another view of the participants' functioning. Pressures of time and resources, however, limited the scope of the current study. It would have been extremely helpful to have gained more information from the perspectives of others important in the care of this group of patients, for example, the clinical nurse specialist who provides considerable support to the young people and the doctors in charge of the medical side of care. In addition, it would have been valuable to gain some insight into the views of the parents of the adolescent participants in this study. Indeed, many parents asked the researcher for the opportunity to participate in any further studies on the impact of bladder exstrophy on families.

Stiles (1993) gives accounts of two further types of validity checks that can be used to evaluate qualitative research; testimonial and catalytic validity. Testimonial validity refers to the further checks on interpretations achieved by asking participants whether the analysis provides an accurate account of their experience. Unfortunately, time constraints did not allow for this in the present study. Also, due to the wide geographical dispersal of the participants, it would have been difficult to arrange further meetings or risk a poor response rate by trying to get a postal response. However, all participants will receive a summary of the findings of the research and be invited to comment on them.

Catalytic validity refers to the extent to which "the research process reorients, focuses and energises participants" (Stiles 1993, p 611). In the current study, all participants expressed enthusiasm during the interviews. Several commented that they had not had opportunities in the past to discuss their experiences or their feelings about the impact of bladder exstrophy and that they had found it helpful to have the opportunity to do so. In addition, members of the medical team and the parents of the participants showed considerable interest in the study and expressed their interest in participating in further studies.

Generalisability of the findings

As with all qualitative research, the results and conclusions of this study must be considered tentative in their wider generalisation beyond this group of patients. However, several features of the study make it possible to consider whether some of the factors discussed might be relevant to others with bladder exstrophy or related urological conditions.

Firstly, whilst the sample size is relatively small, it does represent a significant portion (46%) of the population for whom addresses were available and is large in comparison to those used in other studies. There were a number of people contacted who declined to take part in the study, either through not opting in or by their non-attendance at appointments. For those who would have needed to make a special trip to London, the inconvenience would probably explain their unwillingness to take part in the study. There was no indication given by the others who were unable to participate. It is possible that they did not feel able to talk about any difficulties they might have, or did not see the point in this type of research.

In comparison to other studies, this one has a considerably smaller age range, and as such might represent a more accurate picture of issues relevant to the particular developmental stage of late adolescence. Even with a tighter age range, there is however, a possibility of differences in relative importance of specific issues for participants at different stages of adolescence, i.e. between the older and younger participants. Because of the relatively small sample size it was not possible to investigate these differences as part of the analysis.

As discussed above, it is difficult to interpret the results of the quantitative data used in this study, particularly as the small sample size would not be large enough to detect small effect sizes. It is possible that general measures are not sensitive to some of the specific difficulties experienced by young people with bladder exstrophy; genital appearance, for example. However, this data is helpful in providing evidence that young people with bladder exstrophy present themselves, in terms of self-esteem and psychological symptoms, in ways that are consistent with what would be expected for their chronological age.

In spite of all of these reservations, it is likely that the broad conclusions which can be drawn from this study might apply to other groups of young people with urological conditions, particularly those which share some of the features of bladder exstrophy. In Woodhouse's (1998) study, which considered the sexual functioning of boys with hypospadias and micropenis, similar concerns emerged to those described in previous studies of bladder exstrophy and in the current investigation. It is also likely that, as these and other urological conditions share the same location of difficulty and affect the appearance of the genital area, some of the concerns expressed by one group might be shared by the others as well as those specific to their condition. This adds to the clinical relevance of the current study, beyond the small group of children with bladder exstrophy to other areas of paediatric urology.

Further research

The results of this study suggest the need for considerable further research into the psychological outcome for young people with this type of condition. The problems with previous research continue to make it difficult to draw clear conclusions and interpret the results of different studies in relation to each other. In addition, many of the studies are now quite old, and advances in surgical technique will make it difficult to compare cohorts of patients unless matched for the type of surgical intervention they had received and the age at which they had received it.

In light of the previous findings indicating that patients experience more difficulties in childhood compared to adulthood and bearing in mind these cohort effects, it would be important to conduct a longitudinal investigation, tracking the changes within individuals over time, which would address some of the questions about the development and use of coping strategies. In addition, there has been a move in the clinical health literature towards the consideration of resilience and coping with adverse events and situations (e.g. Seligman and Csikszentmihalyi, 2000; Coyne and Racioppo, 2000), this type of approach might go further to exploring what helps these patients to manage to cope with their difficulties so effectively.

As a result of the limitations of small sample sizes, the impact of culture has not been considered at all in the literature. Most studies have been conducted in first world countries (primarily in Scandinavia, the United States and the UK.). Given the sensitive nature of many of the issues for children and adolescents with bladder exstrophy, it is likely that they will vary between cultures depending on the meaning placed on deformed genitals. Further investigation might also allow consideration of the influence of these difficulties on identity formation, for example during adolescence.

Finally, in response to the reaction of many of the parents I spoke to in the process of completing this study, it would be extremely valuable to conduct some investigation into the impact of bladder exstrophy on parents and families of patients. This could be done using a similar methodology to the current study in order to gain an in-depth picture of their views and experiences.

Clinical Implications

Several authors have commented on the lack of psychological support that has been available to families with a child with bladder exstrophy and a current lack of provision of psychological services to paediatric urology teams. The participants in the current study noted this, and described feeling that such services would have been appreciated both for themselves and for their parents.

Although the majority of studies into the impact of bladder exstrophy recommend the provision of some psychological service to this group of patients however, the nature or amount of this is rarely defined. It is unclear how much of this advice has been heeded or how different services treating urology patients generally are able to access psychological services. The general impression, from a study currently being conducted (Christie, D. personal communication, 2001), is that very few urology teams throughout the UK have any input from clinical psychologists. This study has provided a detailed insight into the experiences of a group of young people with bladder exstrophy, but their experiences can be used to inform clinical work by several groups of professionals to assist the progress of similar young people. Psychological intervention could take place at a number of levels: in the delivery of the service through training or networking between professionals, and in supporting groups or individual patients and their families at any stage in their treatment.

There would appear to be a case for contact with a mental health professional to be a greater part of the annual review process to introduce discussions of emotional issues and enable the early identification and treatment of any concerns. The issues raised by participants in this study could provide areas for assessment, specifically in the formal investigation of levels of depression and anxiety and enhancing coping mechanisms used by the young people already. The results provide indication of significant concerns over physical appearance, which could be investigated and discussed, with the potential for interventions following a cognitive-behavioural framework, for example. This might allow the detailed analysis of thought and behaviour patterns in relation to these and other issues and the further extrapolation of helpful coping strategies, such as the "rationalising" described by several participants.

Mental health professionals could also serve a networking function to enable the development of programmes to facilitate communication and change as described by Christie and Fredman (2001). This might assist with smoothing transitions between service providers, such as between paediatric and adult/adolescent services. In addition, the difficulties associated with the understanding of peers and school could be addressed by direct contact between the school or parents and the medical team, which could be seen as part of the role of the paediatric/ adolescent liaison clinical psychologist or similar clinical specialist. This model is followed in other medical specialisms, and is commonplace, for example in endocrinology teams dealing with children with diabetes (Court and Lamb, 1997).

The difficulties described by some participants in understanding and thinking about advice from medics could be assisted by some kind of group or family intervention similar to that described by Vandvik and Storhaug (1985). However, a programme such as theirs is extremely intensive in terms of resources and time for both families and professionals. A less intensive and more accessible type of support is available in the UK through the voluntary sector in the form of the Bladder Exstrophy and Epispadias Support Group (BEES). Professional psychological support could complement this by providing an ongoing service for all patients (and their families) attending clinics and assist with the consideration of psychological matters as they arise.

There is also an indication for the training of urologists and other urology team staff in the recognition of psychological difficulties and the possible presentation of these in a clinic situation. It is possible that if professionals had more idea of appropriate questions to ask, this could empower patients and families to come and ask for help as necessary, as opposed to carrying on in isolation.

