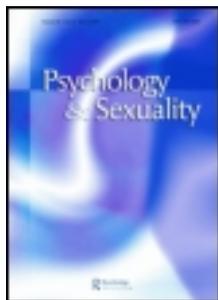


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Psychological research and intersex/ DSD: recent developments and future directions

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Psychological research and intersex/DSD: recent developments and future directions

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Clinical management of intersex/DSD has been evolving, since the early 1990s, towards a goal of holistic, patient-centred care offered by specialist multidisciplinary teams (MDTs). This evolution has been championed by service users and practitioners alike. With the Consensus Statement on the Management of Intersex Disorders came clarification of MDT functioning and further recognition of psychological/psychiatric services as a key part of clinical management. In this article, we look at the intersection where academic and clinical psychologies converge with patient care in the case of the intersex/DSD individual, post-consensus statement. First, we map out conceptual advances in understanding psychosocial and psychosexual well-being, pointing to areas where psychology stands to make a significant contribution. We then discuss recent outcome research focusing on affected adults, youth, children and their parents. We address advances in service provision, focussing on the specific issues of disclosure of diagnosis and potential gender assignment. Finally, we point to trends and ideas for future research and highlight a gap in the literature bridging psychosocial and neuropsychological approaches. We recommend better engagement across research paradigms, in the interest of optimal health care approaches for people who live with intersex/DSD.

Keywords: DSD; gender identity; intersex; psychosocial outcomes

The consensus statement on the management of intersex disorders (Hughes, Houk, Ahmed, & Lee, 2006) marked a significant shift in addressing the gap between medical and psychosocial perspectives where sex development is atypical. As part of the multidisciplinary team (MDT) imperative, the call for more holistic care incorporating psychosocial concerns became a permanent part of the landscape. Here we highlight important developments and new directions within psychological research concerning intersex/DSD.¹ First, we map out recent psychological research relevant to diverse sex development. This first section is divided into two parts focussing on (i) recent conceptual advances in psychological research (the only place in this text where we allow our two voices to be explicitly distinguished from one another) and (ii) recent findings on psychological outcomes. In the second section, we outline some research-based advances in service provision, focussing on (i) disclosure and (ii) gender assignment. The third section focuses on gaps and trends in psychological research and highlights suggestions for future research.

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Psychological research

Conceptual advances: neuropsychological studies of gender development

Vickie Pasterski

From an early age, typically developing boys and girls may easily be distinguished according to sex, behaviourally as well as biologically. For example, boys and girls differ, on average, in their identification as male or female, as well as in their playmate preferences and play style preferences (Pasterski, Golombok, & Hines, 2011). Research evidence indicates that girls, compared to boys, typically identify as female, prefer to play with toys such as dolls and tea sets, choose girls as playmates, and prefer lower levels of activity. By contrast, boys typically identify as male, prefer vehicles and weapons, boys as playmates, and rough-and-tumble play (for review, see Pasterski et al., 2011). As children grow into adulthood, the primary differences centre on gender identity and sexual orientation (Hines, 2011b). The majority of women typically identify as female and are androphilic (sexually attracted to men), whereas the majority of men typically identify as male and are gynephilic (sexually attracted to women).

Neuropsychological research assessing gender-related behaviour intersects with intersex/DSD at two key junctures. First, much of what we know about neurobiological influences on typical development of behaviours that show sex differences in humans comes from studies where neurobiological developmental processes have been interrupted, as is the case with congenital adrenal hyperplasia (CAH; Speiser et al., 2010) or androgen insensitivity syndrome (AIS; Hughes et al., 2012). Extensive experimental research in animals suggests that gonadal hormones exert powerful influences on gender-related behaviour (see Hines, 2011a for review) and both CAH and complete form of AIS (CAIS) present situations where these effects can be observed. In the case of CAH, individuals with female-typical sex chromosomes (46,XX) raised as girls would have been exposed prenatally to male-typical levels of testosterone (Speiser et al., 2010). In the case of the CAIS, all individuals have male-typical sex chromosomes (46,XY) and are likewise exposed to male-typical levels of testosterone but their bodies appear to be resistant to the effects (Hughes et al., 2012). The second intersection of neuropsychological research in gender-related behaviour and intersex/DSD is the case of predicting possible gender-related outcomes for newborn infants with intersex/DSD conditions. Outcome literature is critical for determining best practice in cases of gender assignment. While the inclusion of patients with intersex/DSD conditions for normative studies has been criticised, findings from these studies are directly applicable to clinical management. Many parents of patients with intersex/DSD conditions want to know what to expect for their children in terms of gendered behaviour as well as physical sex development.

What has been learned regarding neuropsychological research is that gender-related behaviours likely develop as complex interactions of biological (e.g. hormones and genes), social and cognitive processes. In terms of the progression of development, a biopsychosocial model would suggest that there are biological limits upon which other influences in the environment act (Udry, 2000). For example, girls with CAH are more likely to show masculinised behaviour both in childhood and adulthood due to prenatal exposure of testosterone (Meyer-Bahlburg et al., 2004). In childhood, they are more likely than non-CAH girls to express a preference for toys usually associated with boys, to have boys as playmates and to engage in higher levels of physical activity. In adulthood, the majority identify as women but are about 600 times more likely than non-CAH women to express a desire to live as a man (Hines, 2011b). Given that girls with CAH are typically socialised as girls (Pasterski et al., 2005), this observation supports the role of biological influences in

gender identity. Such findings can inform our understanding of gender development more generally, and contribute to the ongoing debate about gender assignment for more virilised 46,XX individuals (Lee & Houk, 2010).

Conceptual advances: psychosocial research

Katrina Roen

In this section, I review some recent research that has asked psychosocial questions. The purpose is to indicate how psychologists contribute to thinking about atypical sex, about childhood difference and about how health professionals respond to new evidence. In the latter part of this section, I identify specific roles that psychologists can play in conceptual developments in this area, and I point to examples of psychological research where innovative conceptual work is underway.

