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A values-driven and evidence-based health care psychology for diverse sex development

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The integration of psychology into multidisciplinary care for people affected by 'disorders of sex development' is acknowledged in most recent care standard documents. However, psychological evidence that can inform service development is currently insubstantial for specific reasons, some of which are outlined in this article. We argue for psychological activities and their prioritisation to be equally driven by the professional values embedded in clinical psychology and to seek user input in key activities. These values include critical engagement with research literature, theoretically informed question and problem formulation, development of interventions to boost health and well-being, honouring of personal agency, equality and diversity, team development facilitation, psychological education and training for non-psychologists, audit and research that can benefit patients and contribution to social change. We outline target areas that reflect these values and, where possible, draw on empirical evidence developed in diverse sex development (DSD) and other clinical contexts to support our recommendations.

Keywords: DSD; intersex; psychology; quality of life; values-based medicine

Background

Professional psychological input into the health care provision for people with 'intersex' conditions and later 'disorders of sex development' has been proposed since the mid-1990s. However, service delivery – its theoretical frameworks, service priorities and methods have never been coherently articulated (Liao, 2007). As a discipline, psychology has, for half a century, been profoundly implicated in the lives of people born with genetic conditions that are associated with atypical sex development. Until relatively recently, however, workers have mainly been academic researchers working within a 'brain gender' paradigm (see Jordan-Young, 2011). As a result of this narrow perspective, there has been no methodical analysis of the nature and extent of psychological needs to inform service design and evaluation. Furthermore, because psychological interventions would invariably be influenced by an ideology of self-acceptance, it is not immediately obvious how this might fit with the centrality of 'corrective' medical interventions (Liao & Boyle, 2004) and, increasingly, the race to discover molecular 'pathology' that causes the 'aberrations'.

The early to mid-1990s saw the emergence of intersex patient advocacy/support groups, e.g. UK-based Androgen Insensitivity Syndrome Support Group (AISSG,

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<http://www.aissg.uk>) and US-based Intersex Society of North America (ISNA, <http://www.isna.org>). These groups campaigned for a number of changes to clinical management, including access to tailored, professional psychological support. In the United Kingdom, from about the mid-1990s, there was a mutual endeavour by the AISSG and specialists at the then Middlesex Hospital in London to pioneer a multidisciplinary service for women with XY conditions. The fledgling network to which we both belonged subsequently developed into the ‘Middlesex Clinic’ for ‘disorders of sex development’ at University College London Hospitals. The provider/user conference in 2002 reflected this new form of collaboration (Creighton, Minto, Liao, Alderson, & Simmonds, 2004).

Since then, formal acknowledgment of the need for psychological services can be identified in almost all key clinical documents relating to ‘disorders of sex development’. The ‘Chicago consensus statement’ (Hughes, Houk, Ahmed, Lee, & LWPES/ESPE Consensus Group 2006) had this to say about psychological care:

Psychosocial care provided by mental health staff with expertise in DSD should be an integral part of management to promote positive adaptation. This expertise can facilitate team decisions about gender assignment/reassignment, timing of surgery, and sex-hormone replacement. (p. 4)

Subsequently, a widely endorsed UK care standard document (Ahmed et al., 2011) proposed that:

Early psychological input, provided by a specialist clinical psychologist with experience of supporting people with DSD and their parents, will allow the latter to examine and understand their early emotional reactions as well as explore present and future worries, adjust to the period of uncertainty during the diagnosis process and facilitate inclusion in informed decision making about themselves or their child. [...] In addition, all adolescents with a newly diagnosed DSD or existing DSD requiring medical or surgical attention should be routinely offered clinical psychology input in addition to any support offered to their parents or wider family. (pp. 13–14)

It is up to each service to operationalise these broad suggestions. Thus the range, depth and quality of psychological work can be expected to be highly variable between services. What can be said about all services is that they are directed and staffed mainly by medical doctors, who are unfamiliar with psychological knowledge, methods and professional governance. Psychologists in this highly specialised context can expect to find themselves having to manage expectations and assumptions that are at odds with their personal, professional and epistemic values. Aptly expressed by Roen (2008), ‘psychology’ could to medical doctors be a ‘catch-all concept’ that embraces anything after doctors have done their work (p. 60). She drew attention to the danger of being complicit in framing patient dissent as ‘psychological’ rather than understanding it as a valid expression for care providers to take on board.