Group or individual support for families, children and young people with bladder exstrophy could take several forms, and would need to be responsive to individual needs. It could include group discussion of issues related to talking to others about the bladder exstrophy, dealing with bullying, developing self-esteem and assertiveness. This could follow a cognitive-behavioural framework through structured activities or a more open discussion forum. The aim of this type of intervention would be to assist in the development and optimisation of the coping strategies described by many to be helpful in dealing with bladder exstrophy. Groups could also be useful in facilitating the sharing of such coping strategies between patients and the sharing of experiences, helping individuals to feel less isolated. These approaches could also assist the young people in the development of helpful and supportive narratives of their situation (Freeman, Epston & Lobovits 1997) relating both the their appearance to those around them and in their ability to cope with this.

Issues relating to body image have been addressed in other areas of clinical psychology, most notably within the eating disorders literature (e.g. Lask and Bryant-Waugh 2000). If, through psychological assessment, significant difficulties were described a similar treatment protocol could be amended and applied, not only with young people with bladder exstrophy, but possibly for young people growing up with other chronic illnesses which impact on their body image (e.g. cystic fibrosis, juvenile inflammatory arthritis-to name only a few).

These are general suggestions for the implementation of some of the conclusions drawn in this study. Most importantly, it seems crucial that the psychosocial difficulties that can arise in bladder exstrophy are recognised, and that psychological assistance is provided when necessary. Although it is clear that most patients manage extremely well, the process of learning to cope might be hastened by timely intervention and those patients that do develop serious psychological difficulties must gain quick access to appropriate services.

Although this study has represented the experiences of a small number of young people with a very specific condition, many of the more general themes relating to growing up with a chronic illness may be relevant to a much larger group of young people. In particular, issues relating to not feeling normal might connect with young people with physical disabilities or diabetes for example. It is likely that other young people find it difficult to talk to others about their experiences; children with cancer, for example or with conditions requiring ongoing medical support. In relation to this, it is possible that adolescent's living with a chronic health condition might be more vulnerable to isolation and bullying by other children. It is vital that this is attended to by those providing them with support.

Many of the issues and interventions suggested above may be of relevance to young people with bladder exstrophy and other groups of young people: communication and networking between hospital home and school, issues of anxiety and depression, thinking about issues of body-image might have a useful place in helping young people to adjust to their condition and continue to have as normal a life as possible.

Concluding Remarks

Overall, this study has provided a detailed account of the experiences of a group of young people with bladder exstrophy. They spent considerable time and effort in meeting with me, the researcher, and were willing to share their thoughts feelings and experiences in great detail, something that many of them had not done before with anyone. This study has been able to give these young people a way of telling those responsible for their medical care about their experiences.

The study contributes not only to the growing body of qualitative research within the health literature, but also to the development of understanding about the impact of this particular type of urological condition. It illustrates the role qualitative research can play in expanding the information available to health professionals working with these patients, with a view to informing and developing their work.

In conclusion, it has been inspiring to work with such a self-reliant group of people with admirable resilience and determination to overcome any difficulties they might face. The task for their carers now is to support the mobilisation of these resources and help those who are struggling to find them.

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Appendices

UCLH DEPARTMENT OF CHILD &
ADOLESCENT
PSYCHOLOGICAL SERVICES

North House
Middlesex Hospital
Cleveland Street
London W1N 8AA
Telephone: 020 7380 9086
Fax: 020 7380 9268

Date
Address of Participant

Dear …….,

Re: Psychological research into bladder exstrophy.

I am a Trainee Clinical Psychologist working at the Middlesex Hospital. I am completing some research into the psychological impact of bladder exstrophy on adolescents. I am working with Mr Woodhouse who has suggested I write to you to invite you to take part in the research study.

Participation in the study would involve you staying at the hospital for about an hour and a half after your next clinic visit. It would involve talking to me and filling in some questionnaires about your experiences and how you think having bladder exstrophy has affected you.

Please find enclosed a patient information form that will tell you more about this project and a consent form for you to sign and return to me in the enclosed envelope.

You do not have to take part in this research and a decision not to participate will not in any way prejudice present or future treatment you would receive. We are aware that taking part in research is time consuming but your input will be invaluable and we would gratefully appreciate your contribution.

Only the researchers will know the identity of those who take part and any responses you give will be entirely confidential and anonymous.

If you or your parents or guardians would like to talk to me about what would be involved or about the project in general please call me on 020 7380 9086 and I would be happy to talk to you.

I will contact you shortly to confirm whether you might be willing to take part in this study.

Yours Sincerely

Christine Wilson
Trainee Clinical Psychologist

UCL
HOSPITALS

The University College London Hospitals

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital.

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PATIENT INFORMATION

Exploration of the Psychological Outcome For Adolescents with Bladder Exstrophy

We would like to ask your permission to include you in this project.

1. The aim of the study
The aim of this project is to investigate the psychological impact of bladder exstrophy on adolescents. The study will look specifically at adolescent's views of their experience and the effect it has had on their lives.

2. Why is the study being done?
Bladder exstrophy can mean that children may have many experiences of being in hospital and having operations, as well as using the toilet in a different way to their peers. It is unusual for children and their families to have contact with psychologists to help them adjust to their treatment but doctors think this may be useful for some families. We want to find out how the children feel about their experiences and any difficulties they may have had to help us to target psychological input for other families.

3. How is the study to be done?
If you agree to participate in this study, you will have an interview with a trainee clinical psychologist, which will last for about an hour and a half. The interview will be tape-recorded and will be arranged to coincide with a normal visit to the urology clinic. There will be some questionnaires to fill in to look at how you feel about yourself and one about your general health. The interview will focus on what you think about the things that have happened to you and how it has affected your everyday life and relationships. We will talk about how you get on with your friends and what you would like to happen in the future.

4. What are the risks and discomfort?
No risk to you can be foreseen. Some people might find it difficult or tiring to talk about these issues. The interview timing can be flexible and follow-up after the interview is available for anyone who wants to talk further.

5. Who will have access to the case/research records?
Only the researchers and a representative of the Research Ethics Committee will have access to the data collected during this study.

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6. What are the arrangements for compensation?
This research has been approved by an independent Research Ethics Committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This will require you to prove a fault on the part of the Hospital and/or any manufacturer involved.

7. What are the potential benefits?
This study may enable you to talk confidentially about your experiences with a health professional in a way that you may not have done before. It is hoped that it will be interesting and helpful for you to think and talk about these issues in this way. It will also help us to provide a psychological service to other families with a child who has bladder exstrophy.

8. Do I have to take part in this study?
If you decide, now or at a later stage, that you do not wish to participate in this research project, that is entirely your right and will not in any way prejudice any present or future treatment.

9. Who do I speak to if problems arise?
If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via the Research and Development Office, Institute of Child Health, 30 Guilford Street, London WC1N 1EH, or if urgent, by telephone on 020 7242 9789 ext 2620 and the Committee administration will put you in contact with him.

10. Details of how to contact the Researcher:

Christine Wilson	Dr Deborah Christie
Trainee Clinical Psychologist	**Consultant Clinical Psychologist**

Department of Child and Adolescent Psychological Services
North House
Cleveland St
Middlesex Hospital
London W1N 8 AA

Tel: 020 7380 9086
Fax: 020 7380 9268

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Consent Form for Young People
CONFIDENTIAL

Study Title: Exploration of the Psychological Impact of Bladder Exstrophy

Pleas ask yourself the following questions. If you feel that you can answer yes to them all, please sign below if you wish to participate in this study. Young people over the age of 16 years can give their own consent and do not require their parents to also consent.

- Have you read the information sheet about this study?
- Have you had the opportunity to ask questions and discuss this study?
- Have you received enough information about this study?
- Do you understand that you are free to withdraw from this study......
    at any time
    without giving a reason for withdrawing
    without affecting your future medical care?
- Do you agree to take part in this study?

Please note here the researcher you spoke to about this study.

Signature of young person..Date.........................
Signature of investigator..Date.........................

Thank you

Mr C.R.J. Woodhouse, Reader in Adolescent Urology
Dr Deborah Christie, Consultant Clinical Psychologist
Christine Wilson, Trainee Clinical Psychologist

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Date
Name and address of Participant

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Re: Psychological research into bladder exstrophy.

I am a Trainee Clinical Psychologist working at the Middlesex Hospital. I am completing some research into the psychological impact of bladder exstrophy on adolescents. I am working with Mr Woodhouse who has suggested I write to you to invite you to take part in the research study.