One area of conceptual development, where psychologists have made a particular contribution, relates to what is prioritised in research on outcomes. Where earlier approaches may have considered normative functions of the genitalia and relative absence of patient complaints as indicators of good outcomes, current approaches point to a need to reformulate outcome evaluation and specifically to raise a wider range of psychosocially oriented questions. By investigating the psychosocial consequences of early surgery, psychologists have found that, for example, in the case of boys with hypospadias, ‘there is no empirical evidence that corrective surgery at the youngest possible age leads to a better psychological development’ (Schönbucher, Weber, & Landolt, 2008, p. 530). On the basis of their systematic review of psychosocial outcomes for boys with hypospadias, these authors concluded that ‘optimal medical care for hypospadias cannot merely be achieved by optimizing surgical results’ (Schönbucher et al., 2008, p. 531). In addition, some surgeons have argued against early surgery in specific instances (e.g. in the case of distal hypospadias: (Mundy, 2011); in the case of female genitoplasty: (Creighton, 2011) on the grounds of unsatisfactory cosmetic outcomes).

The significant conceptual shift indicated here is a shift from thinking that treatment outcomes will be optimised via better surgical technique and timing, towards arguing that cosmetic genitoplasty for infants and children is not defensible. This is a psychosocial issue because early cosmetic genitoplasty has been defended on psychosocial grounds. It has now been repeatedly demonstrated and argued that these psychosocial grounds are spurious and dangerously misleading.

One of the blocks to accepting evidence of poor outcomes has been the difficulty of accessing a non-treated atypically sexed sample for comparison. The largest study to date reports data from 56 adults with ‘uncorrected’ glanular hypospadias (Dodds et al., 2008). They report that only one ‘presented with a complaint referable to the hypospadias’ (p. 682), while 18 (32%) were not aware of having any genital anomaly. Further, none ‘pursued an interest in corrective surgery’ and ‘most stated that they were satisfied with the appearance of the penis’ (p. 682, abstract). While the case of glanular, or distal, hypospadias is considered quite mild (the mildest form), it is so far the only case where such a large cohort may be studied. The findings nevertheless highlight the point that cosmetic anomalies left uncorrected have little impact on psychological well-being. This point is consistent with quantitative psychological research involving non-clinical populations that has shown how children’s subjective distress is not predicted by their rating of themselves as atypical. Rather, it was children who felt under pressure to conform who reported higher levels of distress (Yunger, Carver, & Perry, 2004). This non-clinical psychological research suggests that children raised with visible atypicality may not

necessarily be distressed by that atypicality, but may actually be distressed by interventions (i.e. manifestations of social pressure) to make them appear more typical.

Bringing together the findings of Dodds et al. (2008) and Schönbucher et al. (2008), as well as others who have pointed to the persistence of unsatisfactory surgical outcomes over the years (e.g. Mundy, 2011; Pfistermuller, O'Flynn, & Cuckow, 2011), it would seem very hard indeed to continue supporting early cosmetic genitoplasty in the case of distal hypospadias (at the very least). Yet, conceptual shifts do not take place on the basis of research evidence (or lack thereof) alone. Numerous psychological studies have examined how experts (and non-experts) embark on conceptual shifts when presented with evidence that existing understandings fall short (for examples, see Feist & Gorman, 1998; Kruglanski, 1994). One role for psychologists is to draw from the existing, substantially quantitative and cognitively oriented knowledge base on how conceptual shifts take place, and use this knowledge to facilitate the process of change taking place with regard to the treatment of atypical sex development. Another role for psychological researchers here is in the production of evidence about psychosocial outcomes, and the interpretation and discussion of that evidence. Crucially, psychologists need to engage critically with the frameworks of understanding through which some 'evidence' becomes grounds for a paradigm shift, while other 'evidence' is soon forgotten.

This is a process of negotiation in which psychologists have an important role to play if the ongoing debates about treatment are to be substantially informed by psychosocial theorising and research. We may usefully understand the shifts in thinking about cosmetic genital surgery (from the era of Money's theorising about the role of typical sexual features to today) in relation to Hacking's concept of 'styles of reasoning'. Hacking explains how 'a style of reasoning introduces . . . ways of finding out the truth and determines the truth conditions appropriate to the domains to which it applies' (Hacking, 2002, p. 1, abstract). Psychologists who wish to contribute to shifts in thinking in this area, may do this by making more visible the 'styles of reasoning' that are operating, where spurious psychosocial arguments are used to justify potentially questionable medical interventions.

Approaches to the psychosocial that go some way in this direction include feminist deconstructionist approaches, queer approaches, critical psychology and critical sexology. Such approaches have been used by some psychologists to question the surgical imperative (Roen, 2008); to question heteronormative imperatives (Liao, 2007); to question gender-normative assumptions underpinning some neuropsychological studies (Jordan-Young, 2010); and to question what an offer of surgery might mean when a woman feels her genitalia are atypical (Liao & Creighton, 2007).

Liao (2007) draws understandings from feminist and queer theorising, and critical sexology, in seeking to decentre heterosexual intercourse as a therapeutic goal. She points out that, in her therapeutic work with women with intersex/DSD conditions, 'few heterosexual women allude to pleasure as the reason for wishing to engage in sex' (p. 400). Liao continues, it may be that 'the cultural context that devalues their difference has taught some of them to be satisfied with less than positive sexual experiences' (p. 401). This suggests that outcomes in the form of 'satisfaction' should not be taken at face value but, rather, interpreted critically in the light of a cultural context where some women have learnt to be 'satisfied' with barely satisfactory sexual experiences. Another key message here is that assuming heterosexual intercourse will be a central therapeutic goal for women is highly problematic and likely to give misleading impressions of what constitutes a successful treatment outcome.

What emerges from this brief overview of selected publications is that psychologists are in a position to advance thinking in this field in various ways. While the move to including

psychological input, in clinical teams specialising in sex development is significant and worthwhile, it is still open to negotiation whether the psychologist's role in that situation allows for substantive conceptual contribution. In some cases, it may be that psychologists' role is reduced to managing support and information flow. The potential, however, is for more substantive conceptual contribution from psychology.

Psychosocial and psychosexual outcomes: children and youth

There has been a steady stream of research reporting on psychological outcomes in children with intersex/DSD conditions since the 1970s, though the aim has largely been one of charting underlying mechanisms related to typical development. Research that focuses directly on psychosocial and psychosexual outcomes in children and youth, specific to disease characteristics and treatment protocols, has been sparse. One reason for such scarcity is that the conditions themselves are extremely rare. Second, researchers and health care professionals must be mindful of respecting patients' privacy. We cannot know the outcome for every patient. Nevertheless, there is a small body of literature from which we can determine trends in thinking about outcomes in recent years. Specifically, most studies have focused on satisfaction/contentedness within the context of genital surgery and/or gender assignment.