In ‘disorders of sex development’, as in other medical specialties, the risk for psychological services of being an emotional repository without any capacity to influence the overall service ethos is relatively high. The aim of this paper is to dissuade health care psychologists from the Band-Aid approach of fixing individual distress. Psychological therapy could be a valid professional priority in the field (see for example British Psychological Society, 2012). However, the broader skill base of psychologists should also be strategically deployed to intervene in health care transactions that cause undue distress in service users. We challenge psychologists to take seriously the duties and responsibilities enshrined

in their job descriptions to develop a multi-layered presence that penetrates medical practice in order to improve user experience and outcome, and we signpost areas that require their strategic attention.

What we refer to as diverse sex development (DSD) in this article overlaps largely with but is not restricted to conditions subsumed under ‘disorders of sex development’ in the Chicago nomenclature. We make this choice partly in recognition of the fact that many affected individuals consider their bodies to be different rather than disordered, and partly because the principles underlying our suggestions are relevant to a broader range of clinical scenarios, such as early or late puberty, breast development in men, mastectomy in women and infertility in both. Molecular science divides and classifies *bodies* along genetic lines, but *people* for whom normative sex embodiment is challenged, share dilemmas that are located in the overall temporal, cultural and geographical frame.

Values-driven psychological practices

Evidence-based practice is a central consideration for all clinical disciplines. Two observations are noteworthy in relation to this issue in DSD. First of all, clinical decisions are not always governed by the best evidence available (see Creighton, Michala, Mushtaq, & Yaron, *in press*). Second, reliable evidence is currently unavailable to guide important aspects of professional practice. Nevertheless, and rightly too, clinical decisions are made everyday, influenced to a greater or lesser extent by prevailing social values that are seldom made explicit and therefore do not lend themselves to scrutiny. We argue that psychological care should, first of all draw, on evidence-based service developments in other areas of medicine and second, be based also on explicit professional values.

Values-based medicine is an emerging formulation for working with complex and conflicting values in medical research and practice. Disciplinary resources for the formulation include clinical ethics, decision theory, health economics, the social sciences and the medical humanities. Although the roots can be traced back to linguistic analytical philosophy of the ‘Oxford school’ in the middle decades of the twentieth century, there is an emphasis on learnable, translational clinical skills that can tangibly inform and improve health care (Fulford, 2004; Woodbridge & Fulford, 2004). From 1989, Fulford and colleagues developed the principles by attending to the meanings of terms such as ‘illness’, ‘disease’, ‘disability’, ‘function’ and ‘dysfunction’.

Increased interests in values-based medicine reflect the dilemmas presented by the increasingly wide range of value-laden elective investigation and treatment options brought about by developments in science, technology and commerce (e.g. pre-implantation genetic diagnosis). The elaborations of ethical and clinical governance and quality assurance processes in health care provision are influenced by these rumblings. User involvement is embedded in the formulation of these interventions that aim to increase transparency for external scrutiny. The notion of skilful teamwork amongst clinicians and the consequent interdependence in medical decision-making based on the differential and diverse values of different professional groups is another strand of development.

These ideas are particularly pertinent for DSD services. Although the 2006 consensus statement adopts the term ‘multidisciplinary’, it describes a style of collaboration that is more accurately labelled ‘interdisciplinary’. A multidisciplinary team utilises the skills and experience of individuals from different disciplines, with each discipline approaching the patient from its own perspective. Interdisciplinary teamwork synthesises distinct contributions from different approaches into a single consultation model without confusing professional boundaries (see also Pless, 1995). Fully integrated interdisciplinary

care is envisaged in the consensus document, but most DSD teams may be limited to multidisciplinary in function and values at present.

In the United Kingdom, the professional values embedded in clinical psychology include critical engagement with relevant literature; theoretically informed problem formulation; interventions to effectively reduce distress, boost well-being, promote personal agency and honour diversity and equality; facilitation of team development; psychological training and support for non-psychologists; and audit and research for service improvement. We discuss a broad range of values-driven psychological activities to assist children, parents and adults affected by DSD.

Championing emotional safety, dignity and respect for families

Clinicians have remarked on the shock, grief, anger, shame and guilt observed in parents' reactions to the birth of an intersexed child (Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000). Paediatric psychological research across disease contexts has identified high levels of parental stress to be an important determinant in unhelpful coping strategies such as distancing, escape and avoidance (Mednick, Gargollo, Oliva, Grant, & Borer, 2009), and fathers are thought to be more likely to distance themselves than mothers (Azar & Solomon, 2001). Parental stress is reduced by being adequately informed about the child's condition and any interventions, and by opportunities to speak to other parents who have lived through similar experiences (Hartman, Radin, & McConnell, 1992). High maternal health, high maternal support, low maternal worry and child-perceived control are associated with positive psychological adjustment in the diagnosed child (Immelt, 2006). It is obvious that parents affected by DSD first and foremost require sustained psychological support, but this does not seem to be the central focus in paediatric management.