Participation in the study would involve talking to me and filling in some questionnaires about your experiences and how you think having bladder exstrophy has affected you. I would arrange a mutually acceptable time when you could come to the hospital some time in January. I would be able to reimburse your fare, so apart from the hour and a half spent on the project; you could spend some time in central London!

Please find enclosed a patient information form that will tell you more about this project and a consent form for you to sign and return to me in the enclosed envelope.

You do not have to take part in this research and a decision not to participate will not in any way prejudice present or future treatment you would receive. We are aware that taking part in research is time consuming but your input will be invaluable and we would gratefully appreciate your contribution.

Only the researchers will know the identity of those who take part and any responses you give will be entirely confidential and anonymous.

If you or your parents or guardians would like to talk to me about what would be involved or about the project in general please call me on 020 7380 9086 and I would be happy to talk to you. I will contact you shortly to confirm whether you might be willing to take part in this study.

Yours Sincerely

Christine Wilson
Trainee Clinical Psychologist

Semi Structured Interview for Adolescents with Bladder Exstrophy.

Following the procedure suggested by Smith, Harre and Langenhove (1996)

Introduction

Introduce self and project, go through confidentiality issues and consent to take part, also ensure they know they do not have to be there or answer anything they do not want to. They can ask questions at any time and if it brings up any difficult issues for them they can call CW or DC at any time to talk about them.

Personal & Demographic Information

Age, at school, college or working? What do they do?
Do they live alone, with partner or with parents? Do they have children? Favourite leisure or relaxation activities?

Bladder Exstrophy

Could you tell me brief history of your bladder exstrophy as well as you remember it or from what other people have told you?
    Could you describe what happens to you because you have this condition?
    When these things happen, how do you feel? (physically, mentally , psychologically)
How does it make you different from other people?
    How does it affect your every-day life? (work/school? interests?)
If you had to describe what bladder exstrophy means to you what would you say?
    Words that come to mind? images?

Disclosure

Who else knows that you have this?
    What about people outside your family?
    How did they find out?
    How did you decide who you could tell?
    How did they react?
    How does it make things different now?
    Do you think people think differently about you than they do about other people?
    Who do you think it is most difficult for?
    How do they show you that it is difficult?

Body Image/ Self Concept

Do you think it makes you see yourself and your body differently compared to other people your age?
    What is your favourite part of you?
    What is your least favourite part?
    Does it stop or help you do certain things?
    Do you think this will change as you get older?

Relationships with Others

Tell me about your friendships and relationships with other people your age?
    What sorts of things do you like to do together?
    Do you think the bladder exstrophy has made a difference to how you get on with other people?
Do you currently have a girl or boyfriend?

Would you like one?
What are the things you like (would like) most about having a boy/girl friend?
Are there things that worry you about being in a relationship like that?
How do you/ might you try to deal with that?

Thoughts of the Future

How do you see yourself in the future (2 years? 5 years? 10 years? Even longer?)
What do you see yourself doing?
Do you imagine you will be in a relationship?
Do you think you might have children?
What would be the best thing?
What would be the worst thing?

If someone waved a magic wand and cured you of this so you did not have bladder exstrophy any more, how would things be different?
How would you be different?
Do you think your thoughts of the future would be different? How?
Do you think you would feel differently about yourself? How?
Would you be different with other people?

Thank participant again for taking part, reiterate availability of psychologists to see again if difficult issues were raised.

Interview Transcript (P 10)

(Key, P=participant, I= interviewer, series of ..... indicates a pause of more than 5 seconds, [ ] indicates where editing was necessary to maintain confidentiality)

I: Introduction to the interview, reiterated information on confidentiality and that the participant could leave any time if uncomfortable or did not want to answer any of the questions. Just to start off with could you say how old you are?

P: 21, coming up to 22

I: When are you 22?

P: [Date]

I: What are you doing at the moment, are you at work or.. What is it you do?

P: I work for, its local government, I work with computers basically.

I: And do you live at home with your parents?

P: Yeah. For now. They're putting up with me, just.

I: Are you thinking about moving on?

P: Yes possibly. Its just saving up and thinking about what I want to do next.

I: What I'd like you to tell me a little bit about your bladder exstrophy as you've seen it and how you've seen it over the years, maybe also a bit about when you were younger about what your parents have said...

P: Well its, a lot of the time its been sort of my mum and dad it was more when I was little, they told me er a lot of the time obviously they made the decisions when I was small. But then there came a time when hey said look you've got to decide, and obviously only then I found more about what it meant..

I: What was it you had to decide?

P: It was sort of to do with operations and how it would affect me later on in life and do we go down this route or do we go down that.

I: Do you know how old you were when you were talking about that?

P: I was about 13. Um so obviously before then I didn't really understand.

I: Do you remember having any thoughts about it?

P: Not really, not really, it was just in and out of hospital, it wasn't, you know but obviously when I was in junior school it didn't matter so much, it didn't effect me as a person. Because we were small no-one sort of really cared but obviously as you get older you become more aware of yourself and obviously relate to other people.

I: So when you were at junior school were you continent or were you still in pads?

P: I was still in a pad, yeah. I had to have an operation where I had a mitrofanoff, so I can catheterise, but before it was, there was nothing.

I: When did they do your mitofanoff?

P: Ummm it was about 8 years ago… (mumble) about 93 something like that..

I: So you were about 13?

P: Yeah

I: And what do you remember about that?

P: Well I remember before I was getting an awful lot of infections, um because I couldn't catheterise before I wasn't necessarily getting it all out when I went to the toilet, therefore..

I: Could you go to the loo?

P: Oh yeah, and it was a question of I wasn't passing all of it so I was getting infections on what was left in the bladder. Um so I had my consultant, was [name of surgeon] who said I thought it would be a good idea to have a, regular to catheterise me, so that when I go normally I can drain it all and there's none left in it.

I: So did you start catheterising once or twice a day?

P: Yeah. I was abit anti that.

I: What was that like?

P: It was, well it was a bit sort of strange putting something into your body to make yourself go rather than go naturally, it was a bit sort of strange, um but obviously it took abit of training and perseverance. I'm still not particularly OK with that. I don't like it but I just sort of get on with it er in life cos I've had injections to make the wall of my bladder tighter so the only way to go is to catheterise, but my only worry with that is, say I go out, for a drink and you know have a few pints, say I pass out, it they've tightened the muscles up too much its, there's no way for it to go out other than..

I: So have you got a hole in your belly button or?

P: Its at the side, its um, they used my appendix as the actual mitrofanoff channel.....

I: So you're still not too happy about catheterising?

P: No its not.. I'm not,,,

I: What is it about it that you don't like?

P: Well it just feels different basically....

I: You can feel it going in?

P: Yeah, and it you know normally when people go to the loo its five minutes whereas I sort of take 10 minutes sometimes.

I: So do you catheterise every time now?

P: Yeah. I tend to more at work, cos I feel its safer that way, but I can still at the moment, I can still pass normally, but it takes a bit of effort. Cos they've used the injections to make the walls of the bladder tighter it take a lot of effort, whereas before it was literally going, going normally.... Just get on with it unfortunately....

I: But it's a little bit of trouble?

P: Yeah, I kick and scream quite a bit but my mum doesn't, you know have to get on with it.

I: So how do you kick and scream?

P: Well its, a bit anti, I don't want to do it and you know its just a question of getting on with it really, its just me being awkward rather than any thing else. Um.

I: Its quite a big decision anyway..

P: Yeah.

I: So what do you remember about other operations?

P: Er, well, mmm....I can remember one when I was, I think I was about 7, I was in for about 6 weeks, the reason I remember it was because I had my birthday in the hospital and it was obviously remembering something like that it sticks in your mind a bit.. Its just some of the time because I've had the operations and that I feel, especially with like high school I missed huge chunks er so when it came to like GCSE's obviously I wasn't up with everybody else um and one of the worst things, I feel anti about explaining to people. Its like with work I haven't told anybody, its just I need to book a day off work. I don't feel the need to tell them. Er but in one way I feel like I'm lying. Cos my mum says well if you tell people, people will understand more, rather than think well taking a day off every six weeks or so to go up to London, why is he going up to London all the time? Mm...

I: So that's quite tricky?

P: Yeah
I: So you were saying that you feel quite awkward telling people, what has that been like? Are there people that you've told?