Psychosocial and psychosexual outcomes in the context of genital surgery are of particular importance and investigations of them, that have been called for by patient advocacy groups, have been the impetus for what we are starting to see as a paradigm shift. One example of this is quality of life research that has questioned the validity of surgery to correct hypospadias in a study of 77 boys (aged 7–17 years) (Schönbucher, Landolt, Gobet, & Weber, 2008a). These researchers examined a range of factors relating to quality of life, adjustment, development, surgical outcome and surgical timing, and they used a control sample of boys who had undergone hernia repair surgery. They concluded that there was no significant difference between the two samples on various measures concerning the boys' gender role behaviour, first sexual experiences, sexual attitude and how they perceived their penises (Schönbucher, Landolt, Gobet, & Weber, 2008b). They explain that 'most authors suggest that medical characteristics such as severity of hypospadias, number of operations, and age at first and final surgery bear a minimal influence on the patient's psychological adjustment' (Schönbucher et al., 2008a, p. 865). Their research sets out with the claim that, in fact, 'guidelines for surgical treatment are partly based on psychological assertions that have not been empirically confirmed' (Schönbucher et al., 2008, p. 531) and goes on to raise substantial questions about the validity of possible psychological grounds for surgical treatment independent of medical necessity.

More recently, the same team reported on a pilot study investigating the often-repeated idea that earlier surgery is advantageous in the case of hypospadias repair. They conclude that their study has not provided evidence to support recommendations concerning the ideal age for hypospadias repair (Weber, Schönbucher, Gobet, Gerber, & Landolt, 2009, p. 345). However, others suggest that there may be advantages to early surgery. Jones and colleagues (Jones, O'Brien, Chase, Southwell, & Hutson, 2009) found a correlation between recollection of surgery and dissatisfaction with body appearance. As with the studies reported above, this group found the majority were satisfied with surgical outcome, but those who recalled going through the process, e.g. those older than 5 years at the time, reported poorer body-image satisfaction.

The issue of surgical timing is one place where styles of reasoning can be seen at work: presenting data and analysis may be understood to have the effect of establishing truth

conditions. According to some conditions set up through research reports, the possibility of continuing early hypospadias repair is presented as justifiable on psycho-social grounds. Meanwhile, according to the conditions set up in other research reports, the absence of consistent evidence of psychological grounds for early surgery is read to indicate that non-essential genital surgery on infants and small children is unjustifiable. This is not a reflection on the individual research teams whose work is cited in the present article; rather, it is a phenomenon that is observable across research fields (Hacking, 2002).

With respect to treatment outcomes in relation to other diagnoses, researchers have identified significant differences between the stress and coping scores of children and adolescents with CAH, in comparison with children with other health issues and pointed to the value of training in coping strategies (Reich, von Hagen, & Schwarz, 2011). Others have compared young adult males with anorchia and healthy young males, using questionnaires on general health, psychological health and sexuality and finding no significant differences between participant groups (Poomthavorn, Stargatt, & Zacharin, 2009). Some have sought to identify psychological issues relevant to patient care, using qualitative interviews with patients with CAH, and finding that a ‘major source of anguish’ is a ‘sense of loneliness when dealing with the disease’ (Telles-Silveira, Tonetto-Fernandes, Schiller, & Kater, 2009, abstract). There is room here for a series of systematic studies, focusing on the psychological (including psychosocial and psychosexual) aspects of specific types of atypical sex development.

As attempts to research psychological outcomes continue, it becomes apparent that measuring specific aspects of psychological well-being (including quality of life, body image, coping and adjustment) does not necessarily capture the psychosocial challenges faced by children and youth diagnosed with DSD/intersex conditions. Instruments designed for a normative sample may not be well designed to detect the specific distresses experienced by some children with diverse sex development. Some psychologists are responding to this problem by developing better tailored instruments, e.g. for assessing paediatric penile perception (Weber, Schönbacher, Landolt, & Gobet, 2008), and for assessing health-related quality of life (Sandberg et al., 2011).

Outcome studies: adults

A variety of clinical and social psychological studies have taken qualitative approaches to finding out about what is important, psychologically, from the perspectives of adults who have experienced atypical sexual development. Some studies with adults have demonstrated that their experiences of early intervention can lead to feelings of devaluation (Alderson, Madill, & Balen, 2004), issues with sexual sensation (Crouch, Liao, Woodhouse, Conway, & Creighton, 2008), fears of not meeting sexual partners’ needs (Schönbacher, Schweizer, & Richter-Appelt, 2010), fear of rejection (Boyle, Smith, & Liao, 2005), feeling discredited (as men) and experiencing social isolation (Chadwick, Liao, & Boyle, 2005) and negative body image (Schönbacher et al., 2010). Recent research has also investigated intersex/DSD adults’ body experience and satisfaction (Prochnow, Schweizer, & Richter-Appelt, 2010).

In addition to these productive small-sample qualitative studies, understanding of adult outcomes has been enhanced by reviews such as Bean et al.’s (Bean, Mazur, & Robinson, 2009), which draws psychological outcome data on Mayer–Rokitansky–Küster–Hauser (MRKH) syndrome from 52 years’ worth of literature. The authors conclude that successful psychological outcome is not ensured by creation of a vagina, and that health professionals’ language-use impacts on women’s experience of MRKH.

Some have sought to assess levels of psychological distress among adults with intersex/DSD, paying particular attention to self-harming as an expression of distress (Schutzmann, Brinkman, Schacht, & Richter-Appelt, 2009). These researchers studied a group of 37 adults, plus comparison groups. They found that prevalence rates of self-harming behaviour among adults with intersex/DSD conditions were twice as high as the non-traumatised control group and similar to the groups that had experienced either physical or sexual abuse. The reported level of distress was independent of the age at which genital surgery was carried out, and independent of the level of genital atypicality at birth.