Social science research in DSD suggests that interactions between doctors and parents are at risk of preventing the latter from carrying out their duty of care towards their children, that 'parents are not given the chance to imagine their children's lives in any way except in need of immediate correction' (Feder, 2002, p. 313). Doctors may well believe that parents have all along been equal partners in decision-making regarding gender assignment and elective genital surgery, but detailed studies with medical experts have failed to identify clear examples of parental participation (Kessler, 1990, 1998). The ethical integrity of medically non-essential genital surgery on infants is significantly challenged by a combination of factors: the emotional vulnerability in parents, the lack of well-developed collaborative processes and the evidence of poor adult outcomes of surgery (see Tamar-Mattis, Baratz, Baratz Dalke, & Karkazis, *in press*).

Genital surgery also places children at risk of potential negative psychological effects of repeat intimate examinations, because surgeons are compelled to monitor and evidence the results. Paediatricians in DSD have alluded to 'the repeated psychological insult caused by frequent genital examinations and operations' (Jaaslekainen, Tiitinen, & Voutilainen, 2001, p. 73). Some clinicians have further warned of the potential harm of medical photography (Creighton, Alderson, Brown, & Minto, 2002). Although there has been no attempt to evaluate the negative impact, few would disagree that much of the medical photography relating to DSD were anything other than humiliating for patients in the medical gaze. Interviews with adults have identified medical sexing and related scenarios as 'degrading and shaming' (Preves, 1998). Psychological therapists have drawn attention to the incapacity in some adults to express their overwhelming distress that previous paediatric encounters have given rise to (Williams, 2002). Genital surgery for ambiguous genitalia

is intended to normalise children. Ironically, the attendant scrutiny that follows surgery is anything but normalising.

Interestingly, the 2006 Chicago consensus statement notes that psychological harm could follow from repeated genital examinations, medical photography and ‘medical interventions’ without specifically naming repeat surgery as potentially psychologically damaging (Hughes et al., 2006). This serious if cryptic reference to surgery by the group of experts should have led to a more conservative approach. The absence of such indications (Creighton et al., *in press*) raises interesting issues. The debate has received considerable attention elsewhere. Suffice it to say here that the ethics of childhood genital surgery are often justified by suppositions of psychological benefits, and that its proponents continue to fail to understand that ‘a patient may suffer psychologically precisely because clinicians and parents do not give due consideration to the ethics of treatment’ (Morland, 2011, p. 155).

In recognition of the implications that medical practitioners’ behaviours have on their patients’ well-being, team development and communication skills training are increasingly emphasised by DSD service users, advocates and clinical psychologists (D’Alberton, 2010; Karkazis, Tamar-Mattis, & Kon, 2010; Liao, Green, Creighton, Crouch, & Conway, 2010). In the field of cancer, collective commitment to improve clinical interaction gained so much momentum in the past twenty years (Fallowfield, 1992; Fallowfield et al., 2002; Farber et al., 2002; Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999) that training is now firmly rooted in service ethos (see: Connected, <http://www.connected.nhs.uk>). Based on the same values and principles, and drawing on this evidence, we have elsewhere offered initial suggestions for managing difficult communications and interactions in ways that can maximise psychological safety and minimise psychological harm in DSD (Liao & Simmonds, 2013). Routine data collection on user experiences is now recognised as the key marker of care quality (Chisholm & Askham, 2006) and can inform service improvement strategies.

In other areas of paediatrics (e.g. cleft lip and palate, cystic fibrosis and bone marrow or organ transplantation), psychological assessment is often carried out as part of an agreed protocol to identify children and families who are at an increased risk of developing psychological difficulties (Jacobs, Titman, & Edwards, 2012) and to agree on a follow-up plan to meet the needs of ‘ordinary families facing extraordinary stressors’ (Kazak, 1997), taking into account siblings whose developmental needs could be compromised (Barlow & Ellard, 2006). The idea of individualised needs assessment was mentioned in the consensus statement, but paediatric psychologists have not yet been able to access the resources required for developing sensitive and acceptable methods for monitoring psychological well-being across time.

Engaging parents in dilemmatic conversations

Whatever treatment decisions parents might make on behalf of their child, a central psychological task in subsequent years involves communication with the child about his or her body differences in stages (Carmichael & Ransley, 2002; Goodall, 1991). Adults who have grown up with DSD suggest that parents need to ‘come to terms’ with the diagnoses in order to help their children to do likewise (Simmonds, 2004). ‘Coming to terms’ may require sustained support for coping with losses and fears and for examining taken-for-granted beliefs about ‘normal sexuality’ and ‘normal life’ (Liao, 2003). Crissman et al. (2011) interviewed 41 parents of children with mixed DSD diagnoses and identified a

‘discordance between scientific and parental understandings of the determinants of “sex” and “gender”’. Continued exploration of these complex topics, if uncomfortable and uncertain, may require high level consultation skills and a robust therapeutic alliance. Elsewhere, we offer preliminary suggestions on communicating with clients in ways that are more likely to generate enabling narratives (Liao & Simmonds, 2013).