P: Yeah, there's a circle of friends that obviously I've told and when I go round its, staying round at peoples houses and stuff, I've had to say look, you know,...um I need such and or I need to catheterise and I do this and I do that and its, its not easy. Whereas most of my friends are like oh yeah I'm staying over with such and such and they just go off and do it, whereas you need to ring up and go "blah blah " and there's so much more planning involved, um, so it's a bit of a noose round you neck unfortunately, you just want to get up and do something but there's always that holding you back.

I: What holds you back? The planning?

P: Yeah, oh yeah, sure. It's the actual bladder exstrophy itself cos it...I can't, I've said to my mum before, I don't feel normal, I sort of feel different to other people. If I was taken to one side I would feel different. If I was in a group of 20 people I feel I would be able to be picked out as different. Its not that I've got antennae and all that I just feel different in myself......so that's....

I: What's that like for you?

P: Its...well its hard, um socially I'm fine you know I'm not, I get on well with people but I still sort of feel obviously with me getting older erm especially sort of between the opposite sex obviously, all my friends are like this that and the other and its like oh sort of anti this and don't come off that subject and its just, certain areas I try and avoid....

I: When talking to people?

P: Yeah, its sort of a bit of both, um you know....especially if you're out in a pub there's not the time to explain um to someone, it's the spur of the moment and um, you know, whereas I try to sort of get to know people first and then think well perhaps I think I can tell you...um...

I: How do you decide whether people are OK to tell?

P: Well...its abit hit and miss.....sometimes its like the jungle telegraph...at times, tell the one person and its oh god, (laugh).. everybody knows. Tricky enough, you have to choose the right...

I: Has that ever happened to you?

P: Yes, yes it has, someone I told I thought oh I've known her for like ages and ages and ages and I and someone in passing said oh I didn't know about... and I thought how the hell do you know...oh....

I: So what was that like for you when the jungle telegraph gets beating?

P: Well it kind of knocks you back from it cos you think well who are my allies and who are my friends..its..you know sometimes you'd rather tell them yourself but you think well its out in the open at least um....

I: So there is some way you can feel a bit glad that that happened?

P: Yeah but in other ways its something sort of personal to you its like anything, um if something like that's happened in your life its personal to you and obviously if the whole world knows its um, not quite the same...

I: Especially if you haven't chosen that.

P: No, I think that's the other thing as well, it wasn't, sometimes I feel that I didn't ask for this but it was, you know...give it to him, give it to him....Why?

um but I tend to find sometimes, cos there's the BEES group which we've been to...

I: Are you part of that?

P: Yeah and sometimes I find, especially with groups like that, because they do more stuff now when they're younger, whereas I was done over, well at 7 we'll do X operation and when he reaches 12 we'll do this.. and.. its all done when they're small whereas I've had to wait as I've gone along, so they don't have the problems....

I: So do you think that the kids that come along now with it gave it a bit easier?

P: Yeah, because there dealt with as soon as it happens, the research, obviously when I was born in [year of birth], it was, you know, unheard of um and that's how I ended up, you know, up here.

I: So were you born in [name of place]?

P: Yeah

I: And then..

P: Transferred, I think it was [Name of hospital] and then they moved me up to here and [name of hospital] so its, been all over the place...So now do they do the whole lot so they're continent from birth, I think from the last BEES meeting I went to from what [name of surgeon] and sort of stuff like that were saying, a lot of that was done when they are tiny cos obviously then they're not aware of it and just do it and when they obviously get older there sort of like this is what you're doing in your life and they don't have any way to sort of choose.

I: How do you think that would be different to what your experience has been? What things do you think would be a bit different?

P: Well I think there'd be less reluctance.......you know..

I: Like to catheterise?

P: Yeah, they'd get on with it whereas when they turned round to me and said right you're going to be catheterising, I thought oh god what's this.

I: Yeah, and when they showed you the tube what was that like?

P: Well it was awful, its all the preparation and you think I didn't need this...um...

I: So that would be different. What other things might be different do you think?

P: ...um.......

I: Do you think there'd have been stuff that different?

P: Yeah I suppose it would because I think especially for someone my age, I'm more socially aware um, cos obviously when you're young yore not so out and about, your mum drags you round wherever you're going, but obviously when you get to a certain age and you're out and about and doing various bits and pieces you're more aware um sort of how you relate to other people......but I think its just sort of the way people take it on, um obviously for me, because like I said it was done in various stages, unfortunately you have time to mull it over, um, and I'm one of these people, if I mull something over and I dot like it, I tend not to like it more, it gets worse and worse, and I just...

I: So you brood on it would you say?

P: Yeah, I tend to find oh I don't like this and it gets worse and worse and worse...which is, some of the time, which is I've had arguments with my mum and dad, because... when they've signed the papers to say oh yes he can have such and such done, sometimes I've said well why? You know and they've said that because I wasn't old enough to make the decision.. but now I am obviously, I'm in control more of what's going on, in it...

I: Is it recently you've argued with your parents about decisions they made?

P: Yeah, yeah, cos they were saying about having the bladder muscle tightened and I was saying well I like it the way it is, OK, you know, I'm wet every so often, um, but I said I can still go normally and catheterise, you know, if I can't get it all out I catheterise, whereas now I catheterise all the time which is a pain, so anywhere I go I have to take a catheter with me which is a pain, shopping anything. I mean that's another thing, its taking stuff with you all the tine. You know, if people want to go out and go shopping, they don't think well I've got to take this with me, take that with me, take that, they just go, take their money and they're off. Whereas I've got to think well is there loos, is there this is here that, where am I, if I need to go can I get there in 2½ minutes? It's a bit like carrying a stop watch round with you and saying well I did that quite well, its kind of strange, and also, I tend to find at work because I'm the youngest one..I tend to like people around my own age around me, I don't know why I tend to relate better, but because everyone's older than me, its like I wont bother about you know, wont worry them its like nothing to do with them, er, but my mum and dad were saying a couple of nights ago that one way or another they're going to find out, and she said they could turn round and say well why didn't you tell us before and we could understand why, you know, whereas you're being deceitful in a way cos they don't know and it could be that you know, I need two or three weeks off if I need the operation, whereas if they knew they can make allowances, and say right OK we know why you're off, so..

I: So at the moment are you thinking about whether or not to tell them?

P: Yes

I: Is there something that you're worried about will happen.

P: ....the worst thing I hate is that sometimes people feel sorry and I don't want people to feel sorry, you know, look I was unfortunate, don't feel sorry for me, let me get on with it and you get on with what you.. but people tend to say ohhh, poor [name of participant] and its like No! (laugh)

I: Have you had that before?

P: Yeah I have.

I: Often?

P: Quite a bit, especially with some relations that I stay with its like treating me with kid gloves and its like 'I'm not going to break, honestly' um you know 'are you sure you're OK to go out da dah da dah' and 'do you want this or that?' 'No I'm fine honestly'..

I: What is that like for you? How does that feel?

P: Its awful, cos it....I feel like I'm putting a burden on other people, um and that to me, upsets me in a way, because obviously I don't want to put that on people um, that's one of the reasons I'm possibly not going to tell them at work cos they'll just turn round and worry all the time, er they'll be another lot who are like poor such and such, and poor X he's got such and such, um whereas obviously when people knew at junior school they didn't care . Nobody was like that, who cares? Um but obviously with high school and going up um I was off, when I had my mitrofanoff done I was off for 3 or 4 weeks. The head teacher jut walked into the class and said 'oh [name of participant has got such and such and he's had more operations than hot dinners' and it was hell as soon as I got back, it was awful.

I: So she walked in and told everybody? Did she tell them exactly what happened?

P: Oh yeah, yeah, I just sat there and I thought why? And they said 'oh they won't pick on you now' I though they'll pick on me even more now, thank you, you know it was just awful when someone went in and did that and I said why? And they said well at least its out in the open but I said you didn't ask me you just went off and did it...

I: Did they ask your parents?

P: Not that I'm aware of, um but obviously medical records and all the rest of it...

I: Even so, teacher going in and all that...

P: Yeah, blown the cover..

I: So after that were you teased more?

P: Yeah, they tend to sort of. I tend to find because of that they like pick on bits of it and you know, oh you're different to the rest of them, oh and its like oh, you don't need it, I mean people can be really nasty if they want to be nasty.

I: Have you had lots of experience of people being really nasty?