Schweizer and colleagues (Schweizer, Brunner, Schutzmann, Schönbacher, & Richter-Appelt, 2009) carried out a mixed-methods study concerning coping and gender experiences in seven intersex/DSD persons living as women. One productive aspect of this study is its focus across a range of experiential and psychological issues. The researchers identified recurring themes in the participants' reports, citing significant emotional and subjective effects. Based on these recurring themes, they give examples of data suggesting that 'coping with feminising medical intervention produced feelings such as hope and disappointment . . . not only . . . [in relation] to genital surgery but also to gonadectomy and HRT' (p. 197). One participant referred to the effects of painful dilation, saying 'you start to hate your vagina' (p. 195). Another reflected on hormonal intervention: 'I hated HRT because it reminded me of my problem daily' (p. 195). A third commented on the way that treatment impacted on her sense of self: 'I often had the feeling of not being real, but rather a patchwork of surgeries and hormones' (p. 195). Given how specific these kinds of distress are to clinical intervention for sex development issues, it is understandable that a standard psychometric measure may not detect them. Though one may argue that medical intervention is now better than it was formerly, psychologists nevertheless need to be able to work well with people who have been exposed to earlier treatment methods.

This study stands out for its detailed engagement with questions about gender identity and gender experience. The researchers examine a number of questions relating to the ways in which participants see themselves with regard to the concept of gender. Questions concerned gender in fantasy, gender satisfaction, gender certainty, sense of femaleness or maleness, and in-between gendered possibilities. Participants described their sense of their gendered selves in diverse ways, with varying degrees of gender uncertainty, defying any simple categorisation, but none of them had sought gender reassignment. These authors demonstrate the value of a mixed-methods approach that allows for complexity and richness, rather than reducing participants' experiences and genders to pre-defined categories.

While attempts to measure psychological outcomes for adults have produced mixed results, qualitative and mixed-methods studies are offering substantial detail about the kinds of distress experienced. Some of this distress relates to the effects of medical treatment, and some of it relates to the experience of diverging from norms without having someone supportive to talk to about that (Schweizer et al., 2009).

Outcome studies: parents of children with intersex/DSD conditions

The few studies of parents whose children have been diagnosed with intersex/DSD conditions have primarily focused on experiences of finding out about their child's diagnosis and coping with subsequent stress.

Attempts to measure parents' coping have led to the suggestion that a mixed-methods approach may be better than a purely quantitative approach (Duguid et al., 2007). While the quantitative measure used in this study did not register atypically high stress levels or

coping difficulties among the parents studied, the qualitative interviews shed more light on parents' potential for stress and pointed to issues concerning clinical information exchange. Further, these authors found that measures of the parent's stress do not necessarily correlate with the degree of the child's genital atypicality (Duguid et al., 2007), an interesting finding given the long-held assumption that early surgical alteration of anomalous genitalia is necessary for the sake of facilitating parental coping. Two studies lend further support (Crissman et al., 2011; Pasterski, Mastroyannopoulou, Wright, & Hughes, in press). In both cases, uncertainty about diagnosis and prognosis were found to elicit greater distress than physical sex ambiguity.

One study seeking to examine parents' experiences of bonding with their child showed that some parents found bonding difficult, citing repeated clinical interventions as one of the reasons for this (Sanders, Carter, & Goodacre, 2008). Key aspects of parents' experience, reported in a number of studies, relates to issues of (un)certainty, communication and decision-making. Salient aspects of parents' experience, that psychologists need to contend with, is that parents can experience the uncertainty associated with their child's sex development as particularly distressing (Sanders et al., 2008) and may also be distressed by complex medical explanations (Sanders, Carter, & Goodacre, 2011). In relation to the topic of decision-making, parents' reports suggested that they were not aware of the possibility of not going ahead with surgery, nor were they aware of the controversy surrounding such surgery in childhood (Sanders et al., 2008). Parents' perceptions of medical problems and solutions, their process of engaging with confusing and complex information given to them by medical specialists, and their process of coping with the emotional challenges of learning about their child's diagnosis, substantially impact on their ability to play an active role in the processes through which their child is going. What it means to play an active role, making complex decisions on behalf of their child has begun to be articulated (e.g. Roen, 2009) and could usefully be more thoroughly elaborated by psychologists.

Research-based advances in service provision

Disclosure in intersex/DSD conditions

With the widespread acceptance of the multidisciplinary approach to clinical management and the necessary inclusion of psychological support services, attention has turned now to the specifics and logistics of service provision (Pasterski, Prentice, & Hughes, 2010a, 2010b). Of utmost importance in this regard is disclosure of information regarding diagnosis and management to parents of patients and patients themselves. Support is gathering for the notion that care must be taken from the first words of communication. Historically, the debate regarding disclosure of medical information has been concerned with whether or not disclosure should take place. From a paternalistic view, the goal has been for the patient to remain insulated from shock and despair subsequent to learning his/her circumstance. In Western nations, however, this approach has largely been abandoned in favour of partial or full disclosure, partially due to widespread availability of information and partially due to a shifting model recognising patient autonomy (Hughes et al., 2006). By contrast, other parts of the world continue with a paternalistic model with little to no disclosure (Miyata, Takahashi, Saito, Tachimori, & Kai, 2004; Mobeireek et al., 2008). Nevertheless, with respect to the West, that full disclosure should take place is agreed, attention turns to the consideration of specific conditions of disclosure, i.e. how and when to disclose.

The extant, albeit sparse, literature on disclosure in intersex/DSD briefly addresses both conditions. The question of whether or not to disclose a diagnosis to a

child/adolescent/adult patient has been the topic of two studies of parents and their daughters who have Turner syndrome (TS) (Starke & Moller, 2002; Sutton et al., 2006). The authors of these studies conclude, and most participants agreed, that full disclosure, conducted appropriately, is the optimal approach. Furthermore, Sutton et al. (2006) reported negative effects of non-disclosure, or secrecy, and linked secret-keeping behaviours by parents to their own negative experiences with health care provider(s) (HCP(s)). Parents who kept all or part of their daughter's diagnosis secret reported having been dissatisfied with the disclosure process itself. In this case, disclosure that took place between the HCP and the parents directly affected parents' openness with their daughters which, in turn, affected their daughters' experiences of secrecy associated with being affected.

Three further studies report on parents' and patients' reactions, given that disclosure has taken place, to learning about a diagnosis of AIS specifically (Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000) and intersex/DSD more generally (Crissman et al., 2011; Liao, Green, Creighton, Crouch, & Conway, 2010). Slijper et al. (2000) found that parents and adult patients experienced lasting emotional reactions to diagnosis of AIS including shock, grief, anger and shame. More recent research suggests that though communication appears to be improving, many patients still find the process of obtaining and giving information to be difficult (Liao, Green, et al., 2010). Crissman et al. (2011) have delved further into patient/family experiences using interviews and qualitative analysis. Not surprisingly, they found that uncertainty with regard to diagnosis, prognosis and future disclosure of intersex/DSD status caused quite a lot of distress. This suggests that while we have moved to full disclosure, the manner in which information is given bears refining.

These studies support the intuition that disclosure of fundamental and potentially stigmatising information is a difficult process and must be considered carefully. There is evidence of negative effects of non-disclosure; however, prospective studies charting the process have not been conducted. While reports of disclosure and reactions to disclosure are useful as a starting point, investigations should now (1) chart the process prospectively for accurate assessment, (2) point to specific features of the process which may have beneficial or detrimental effects and (3) develop specific and applicable models which screen for, and intervene in, cases of distress in parents and patients.

With respect to the third point above, an evidence-based model for treating and supporting families with a child diagnosed with cancer, Pediatric Psychosocial Preventative Health Model (PPPHM), identifies events such as diagnosis and emergent medical care as potentially traumatic events (PTEs) (Kazak et al., 2007). The model articulates that it is the interaction between the objective nature of the event and the subjective interpretation of the event which renders it as traumatic or not (Kazak, 2006). This model allows for the identification of at risk families and sheds light on an opening for direct intervention. Likewise, accessing the subjective interpretation at the point of disclosure in the case of intersex/DSD may offer insight towards a more holistic health care protocol. For parents, the experience of having a child diagnosed with an intersex/DSD condition is increasingly being understood as a traumatic event and may very well benefit from models used on other areas of paediatrics.

Gender identity and gender assignment: psychobiological approaches

Probably the most salient psychobiological concern regarding intersex/DSD, as mentioned earlier, is gender identity. Evidence suggests a role for prenatal hormones in the development of gender identity. Because many intersex/DSD conditions occur as a result of

disruption within the endocrine system, such evidence should be carefully considered. Specifically, we must consider that hormones exert their influences in a graded manner (e.g. Nordenström, Servin, Bohlin, Larsson, & Wedell, 2002) and that there are critical sensitive periods for gender-related neural development (Hines, 2011b), but also that there are individual differences and complex interplays between genes, gonadal hormones, socialisation and cognitive processes.

Practices regarding gender assignment in infancy are ever evolving to reflect the growing body of empirically based knowledge about developmental processes. In the 1950s, for example, John Money established guidelines which were based on the precept that gender-related behaviour may be learned socially (Meyer-Bahlburg, 1998). In this context, sex assignment as male or female was considered to be sufficient provided that the individual was raised wholly in the appropriate social role. Practices, of course, have evolved given what we know about biological influences. In fact, what has in recent years been considered the best policy for assignment in cases of girls with CAH or CAIS, has come under debate (Houk & Lee, 2010; Kulshreshtha et al., 2009). Where almost all genotypic females with CAH have been assigned as girls, some suggest that girls exposed to the highest levels of testosterone be assigned to the male social role because of presumed effects of the hormones on brain development (Houk & Lee, 2010). Likewise, the decision to raise all individuals with CAIS in the female social role has also been called into question in the light of several recent reports of gender change in adolescence or early adulthood (e.g. Kulshreshtha et al., 2009). In the latter case, the argument suggests that social influences have not been adequately taken into account.

In any case, current practice is shifting away from cementing social gender assignment with cosmetic surgical correction. While there is general agreement that a social role should be assigned as soon as possible after birth (Hughes et al., 2006), the opportunity for self-assignment/reassignment in childhood or later should be preserved. Early cosmetic genital surgery makes later surgical reassignment substantially more difficult. Outcome data suggesting that such an approach is either beneficial or detrimental do not yet exist given the recency and scarcity of cases. However, research does suggest that ambiguity of the genitalia is not as distressing to parents as was thought (Crissman et al., 2011). This is encouraging in terms of determining best practice policy that satisfies parents, initially, and patients in the long term.

Gaps and trends in psychological research

To conclude, we draw, from the research we have reviewed, some key points that indicate what is still lacking and what directions psychologists may take in future investigations.

Dedicated reviews and outcome studies

Recent publications suggest a growth in psychologically oriented reviews and outcome studies that assess a wider range of psychosocial and psychosexual outcomes, and that report in detail on diagnosis-specific outcomes. This is a welcome development. With this development, comes a fuller awareness of the need to assess outcomes (i) both qualitatively and quantitatively, (ii) at various developmental time points and (iii) from the perspectives of various parties (including children, adolescents, affected adults and parents). In addition, this area of research is highlighting the importance of (iv) more strenuously investigating the relationship between psychological understandings, medical interventions and psychosocial outcomes, rather than relying on popular understandings about gender

norms and psychological well-being. Researchers contributing to this area of work indicate future research directions, suggesting it would be worthwhile investigating ‘the explicit and implicit gender models not only of intersexual persons but also of clinical professionals working with them’ (Schweizer et al., 2009, p. 198). They also suggest that there would be value in understanding the effects of hormonal and surgical intervention on sexual experience: researching the quality of intimate relationships, researching partner-independent sexual activities (Schönbucher et al., 2010) and researching the predictors of persisting gender dysphoria (Cohen-Kettenis, 2010). In addition to outcome studies and reviews, there is important development taking place in relation understanding how children and parents *experience* diagnosis and treatment. In this respect it is argued that qualitative psychological studies can do more to draw out the clinical implications of such experience, and build fuller understandings of parental distress and coping (Duguid et al., 2007) and how psychological input may ease the processes of diagnosis, treatment and parenting.