P: Yeah, you know..

I: Can you tell me a bit about it?

P: Well.....it was... when I was younger I had to have part of my pelvis broken and I had to go on traction and all the rest of it, sometimes, especially when I was younger, like at high school I walked with a limp and they ...'penguin' and blooming all sorts, blooming awful, it was horrible, um and obviously people like that can take something that's unfortunate about someone and spin it round and throw it back in their faces, its not nice. A lot of the time I said to my mum and dad you know, its awful, cos eventually it grinds you down, um, when you get a passing comment, but when its actually in front of your face and I've got enough to put up with without you lot picking, you know, picking on it. Um, you know I've said to my mum, this is awful why should I put up with it, you know, they wouldn't like it if it was them, but...

I: How did you deal with it at the time?

P: We....it was a case of hard hat and shield. Um I just took it in my stride and got on with it, um...

I: So did you try and ignore it?

P: Yeah, but obviously some of the comments are more than others, but...it was...people are just like that unfortunately.

I: So what did that feel like as a kid at school?

P: Well, again, it made me feel different. Um which is, I've always said to my mum all along what I want to try and avoid, you know OK I was unfortunate with what I've got, but I don't want to feel different to anybody else. You know if I'm in a crowd of people I'm in a crowd of people, it's not just, you know, put him to one side and you know, this is this lot and you know... I'm just the same, I'm the same as everyone else in sort of every other way its just unfortunate....

I: I was wondering if the feeling different comes from you or how other people treat you?

P: It's probably a bit of both...

I: What do you think comes from you?

P: Mmmmm,...um, I suppose some of the feeling different and how people look at me. As an actual person when they get to know me its, one of the things I worry about once I've told people is, you know, cos some people don't think a lot of it but others its like," when are you going into hospital next", just let me get on with it you know people tend to be like, and they go and tell their mums and their dads and their mums and they dads are going "are you all right na na" you know I go round to a friends house and I get a flea in my ear, I get this at home thank you.

I: So do people try and look after you a lot?

P: Yeah, and I don't like that.

I: And that makes you feel different too?

P: Yeah, and the other thing is I'm worried about what to say, my friend or whoever, how they see it all, they think why is my mum and dad treating him like...you know,,,their own?

I: Have you ever asked them?

No, I don't think I dare........its horrible, I'm reaching an age now when I just want to get ion with it, you know, um... but obviously a lot of the time I'm worried about bits and pieces, and sort of what's going to happen next, obviously as I get older, um, I've sort of said to my mum and dad about marriage and blah blah blah..

I: Do you have any fears for the future?

P: Oh yeah... well I feel kind of soppy, I said to my mum and dad, I will get married, well my sister got married when she was 23, and you know she's got a little one and another one on the way and obviously its comparing the two, and like mum and dad go well there's no rush, but in my eyes its being on the same level as her or other people. Cos my other friends have got married and so and so and you know, it makes you feel different. Cos obviously I'd rather get to know people and know that I can trust them, cos obviously it's a big thing to tell somebody, you have to know them pretty well and obviously, especially with girls and all the rest of it its how they are going to react, cos obviously with some of them its, you know you say the slightest thing and they run a mile.. (laugh)..

I: And have you had that happen?

P: Well yeah, especially like at high school its, I felt like, I had antennas, or you know ,15 fingers, its., came from the planet zog, and you know it wasn't like that . um. Its.....

I: What was a bad reaction you've had from someone when you've told them?

P: ...well.. I can remember one of them, she didn't want to know, she didn't want to know me after that, it's just...

I: was she a girl you were hoping to have a relationship with?

P: Yeah, yeah, cos. Well id known her a pretty long while and obviously we were getting on and bits and pieces, um and I think, mm, perhaps if I say something and I said something and obviously we can take whatever and she just didn't like it at all. Um which is obviously like a fear, cos I turned round to my mum and said well if every girl is going to react like that I might be on my own for the rest of my, for the rest of my life. It's knowing sort of who you can tell and what the reactions going to be. Cos obviously when you're younger if you turn round and say oh I've got such and such, they go oh...

I: 'Lets have a look at your scars..'

P: 'Do you want to go out and play football now?' Its, that ended that conversation. But obviously now at this age, people are more aware socially how they, are especially how I am with other people.

I: Do you think after you've told them apart from the feeling sorry or fussing thing, do you think people see you differently, after they've got over the worrying fussing bit, they carry on the same or differently?

P: Um...I don't know, I think people are individual. I mean there was an aunt and uncle, my mum and dad turned round to them and said stop fussing, and they still do and I said to my mum well I don't want to go down there and see them cos I know they're going to fuss over me. You know and its like people, they don't trust me or they don't think I can be left on my own, and I can, its not like I need..

I: So when people fuss it feels like they don't trust you?

P: Yeah and I can, I'm perfectly capable.

I: You've made it to 21 you're doing all right.....

P: Yeah, that's another thing I've found especially, I couldn't go away on trips with school and stuff cos it was, staying in dormitories and all that, no, that's a big no, no.

I: So were there lots of things that your bladder exstrophy stopped you doing?

P: Yeah, well I feel it did...

I: So school trips are one thing, what else?

P: Um, going away on holidays and stuff with friends. So when we all passed our exams, they were all oh we're off to Amsterdam and Germany and such and such and I was like oh no I can't, I can't go and I felt awful cos with my group of friends, um just sort of felt that I can't go on my own cos of all this.

I: What was it you were worried about going away?

P: Just..well....in one way its nice to have my mum and dad there cos if I have a problem I can fall back on them, but part of it is if I'm on my own somewhere and I've got a problem and its just me, er which is one of the reasons I went to university at home, I didn't go away, cos I felt that id be stuck out in the middle of nowhere. And obviously with coming up to London, it would have been even worse if I'd been up in [name of city]..

I: Yeah

P: But its.....its just the way......more things....people do the various normal things that anybody can do, and there are still things obviously that I feel that I can't do, and obviously part of that is when I go away I think oh no...

I: So going away on holiday? And is that just with friends, or with your mum and dad as well.?

P: Oh family is not a problem, umm

I: So even with friends who know?

P: Yeah its still...its...well again, they're going to worry and its like well you're on holiday and its like you don't need that..

I: So is this another time when you feel like a burden?

P: Yeah, yeah, I feel like I'm being dragged round with them rather than.. you know.

I: Has anyone ever made you feel like or said or done anything that's made you feel like that or do you think that....

P: It's probably a perception more than, its actually...

I: Something that's in your head rather than?

P: Yeah, I think a lot of it is just in my head unfortunately, and sometimes its just, if something plays on your mind and you think oh yeah it is true.

I: And I guess the more you think it, the more you're going to see it.

P: Its like anything, if people tell you you're stupid and they keep telling you you're stupid you believe that your stupid.

I: And if you keep feeling like a burden,,,

P: You're going to be a burden.

I: So that's one thing. Did you feel like it stopped you going away to university as well?

P: Yeah.

I: What would you have like to have done?

P: I would have liked to have gone to [name of city] was one of the, cos the course, the actual degree I wanted to do was to do with computers and bits and pieces and they did it up in [name of city] and I said to my Mum, 'oh you know I've got all these good a level results, this is what I want to do', and she said 'oh are you sure?' and I said 'yes definitely um and then I said to her, oh its in [name of city]' and she said 'oh, it's a bit and remember you've got to go to London, and blah blah blah,' and I suddenly turned round and said 'OK then I won't do it then'. And I did something wishy washy at my home one. And since then I've sort of regretted in a way um, you know cos this would have been my final year now up in, you know up in [name of city] and hopefully I would have passed it, um but...its just one of those things unfortunately...

I: It sounds like in a way your parents help you make decisions more, is that right?

P: Yeah.

I: What does that feel like?

P: Some of the time its like you know I wish I could decide cos its my life, but in some ways, I'm being treated with kid gloves and I've said to my mum and dad, stop smothering me basically, you know if I'm going to make a mistake, let me make the mistake rather than you saying well I don't think you should do that.

I: So what sorts of things do they say they don't want you to do?

P: ....er....well its basically bits and pieces, going here, going there, go on holiday with such and such..

I: ..(unintelligible)..