Development of instruments and resources

There are many practical measures and resources that could ideally be developed to ensure that psychological services, and MDT working in general, are appropriate, supportive and user-friendly from the points of view of affected children, young people and their parents. Such resources would aid assessment and intervention with children and adolescents, facilitate support and information-giving to them and their parents, as well as informing the training of health professionals. Some of this development of instruments and resources is underway. Specific examples of what is needed include screening tools to help identify parents who may have more substantial coping issues and may require particular psychological support (Cohen-Kettenis, 2010; Hughes, Nihoul-Fékété, Thomas, & Cohen-Kettenis, 2007). Instruments are needed to enable psychologists to better study quality of life in ways that are relevant for people living with intersex/DSD (Sandberg et al., 2011). There could ideally be development of: understanding about the specific needs of adolescent and adult clients (Liao, Tacconelli, Wood, Conway, & Creighton, 2010); and intersex/DSD-specific learning materials to help parents cope (Cohen-Kettenis, 2010). In addition, there are calls for better understanding of what is taught to health professionals about DSD and how this can be improved to meet the concerns raised by parents and intersex people (Leidolf, Curran, Bradford, & Scout, 2008), as well as meeting the support and information needs of GPs.

Dialogue between neuropsychology and psychosocial approaches

The present article has been co-authored on the basis that that one of us (VP) has particular knowledge about neuropsychological and clinical approaches, while the other (KR) has worked primarily from critical, queer and feminist psychological approaches. The research we have reviewed reflects an ongoing tendency for neuropsychological approaches and psychosocial approaches to fail to establish productive dialogue. This is no surprise and has been addressed in detail elsewhere, for example, by Cromby, who observed: ‘It seems fair to say that between neuroscience and social science there has been something of a history of mutual distrust, a reluctance within each discipline to engage constructively with the others’ theories and research, and a lack of comprehension of each others’ assumptions, methods, goals and findings’ (Cromby, 2007, p. 149). It is interesting to see recent research seeking to engage between psychosocial concerns and neuropsychological research (Jordan-Young, 2010; Stout, Litvak, Robbins, & Sandberg, 2010). The challenge

remains for psychosocial research to incorporate new understandings from hormonal and genetic research as they come to light, and for neuropsychological studies to more fully take into account diverse and psychosocial factors that may impact on gender identity, and the very conceptualisation of gender and gendered well-being.

Note

1. We use the double term ‘intersex/DSD’ in acknowledgement of the unresolved divide between the perspectives: (i) Disorder of Sex Development, as agreed by consensus in 2005 and (ii) ‘intersex’ or ‘Diverse Sex Development’.

Notes on contributors

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References

- Alderson, J., Madill, A., & Balen, A. (2004). Fear of devaluation: Understanding the experience of intersexed women with androgen insensitivity syndrome. *British Journal of Health Psychology*, *9*, 81–100.
- Bean, E. J., Mazur, T., & Robinson, A. D. (2009). Mayer–Rokitansky–Kuster–Hauser syndrome: Sexuality, psychological effects, and quality of life. *Journal of Pediatric and Adolescent Gynecology*, *22*(6), 339–346. doi:10.1016/j.jpjag.2008.11.006
- Boyle, M. E., Smith, S., & Liao, L. M. (2005). Adult genital surgery for intersex: A solution to what problem? *Journal of Health Psychology*, *10*(4), 573–584.
- Chadwick, P. M., Liao, L., & Boyle, M. E. (2005). Size matters: Experiences of atypical genital and sexual development in males. *Journal of Health Psychology*, *10*, 529–543.
- Cohen-Kettenis, P. T. (2010). Psychosocial and psychosexual aspects of disorders of sex development. *Best Practice & Research Clinical Endocrinology & Metabolism*, *24*(2), 325–334.
- Creighton, S. M. (2011). *Timing issues in DSD management: Diagnostic, surgical and psychosocial considerations*. Paper presented at the IV World Congress on Hypospadias and Disorders of Sex Development, London, UK.
- Crissman, H. P., Warner, L., Gardner, M., Carr, M., Schast, A., Quittner, A. L., . . . Sandberg, D. E. (2011). Children with disorders of sex development: A qualitative study of early parental experience. *International Journal of Pediatric Endocrinology*, *2011*(1), 10. doi:10.1186/1687-9856-2011-10
- Cromby, J. (2007). Integrating social science with neuroscience: Potentials and problems. *BioSocieties*, *2*(2), 149–169. doi:10.1017/s1745855207005224
- Crouch, N. S., Liao, L. M., Woodhouse, C. R. J., Conway, G. S., & Creighton, S. M. (2008). Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia. *The Journal of Urology*, *179*(2), 634–638. doi:10.1016/j.juro.2007.09.079
- Dodds, P. R., Batter, S. J., Shield, D. E., Serels, S. R., Gavafalo, F. A., & Maloney, P. K. (2008). Adaptation of adults to uncorrected hypospadias. *Urology*, *71*(4), 682–685. doi:10.1016/j.jurology.2007.07.078
- Duguid, A., Morrison, S., Robertson, A., Chalmers, J., Youngson, G., & Ahmed, S. F. (2007). The psychological impact of genital anomalies on the parents of affected children. *Acta Paediatrica*, *96*(3), 348–352.
- Feist, G. J., & Gorman, M. E. (1998). The psychology of science: Review and integration of a nascent discipline. *Review of General Psychology*, *2*(1), 3–47.

- Hacking, I. (2002). Inaugural lecture: Chair of philosophy and history of scientific concepts at the College de France, 16 January 2001. *Economy and Society*, 31(1), 1–14. doi:10.1080/03085140120109222
- Hines, M. (2011a). Gender development and the human brain. *Annual Review of Neuroscience*, 34, 69–88.
- Hines, M. (2011b). Prenatal endocrine influences on sexual orientation and on sexually differentiated childhood behaviour. *Frontiers in Neuroendocrinology*, 32, 170–182.
- Houk, C. P., & Lee, P. A. (2010). Approach to assigning gender in 46,XX congenital adrenal hyperplasia with male external genitalia: Replacing dogmatism with pragmatism. *Journal of Clinical Endocrinology & Metabolism*, 95(10), 4501–4508. doi:10.1210/jc.2010-0714
- Hughes, I. A., Davies, J., Bunch, T., Pasterski, V., Mastroyannopoulou, K., & MacDougall, J. (2012). Androgen insensitivity syndrome. *Lancet*, 380, 1419–1428. doi:10.1016/S0140-6736(12)60071-3
- Hughes, I. A., Houk, C., Ahmed, S. F., & Lee, P. A. (2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*, 91(7), 554–563.
- Hughes, I. A., Nihoul-Fékété, C., Thomas, B., & Cohen-Kettenis, P. T. (2007). Consequences of the ESPE/LWPES guidelines for diagnosis and treatment of disorders of sex development. *Best Practice & Research Clinical Endocrinology & Metabolism*, 21(3), 351–365. doi:10.1016/j.beem.2007.06.003
- Jones, B. C., O'Brien, M., Chase, J., Southwell, B. R., & Hutson, J. M. (2009). Early hypospadias surgery may lead to a better long-term psychosexual outcome. *Journal of Urology*, 182(4), 1744–1749.
- Jordan-Young, R. M. (2010). *Brain storm: The flaws in the science of sex differences*. Cambridge, MA: Harvard University Press.
- Kazak, A. (2006). Pediatric psychosocial preventative health model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Family Systems Health*, 24(4), 391–395.
- Kazak, A. E., Rourke, M. T., Alderfer, M. A., Pai, A., Reilly, A. F., & Meadows, A. T. (2007). Evidence-based assessment, intervention and psychosocial care in pediatric oncology: A blueprint for comprehensive services across treatment. *Journal of Pediatric Psychology*, 32(9), 1099.
- Kruglanski, A. W. (1994). The social-cognitive bases of scientific knowledge. In W. R. Shadish & S. Fuller (Eds.), *The social psychology of science* (pp. 197–213). New York, NY: Guilford.
- Kulshreshtha, B., Philibert, P., Eunice, M., Khandelwal, S. K., Mehta, M., Audran, F., . . . Ammini, A. C. (2009). Apparent male gender identity in a patient with complete androgen insensitivity syndrome. *Archives of Sexual Behavior*, 38(6), 873–875.
- Lee, P. A., & Houk, C. P. (2010). Review of outcome information in 46,XX patients with congenital adrenal hyperplasia assigned/reared male: What does it say about gender assignment? *International Journal of Pediatric Endocrinology*, 2010: 982025. doi:10.1155/2010/982025
- Leidolf, E. M., Curran, M., Bradford, J., & Scout; Intersex Society of North America, The Fenway Institute. (2008). Intersex mental health and social support options in pediatric endocrinology training programs. *Journal of Homosexuality*, 54(3), 8.
- Liao, L. M. (2007). Towards a clinical-psychological approach to address the heterosexual concerns of intersexed women. In V. Clarke & E. Peel (Eds.), *Out in psychology: Lesbian, gay, bisexual, trans and queer perspectives* (pp. 391–408). Chichester: Wiley.
- Liao, L. M., & Creighton, S. M. (2007). Requests for cosmetic genitoplasty: How should healthcare providers respond? *British Medical Journal*, 334(7603), 1090–1092.
- Liao, L. M., Green, H., Creighton, S. M., Crouch, N. S., & Conway, G. S. (2010). Service users' experiences of obtaining and giving information about disorders of sex development. *British Journal of Gynaecology*, 117, 193–199. doi:10.1111/j.1471-0528.2009.02385.x
- Liao, L. M., Tacconelli, E., Wood, D., Conway, G., & Creighton, S. M. (2010). Adolescent girls with disorders of sex development: A needs analysis of transitional care. *Journal of Pediatric Urology*, 6(6), 609–613.
- Meyer-Bahlburg, H. F. L. (1998). Gender assignment in intersexuality. *Journal of Psychology and Human Sexuality*, 10(2), 1–21.
- Meyer-Bahlburg, H. F. L., Dolezal, C., Baker, S. W., Carlson, A. D., Obeid, J. S., & New, M. I. (2004). Prenatal androgenization affects gender-related behavior but not gender identity in 5–12-year-old girls with congenital adrenal hyperplasia. *Archives of Sexual Behavior*, 33(2), 97–104.

- Miyata, H., Takahashi, M., Saito, T., Tachimori, H., & Kai, I. (2004). Disclosure preferences regarding cancer diagnosis and prognosis: To tell or not to tell? *Journal of Medical Ethics*, *31*, 447–451.
- Mobeireek, A. F., Al-Kassimi, F., Al-Zahrani, K., Al-Shimemeri, A., Al-Damegh, S., Al-Amoudi, O., . . . Gamal-Eldin, M. (2008). Information disclosure and decision-making: The Middle East versus the Far East and the West. *Journal of Medical Ethics*, *34*(4), 225–229.
- Mundy, T. (2011, 17–19 September). *Hypospadias: Long term success?* Paper presented at the IV World Congress on Hypospadias and Disorders of Sex Development, London, UK.
- Nordenström, A., Servin, A., Bohlin, G., Larsson, A., & Wedell, A. (2002). Sex-typed toy play behavior correlates with the degree of prenatal androgen exposure assessed by CYP21 genotype in girls with congenital adrenal hyperplasia. *Journal of Clinical Endocrinology and Metabolism*, *87*(11), 5119.
- Pasterski, V., Golombok, S., & Hines, M. (2011). Sex differences in social behavior. In P. K. Smith & C. H. Hart (Eds.), *Wiley-Blackwell handbook of childhood social development* (2nd ed., pp. 281–298). West Sussex: Wiley-Blackwell.
- Pasterski, V., Mastroyannopoulou, K., Wright, D., & Hughes, I. A. (in press). Predictors of posttraumatic stress in parents of children diagnosed with disorders of sex development (DSD). *Archives of Sexual Behavior*.
- Pasterski, V., Prentice, P., & Hughes, I. A. (2010a). Consequences of the Chicago consensus on disorders of sex development (DSD): Current practices in Europe. *Archives of Disease in Childhood*, *95*(8), 618–623.
- Pasterski, V., Prentice, P., & Hughes, I. A. (2010b). Impact of the consensus statement and the new DSD classification system. *Best Practices & Research Clinical Endocrinology & Metabolism*, *24*, 187–195.
- Pasterski, V. L., Geffner, M. E., Brain, C., Hindmarsh, P., Brook, C., & Hines, M. (2005). Prenatal hormones and postnatal socialization by parents as determinants of male-typical toy play in girls with congenital adrenal hyperplasia. *Child Development*, *76*(1), 264–278.
- Pfistermuller, K. L. M., O'Flynn, E. A. M., & Cuckow, P. M. (2011). *Hypospadias: Are our outcomes improving? A systematic review of 30 years of published data*. Paper presented at the IV World Congress on Hypospadias and Disorders of Sex Development, London, UK.
- Poomthavorn, P., Stargatt, R., & Zacharin, M. (2009). Psychosexual and Psychosocial Functions of Anorchid Young Adults. *Journal of Clinical Endocrinology & Metabolism*, *94*(7), 2502–2505. doi:10.1210/jc.2008-1886
- Prochow, C., Schweizer, K., & Richter-Appelt, H. (2010). Body experience in individuals with different intersex conditions | Körpererleben von Menschen mit Verschiedenen Formen der Intersexualität. *Tagliche Praxis*, *51*(4), 809–820.
- Reich, A., von Hagen, C., & Schwarz, H. P. (2011). Coping and psychosocial adaptation of children: A comparison of three chronic illnesses. *Monatsschrift Kinderheilkunde*, *159*(3), 248–+.
- Roen, K. (2008). 'But We Have to Do Something': Surgical 'correction' of atypical genitalia. *Body & Society*, *14*(1), 47–66.
- Roen, K. (2009). Clinical intervention and embodied subjectivity: Atypically sexed children and their parents. In M. Holmes (Ed.), *Critical intersex* (pp. 15–40). Farnham, Surrey: Ashgate.
- Sandberg, D. E., Gardner, M. D., Kogan, B. A., Grimley, M. B., Cohen, L., Alpern, A. N., & Quittner, A. L. (2011). Assessing health-related quality of life in disorders of sex development: Phase I – Item generation. In M. I. New & J. L. Simpson (Eds.), *Hormonal and genetic basis of sexual differentiation* (pp. 143–146). New York, NY: Springer.
- Sanders, C., Carter, B., & Goodacre, L. (2008). Parents' narratives about their experiences of their child's reconstructive genital surgeries for ambiguous genitalia. *Journal of Clinical Nursing*, *17*(23), 3187–3195.
- Sanders, C., Carter, B., & Goodacre, L. (2011). Searching for harmony: Parents' narratives about their child's genital ambiguity and reconstructive genital surgeries in childhood. *Journal of Advanced Nursing*, *67*(10), 2220–2230. doi:10.1111/j.1365-2648.2011.05617.x
- Schönbucher, V., Schweizer, K., & Richter-Appelt, H. (2010). Sexual quality of life of individuals with disorders of sex development and a 46,XY karyotype: A review of international research. *Journal of Sexual Medicine*, *36*(3), 193–215. doi:10.1080/00926231003719574
- Schönbucher, V. B., Landolt, M. A., Gobet, R., & Weber, D. M. (2008a). Health-related quality of life and psychological adjustment of children and adolescents with hypospadias. *Journal of Pediatrics*, *152*(6), 865–872. doi:10.1016/j.jpeds.2007.11.036