P: Just more or less general stuff, cos and the worst thing is she sits up and she waits, I mean I could come in at half past one in the morning and she's sat there in the front room and going are you all right, and its 'you don't have to wait up for me I can get in thank you', its awful cos it feels like they don't trust me, um, to sort of live under that is awful, you know, that one of the reasons I'm thinking about saving up and moving out to say look OK I'm on my own in the big wide world, you've done your bit up to here now I'm in control, you know. If I'm going to make a pratt of myself I'm going to make a pratt of myself.

I: How do you think they'll feel about that?

P: I don't think my mum will like it, my dad, probably wouldn't mid but my mum.. cos my mums been involved more sort of coming up to hospital and operations and blah, blah, shes affected more cos my Mum said 'get your dad to come up with you' and I was like 'oh no I'll go on my own thank you'.

I: So she wanted your dad to come with you today?

P: Mm, and the other thing I worry about is my mum and dad have to take time off work and its horrible cos obviously they've got their own lives to lead and I feel like I'm, can you take a day off to come up to London for sort of moral support. And there comes a time, like today where I said to them so what I'm coming up on my own, its not like I'm seeing a doctor or having anything done, I'm perfectly capable, I mean like even today she was like 'don't take your wallet, don't take your credit card don't take your mobile phone, you'll get mugged. (laugh).. and its slippery out', she said 'you'll slip'. Its like (laugh).. She worries. It was awful cos I was off with bronchitis recently and it was really cold a couple of weeks ago and my mum sometimes or my dad picks me up from work and my mum rung me up and I was out at lunch-time and I picked up on my mobile phone and she said 'don't go out at lunch-time its too cold and windy' and I was out already, thank you for telling me. Never mind.

I: Is there anything else that you've missed out on because of you bladder exstrophy?

P: Like I said, academically, like I said later on obviously I've picked up, but early on especially towards high school, preparing for your GCSE's and I'm loosing 3 or 4 weeks at a time, and when I come back its...hard catch up. And I found that with the exams, all the teachers turned round and said if you have ant problems let us know. I mean I did fine in them, it wasn't a problem but I still felt behind and a lot of the time I had to study longer after school to catch up, where everybody else was picking up.

I: Sure, what about things like sports and activities and stuff like that?

P: Sport was, I'm no good at all. That was, rugby, urgh.

I: So in a way if you weren't interested in sport, it helped you get out of it?

P: mm.. I liked sport, but it was the actual taking part, er, again I felt different, I got off taking showers and stuff like that and I was completely ribbed for that but it was, I felt completely, I cant let anybody see my scars or anything, just no, not at all...

I: Do you have lots of scars?

P: Yes, I've said to my mum before, I feel like a noughts and crosses board, so it was just no completely, so obviously they turned round and said " how come you're not in the shower after you've been doing rugby and you're covered in mud" " I don't need to take on" and obviously everyone else is taking on and that's a pretty lame excuse. Um, it was just awful, stuff like that. The little things, especially like at high school, that people pick up on and obviously they play on that. Um you know...

I: Has that stopped now?

P: Oh yeah, I mean cos at work nobody knows, at university nobody knew.

I: So you didn't tell any of your friends at university? Was that a conscious decision?

P: Yeah, I said to my mum I've made a definite decision, nobody is going to know and that's it, cos obviously they didn't need to know, cos I was only in 4 hours a day, most of the time was spent at home or in the library studying and doing the various bits and obviously the same with work, no-one needs to know, if I'm getting up from my desk why would they need to know where I'm going..

I: Well everyone needs to use the loo.

P: Yeah, exactly, you don't need to tell and broadcast it.

I: It sounds like in a way that went quite well for you, it stopped all the teasing, was there any times when it was quite tricky, like going out drinking, or people noticing you take longer in the bathroom?

P: Yeah I have had that especially in the pub. I've been taking 15-20 minutes and it's like 'what the hell are you doing in there?'

I: What do you say?

P: Well I don't really say anything, I change the subject straight away 'where's my drink?', type thing, but its typical lads thing.

I: The mates that you hang about with now do they know or?

P: Yeah most of them know, um, there's various girls and stuff that I've known for a long time that know and obviously they're fine with it but obviously its meeting any in the future and what, how they're going to take it, I mean I, the one that ran a mile obviously that still imprints in you mind.

I: How did that feel?

P: I felt awful, I felt tiny you know, so what, you know... I mean you either take me as I am or you don't basically, this is me. I mean I've said to people before, I don't pull any punches, this is it basically.

I: What do you tell people? Different people have different things they tell people.

P: I just say, it was something I was born with and its something they have to keep checking up on basically.

I: Do you say that you've got something wrong with your bladder?

P: No

I: With your kidneys? Or..

P: No just general, I just it was something basically I've got a defect I was born with and it something over time that I've needed to have various operations and obviously they check up on it regularly, its just something I just get on with and obviously a lot of people you worry about what you're telling them, some of them probably wouldn't understand, they wouldn't.....know what it means.

I: So when you tell people do they ask you lots of questions?

P: Some of them do..

I: Is that OK?

P: Well it depends, cos some of them it can feel like I'm on mastermind you know and sat there being bombarded, and its, and I sit there and I think why do I have to answer to you? Who are you to question me?, um you know, I don't go around questioning you why this why that...

I: It sounded like you never say the word bladder to people?

P: No, I try, well, I wouldn't say so I try and avoid it.

I: What for?

P: I just like it that way basically.

I: I've heard people say to me that the word bladder makes people go urgh, say the word kidneys or something non specific then...

P: Its just I don't feel I need to tell them that its just a general thing.

I: You've talked a little but about girls and relationships with girls, what's that been like, have you had girlfriends or?

P: Oh yeah, some longer than others but that's not.... Its just...

I: The same as everybody else?

P: Yes basically, um, but nothing that serious......that was it basically....

I: That sounds like its something you're kind of worried about?

P: Yeah, I've said to my mum and dad, especially with children and marriage and Blah blah, its something that's in the back of your mind you think that I don't need to worry about that now, like my mum says, you're only 21 coming up 22 why worry about it? Plenty of time to get yourself settled in in your job and bits and pieces, but its still in the back of your mind you think to yourself well I would like to get married I would like to have kids. I would like to do this, in some ways I think to myself the sooner its, I start on that path the better and I wont have to worry about it..

I: Does it feel like you think that more than other people?

P: Um.... I don't know...unless you ask somebody that's not got bladder exstrophy I don't know, especially with my mates that I hang around with its...normally the conversation is....about relationships...its not like its an off subject with me but I don't tend to like to dwell on it, it will happen when it happens basically..

I: But at the same time there's a bit of tension thinking that you would quite like it to happen..

P: Yeah, cos um my best friend had two girlfriends in a year last year and its like oh god, you know, its like you haven't had one for a while, yes, taking my time thank you, rather than something like that...

I: Would you say there's a bit of pressure from other people?

P: Yeah, I think there is, especially with my friends, me mum and dad there not worried, everybody knows what friends are like, its your peer group unfortunately and they unwittingly put pressure on you without you realising it and like I say, its like a finger on a nerve and eventually it comes too much and you have to do something about it.

I: When does it become too much, what do you do?

P: Um.. well either change the subject or, basically I just tend to ignore it, um, but people are like that unfortunately. You can have a conversation about something and they think nothing about it but to you it means more, affects you.

I: It sounds like in a way you prefer to know someone quite well before you start a relationship, a sexual relationship,

P: Yeah

I: Do you think that's related to the bladder exstrophy or do you think its not?

P: mmmm..... I don't know really, I don't know if its me or... its probably part and par, part of it is what I've got. I think one of the worrying things is, obviously I was unlucky with it but its whether its hereditary or, you know anything like that. And part of it is if we have kids are they going to get it? One in a 2 million chance and they got it, its like with anything, if you know it can be passed on you avoid it. You tend to.

I: So that's something you're wondering about, whether it can be passed on?

P: Yeah.

I: Do you know if it's going to affect that?

P: I don't know, especially with the BEES meeting, because I feel like I'm one of the oldest ones there its, they tend to talk about things that happen when they're younger, when they're 3 this is the operation and I think well I've had this done..

I: And is that helpful to you?