- Schönbucher, V. B., Landolt, M. A., Gobet, R., & Weber, D. M. (2008b). Psychosexual development of children and adolescents with hypospadias. *Journal of Sexual Medicine*, 5(6), 1365–1373.
- Schönbucher, V. B., Weber, D. M., & Landolt, M. A. (2008). Psychosocial adjustment, health-related quality of life, and psychosexual development of boys with hypospadias: A systematic review. *Journal of Pediatric Psychology*, 33(5), 520–535. doi:10.1093/jpepsy/jsm098
- Schutzmann, K., Brinkman, L., Schacht, M., & Richter-Appelt, H. (2009). Psychological distress, self-harming behavior, and suicidal tendencies in adults with disorders of sex development. *Archives of Sexual Behaviour*, 38(1), 16–33.
- Schweizer, K., Brunner, F., Schutzmann, K., Schönbucher, V., & Richter-Appelt, H. (2009). Gender identity and coping in female 46, XY adults with androgen biosynthesis deficiency (intersexuality/DSD). *Journal of Counseling Psychology*, 56(1), 189–201.
- Slijper, F. M. E., Frets, P. G., Boehmer, A. L. M., Drop, S. L. S., & Niermeijer, M. F. (2000). Androgen insensitivity syndrome (AIS): Emotional reactions of parents and adult patients to the clinical diagnosis of AIS and its confirmation by androgen receptor gene mutation analysis. *Hormone Research*, 53(1), 9–15.
- Speiser, P. W., Azziz, R., Baskin, L. S., Ghizzoni, L., Hensle, T. W., Merke, D. P., . . . White, P. C. (2010). Congenital adrenal hyperplasia due to steroid 21-hydroxylase deficiency: An endocrine society clinical practice guideline. *Journal of Clinical Endocrinology & Metabolism*, 95(9), 4133–4160.
- Starke, M., & Moller, A. (2002). Parents' needs for knowledge concerning the medical diagnosis of their children. *Journal of Child Health Care*, 6, 245–257.
- Stout, S. A., Litvak, M., Robbins, N. M., & Sandberg, D. E. (2010). Congenital adrenal hyperplasia: Classification of studies employing psychological endpoints. *International Journal of Pediatric Endocrinology*, 2010, 191520. doi:10.1155/2010/191520
- Sutton, E. J., Young, J., McInerney-Leo, A., Bondy, C. A., Gollust, S. E., & Biesecker, B. B. (2006). Truth-telling and Turner syndrome: The importance of diagnostic disclosure. *Journal of Pediatrics*, 148(1), 102–107.
- Telles-Silveira, M., Tonetto-Fernandes, V. F., Schiller, P., & Kater, C. E. (2009). Congenital adrenal hyperplasia: A qualitative study on disease and treatment, doubts, anguishes and relationships (part I). *Arquivos Brasileiros De Endocrinologia E Metabologia*, 53(9), 1112–1124.
- Udry, R. (2000). Biological limits of gender construction. *American Sociological Review*, 65(3), 433–457.
- Weber, D. M., Schönbucher, V. B., Gobet, R., Gerber, A., & Landolt, M. A. (2009). Is there an ideal age for hypospadias repair? A pilot study. *Journal of Pediatric Urology*, 5(5), 345–350.
- Weber, D. M., Schönbucher, V. B., Landolt, M. A., & Gobet, R. (2008). The pediatric penile perception score: An instrument for patient self-assessment and surgeon evaluation after hypospadias repair. *Journal of Urology*, 180(3), 1080–1084.
- Yunger, J. L., Carver, P. R., & Perry, D. G. (2004). Does gender identity influence children's psychological well-being? *Developmental Psychology*, 40, 572–582.