P: Some of it has been helpful, we've had people that have gone off and had kids and they've stood at the front and said its perfectly fine no problems when you're older and you can do this and this, I've got 2 kids, no problems. And you think to yourself and then there's me, that's you but this is me, you know, some of the ways you think to yourself yes we're the same, with bladder exstrophy but in some ways I might be different,. Um, I think part of it is knowing if you know will it be passed on. In some ways if it can be one would want to avoid that. Um.... Obviously people don't tend to dwell on that subject, or my friends don't tend to.

I: What, having children?

P: Yeah children. Most of them are still drinking 6 pints down the pub and.... Its not what we tend to talk about but I think then again that's my age, but obviously with my sister having one and one on the way I feel under more pressure again, um and I can remember when my sister had her first one they said 'oh my brothers got bladder exstrophy, is there any chance this child could have it?' And I thought' well why? You know this is me, nothing to do with you its me', um but again because the chances of getting it are one in... very minute, its still a worry.

I: What does that feel like for you?

P: Well I felt bad, I felt like it was my fault and I said to her well I didn't ask for this, but it feels like its my fault, somewhere along the line they just decided to give it to me. I think my mum and dad feel bad as well, my sister was fine and then there's me......

I: Do they ever talk about that or is it...

P: They do, they do, saying what it would have been like if they hadn't of done this. Cos I've got into blazing rows with them before saying why did you do this why did you do that?

I: What are the particular things that you were upset with them about?

P: It was more of the operations, they said oh yeah hell have that no problem, and obviously later on in life they say well OK then you can decide, you make the decision, whereas when you're little, you don't have control over you're life as you get older you get more control. Especially for ,me, cos of what I had done when I was little, cos I didn't have a say, its something later in life you have to get on with.

I: What would you have liked them to have done that they didn't do?

P: Well... I suppose, really at that age they couldn't have talked about it cos I wouldn't understand really but there's no harm in saying... I feel like I was kept in the dark, um and its, it was more or less knowing what it was about. This is the operation this is how its going to affect you.

I: So you think that you didn't really know?

P: No, its like with anything its like well I'm doing this now but how will it effect me later on, if I drive on the wrong side of the road it will do this....whereas I didn't.

I: So it was just [name of participant] you've got to do this this and this because we've told you to. Rather than [name of participant] this is what you need to do this is why?

P: Yeah it's the actual knowing.

I: Do you think it was difficult for them to explain to you?

P: I don't know or whether they were reluctant to tell me, I mean they, unfortunately they're the only ones who would know the answer to that question.

I: What would make them reluctant?

P: Probably upset me, if someone turned round to you and said we've done such and such because, it could turn round and make you upset, like with anything, sometimes people don't want to know, something's happened and they don't want to know. I'll accept it and get on with it. Mmm...

I: It sounds as if that's the sort of thing that, the difference its made to your life, its what you've not been able to do and worrying about the future, about children and having a relationship. Have there been problems with having a sexual relationship, or has that been OK?

P: I haven't had any yet..

I: Is it something you worry about?

P: Yeah

I: Do you think you worry more than other people?

P: Yes, yes, I would say so, like I said, because of this is it hereditary, it's a bit reluctant...

I: Are you worrying you're taking more risks by having sex?

P: Yeah.

I: And is there a worry about how the person you're having sex with might react to it?

P: I think so as well, its you know, I feel I like I'm passing the burden on to them....

I: Sort of tied into the telling people thing?

P: Yes.... Again it relates to that.... Um I tend to find that's why I like to get to know people really well, I like to know them as a person, so like OK I can tell you cos I know you, and if I tell you this I know your reaction will be x.

I: Is that something, you said earlier on that you're the kind of person that turns things over in your mind quite a lot, is that something that you think about?

P: Yeah I do, I tend to find, I worry, I'm a worrier, if someone tells me not to worry, I worry, (laugh), why are you telling me not to worry, I'm worried now...What is there to worry about...(Laugh)..Don't panic..why, why am I not to panic?...

I: Have most people reacted OK?

P: Most people have been fine with it, its not, but obviously like with anything there's the minority, like that girl that run a mile, I mean, as I said to my mum, with that reaction she wasn't worth getting to know better, someone like that isn't...

I: I'm struck here with your attitude that's very pragmatic, if things don't go right then you can deal with them and they're not worth bothering about and they're not worth getting upset about, that seems like a really helpful attitude to have and I was just wondering about where that came from or what has helped you to have that attitude?

P: I think because of what's happened its made me a stronger person, things don't get to me as much, um you know because I've had a lot to worry about, things , you know, if say I fail a driving test a lot of people it would bother them, but to me, it would be, unlucky, I nearly crashed the car it's a good thing I did fail! Um you know but to other people it would bother them...I'm made of sterner stuff. I think you have to be, cos unfortunately life's too short to worry, you'd never get any where, you wouldn't be able to get a barge under cheese bridge for falling bodies if everybody worried....(laugh)

I: It seems like it might have helped you to have that kind of attitude, maybe that's a good thing that come out of having it?

P: Its gauging peoples reactions all the time...

I: Does that make you a bit of a psychologist?

P: ...I don't know, perhaps if we swap chairs and I ask you the questions...um I don't know....I s'pose I tend to focus more on peoples minds and, people just sort of say something and I m thinking how would your mind react to what I'm telling you....

I: So you're often gauging how people react, what they're looking like or what there like or..?

P: I think that's a lot of it, how are you going to react to what I'm telling you, its like with anything, if you tell someone something, sometimes you make them laugh, cry or what's their natural reaction to what you're saying to them... but I suppose everyone's different.....

I: Just to move on, do you think that it's made you see your body differently to other people?

P: Definitely, I would say that's a big area that I've always been concerned with, and I think that was one of the reasons. Especially at the high school with the showers that was a... and one of the things...because of all the operations, my body reacted so in adolescents and puberty I was slower than everybody else and I saw [name of doctor] here and I had to have I think it was hormone injections to speed it up a bit.

I: So you didn't go into puberty at the same time as everyone else?

P: No, and obviously...

I: What was that like?

P: Oh horrible.. you know what people are like, they rib you unfortunately..

I: So was than another thing they had to tease you about?

P: Yeah, I think high school was the worst, cos there were a lot of knock backs, ur I think that was one of the things I was angry about why was by body reacting to all the operations I had and suddenly my body clock has decided to switch off or slow down..um..but it.. that was one more thing I didn't need. I said to my mum and my dad, I don't need it, I've got enough on my plate, I just want to pick myself up, dust myself down and get ion with it. But then again it's something else to worry about.

I: Did that make you see your body as something not working?

P: Yeah, I felt to myself, well why?, why is it taking so long, why have I got the highest voice in the class, everyone else has the deepest voice...

I: And did you catch up?

P: Oh yes, everyone said, oh you took your time...

I: So was that another thing you had to explain?

P: No I didn't , I was ribbed for that..... just people unfortunately can be nasty when they want to.

I: And kids often have long memories for things that you don't want them to..

P: Yeah I think that's a thing as well, when you tell an adult something, you don't expect them to get all giggly, and...various bits, but when you tell a younger person you know what they're like, they go off and tell their friends...

I: The jungle telegraph..?

P: Again.

I: So has there ever been a time when having it or reactions of other people have made you feel really bad?

P: Yeah, there's been real time when I've been at home and I've been really upset, and mum was really worried, we went and saw one of the psychologists at home, and she said he comes home and he's really upset and he doesn't want to talk about it, locks away in his bedroom, don't want to know, we see him for means and that's it, why..

I: So you isolated yourself in your room?

P: Yeah, and I sat down and I said, this is just knocking me down so much that I don't want to be with people basically, um its like with anything, if people continually being horrible, you tend to keep away from it and avoid it um, and that was my defence mechanism..

I: Did it make it difficult to go out and do things?

P: Yeah, my defence mechanism unfortunately is to stick my head in the sand and hope it will go away, but it wont.

I: It sounds like you are fighting that head in the sand tendency?

P: Mm

I: It seems like that's what you're doing at the moment, pushed it away now.

P: I think especially with work.

I: Did the psychologist help you?

P: Oh yeah, they sort of said basically so what, if you took everything that everybody said to you seriously you'd never step outside your front door.

I: So did you see them for a long time?

P: I think it was just a couple of sessions, and they wrote into the school and said 'look, he's been affected, people are being really horrible', which is one of the reasons why the head teacher went in and said 'you're being really really horrible to [name of participant], why?' And I just could have died..

I: Were you there at that point?

P: Yeah I was, you could hear my jaw drop on the floor, it was awful, they all said, 'why don't you like[name of participant]?........you come and see me we'll discuss this list, and he said keep a diary of things people have said to you and been horrible with and I thought, god this is awful, you know what its like with a diary, you write various excerpts, and he said well let me have a look at your diary and there were bits and pieces people had said and he went and called them in and said blah blah blah....(laugh).. and I'm like I can't believe he's done that, and then they hated me even more..

I: Of course, you'd got them in trouble..

P: Yeah..

I: I guess that was in the days before bullying policies, and stuff like that, in school...

P: That was awful, they made me feel so tiny, you know. Yes you've been horrible, lets look at why what don't you like about me, but to go to that extreme it's a bit much.

I: It wasn't handled sensitively?

P: No

I: It sounds like that was a time when you were feeling particularly bad and the two things together must have been very difficult..

P: Well then mum came in and did her raving nah nah over it, she just lost it..

I: What did she do?

P: She said 'why have you embarrassed my son? Why have you put my son into a situation like that? This is.. you know, why, why have you thrown him into the lions pit' and you know...

I: Did anything change as a result of that?

P: No off them no, you see people don't tend to care as much. I've found especially at work people say an off the cuff remark and the thing is people can take that in different ways um and everybody's the same, someone will turn around and say something um and it take people in different ways. At that age I'm more conscious of me and how I relate to people, it makes your life hell when people are like that, cos you try and get in with your studies but its always. I can remember one time I was off, there was all scrawls all over my book, and they'd ripped all my books up and I got in trouble with the teacher cos I didn't have me exercise book, and people could be horrible, it was awful..um..but...

I: Just to wind up I want to ask you kind of a weird question, but give it a go.. If you were to go home tonight and go to bed go to sleep, and overnight a miracle happens and you don't have any bladder exstrophy any more, its gone, all healed up that's it, bang, and because its happened while you were asleep, you wake up and you don't actually know that its happened. How would you find out? What would be the first thing you'd notice that was different?

P: Probably not having to catheterise that would be numero uno, being dry, for a start, it's the little things. Wouldn't necessarily be a big thing, just a small thing, um, that's the thing with bladder exstrophy, its not necessarily, its one big thing but its made up of little tiny bits, um..

I: So it's the sum of the parts?

P: That make up the whole picture.

I: What would you say were the main parts that would be different?

P: mm.....I think like I said not having to catheterise and being dry would be the main..

I: Are you wet a lot?

P: Well I was until they did the tightening of the bladder muscles.

I: Is that macroplastique?

P: Yup, that's it, I had to have two injections of that um cos the first one they did was no good, but they were saying they can only do three, um but that would be something that would stick out, and apart from jumping for joy and doing cartwheels on the stairs...um..

I: Do you think other people might notice?

P: I think they'd hear me crashing into the cupboard at the bottom of the stairs, um..but..I don't know, it's hard to tell unfortunately. Cos sadly you know its not going to happen.

I: I guess the main reason for asking would be to find out what the main things It hat it effects in peoples lives that they'd notice would be different. For you it sounds like it would be the planning..

P: Oh yeah its always, a question of I want to do this but I must be one step ahead of what I want to do in order to..

I: And that's the every day grind of it?

P: Oh yeah. But that's one of the reasons, especially with university it annoys me because I wanted to do that, it was what I wanted to do but then again my mum was right, there was no way, if I had a problem with this in any way, there's nobody out there..

I: Have you ever had a time when you had a problem?

P: Oh yeah, there was when I actually, when they put part of my bowel onto my bladder to enlarge it I had to have a catheter in and it had to be changed every six weeks, and one of the times the balloon inside burst and they had to come rushing us straight to [name of hospital] to take it all out..

I: Wow, so it was little things like that which are quite scary might happen.

P: Yes

I: Is there any danger with the mitrofanoff, are there any worries about that?

P: I don't know....well.. I don't know....cos they actually used my appendix as...

I: Clever little procedure they've got there..

P: Doesn't do a right lot the appendix.... its little things like that, like today all the planning and my mum was like 20 questions going out the front door, its awful. Everyone else would think well I'm going to go into [name of street] and they just do it, they hop on the train and I'm going to go and its an end to it, I have to think is there a loo here o is there a loo there, oh I know I can eat there so there has to be a such and such......

I: That's really all the questions I was wanting to ask. I wondered if there was anything else you wanted to tell me about that you though might be important or..

P: No, I'm just worried later in life and I've said to [name of surgeon], I think that was the problem with [name of hospital], because I was getting to be the eldest there, we've come to the end, you need to be with someone who deals with adolescents and all this, you're getting on in life, and sometimes cos I want to talk about things late in life and sexual relationships, I've said to my mum, don't come in the room, you stay there, its I mean mums what, its all right I just want to talk to him.

I: You're lucky she can stay out

P: Sometimes I just don't want her in cos you know its something that personal to you and stuff like that you don't want to talk about in front of your mum. Not they type of stuff you talk about over cornflakes.

I: (..Irrelevant stuff re surgeons' interests)

P: but I've found that handy, cos I tend to find when you talk to someone that's outside the family as well cos they tend to see it from a different point of view.. and you can turn round and say these are my worries and these are my fears and they're like OK well eliminate that and that...

I: so its reassurance...?

P: Yeah

I: Well thank you, I think I have asked about everything I wanted to, did I ask about the things I you were expecting me to ask about?

P: Yeah

I: Is there anything I haven't asked

P: No, covered it all. Something like this is handy for me cos obviously a lot of the time when you bottle things up or, you, sometimes you don't want to talk with your mum and dad or any of your friends and you think I need to talk to somebody else, what do they think.

I: I'm glad its been helpful, I'll stop the tape..

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15 SEP 2000

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor André McLean

Please address all correspondence to:
Iwona Nowicka
Research & Development Directorate
UCLH NHS Trust
1st Floor, Vezey Strong Wing
112 Hampstead Road, London NW1 2LT
Tel. 020 7-380 9579 Fax 020 7-380 9937
e-mail: iwona.nowicka@uclh.org

Mr C Woodhouse
Reader in Adolescent Urology
Institute of Urology
48 Riding House Street

September 11, 2000

Dear Mr Woodhouse

Study No: **00/0184***(Please quote in all correspondence)*
Title: **Exploration of the psychological outcome for adolescents with bladder exstrophy**

Thank you for sending us your project on bladder exstrophy. The Committee thought that the statement on arrangement of compensation in the information sheet was probably unnecessary in the questionnaire study of this kind, although it is formally very much the correct thing. Would you think it helpful to put paragraph 6 line 2 from 'however, research can ...' etc. into a footnote.

This is a suggestion rather than a requirement and the research can go ahead from the point of view of ethics. Please ensure that you have obtained final approval from the Trust (via the R&D office) before proceeding with your research.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Professor André McLean, BM BCh PhD FRC Path
Chairman

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The University College London Hospitals
Research and Development Directorate

Professor Allyson Pollock
Director of R&D

Dr Nick McNally - Manager
Dr Azeem Majeed - Snr Lecturer
Mr Graham Petty - Finance Manager (R&D)
Ms Caoimhe O Sullivan - Statistician
Mr Joseph Eliahoo - Statistician
Ms Beverly Warburton - R&D Training
Dr Bernadette Purcell - SpR

Ms Iwona Nowicka - Ethics Admin.
Mr Philip Diamond - Admin.
Ms Becky Wellburn - Admin.
Ms Doreen Sharpe - Admin.
Ms Nathalie Labarrère - Admin.

26 SEP 2000

25 September 2000

Mr Woodhouse,
Institute of Urology

Dear Mr Woodhouse,

Study No: **00/0184** *(Please quote in all correspondence)*
Title: **Exploration of the psychological outcome for adolescents with bladder exstrophy**

Thank you for registering the above study with the R&D Directorate. I am pleased to give Trust approval for the study. Please ensure you have addressed any outstanding issues raised by the ethics committee before you start your project.

With best wishes.

Yours sincerely

P. D

Professor Allyson Pollock

CC. Dr D Christie

1st Floor Vezey Strong Wing; 112 Hampstead Rd; London NW1 2LT; Tel: 020 7380 9833 .... Fax. 020 7380 9937
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