Parents who decide to defer genital surgery are currently in the minority and likely to require consistent professional and user group support. There are increasing numbers of XY children with ambiguous genitalia being assigned male, and a recent report suggests that male gender assignment is a viable option for XX individuals with congenital adrenal hyperplasia (CAH; Lee & Houk, 2010). Consistent long-term therapeutic follow-ups for these families fulfil a clinical need and offer opportunities for participatory action research (PAR) to improve our knowledge of experiences of families who resist the standard approach of female gender assignment and feminising surgery.

In counselling families about sharing information concerning their child’s DSD diagnosis with the wider community, Cohen-Kettenis (2010, p. 328) rightly posed the question ‘Is living a “normal” life with a secret more harmful than living a life without secrets but with a reasonable chance for stigma or shame?’ However, secrecy may also carry a reasonable chance for stigma and shame. Like the parents they support, paediatric psychologists tread on a tight rope – between empathic understanding of realistic fears and therapeutic paralysis in the face of catastrophic predictions. DSD is not the only challenging and risky topic to discuss. The consensus statement of 2006 acknowledged parallel communication challenges for parents whose children are adopted or conceived via gamete donation or surrogacy. Parents of children who are HIV-positive also share elements of the dilemma.

Parents would be in a stronger position to review their communication strategies around DSD within the family and the wider community when they have been adequately resourced to develop the skills, tools and confidence that they need. The imbalance in resource allocation between surgery and psychology could mean that the latter continually falls short of what is needed to promote well-being and adaptation in families. Poor adaptation is then presented as argument for surgery. The surgical prophecy can be self-fulfilling.

Estimating adult psychological needs

DSD is associated with myriad complex diagnoses. The day-to-day physical treatment demands can vary from nothing (as for some women diagnosed with Meyer–Rokitansky–Küster–Hauser (MRKH) syndrome) to multiple life-saving operations and self-managed catheterisation and stoma (as for men and women born with anorectal malformations). The emotional and social impact is therefore highly variable. On the whole, long-term physical health conditions are associated with higher levels of psychological problems compared to the general population (National Institute for Health and Care Excellence [NICE], 2009). These difficulties are known to detrimentally affect the capacity to self-manage health maintenance and lifestyle changes, leading to poorer health outcome and higher usage of health care services (IAPT, 2008).

In determining psychological service remit, pathways, interventions and goals for adults with DSD diagnoses, psychologists and commissioners may be forgiven for being confused by the adult literature. The number of studies that gathered psychological data of sort may be numerous, but the majority are difficult to interpret. Psychosocial research focusing on affected men is conspicuous by absence.

A confusing and conflicting literature

In terms of psychological distress, a study on women with CAH reported no significant difference between the CAH and the control groups other than a higher prevalence of negative body image and attitudes to sexuality in the former (Kuhnle & Bullinger, 1997). CAH is a challenging metabolic disease. Such findings fly in the face of what we know about the mental health effects of long-term conditions (NICE, 2009). Another study likewise concluded that women with CAH experienced few problems, even though only 4 out of the 18 participants in the 18 to 36 age range were currently sexually active, and 2 out of the 4 reported a total absence of sexual enjoyment (Morgan, Murphy, Lacey, & Conway, 2005). The research question and measures were poorly formulated and, in their overall conclusion, the authors mistook an absence of psychiatric diagnoses for an absence of psychosocial and psychosexual challenges.

Wisniewski and co-workers (2000) reported 'generally satisfactory medical, surgical and psychosocial outcomes' based on a single measurement with a small group of mixed-age XY women. On examination, 80% of the sample had received professional psychological help. Potentially important independent psychosocial variables that could influence results are often left out, in this case engagement with psychological services.

A Danish hospital study involving 70 adult women with mixed DSD diagnoses via structured interview and questionnaire reported a significantly higher degree of mental distress, a higher frequency of suicidal thoughts and a higher frequency of psychological/psychiatric counselling (Johannsen, Ripa, Mortensen, & Main, 2006). Likewise, a Swedish study identified poorer quality of life in a sample of women with CAH (Nordensköld et al., 2008). However, a German study involving men and women with CAH identified only a mild reduction in quality of life (Reisch et al., 2011). These authors attributed the poor quality of life scores in other studies to the exclusive female samples. And yet, a recent study that included men with CAH, which is associated with early physical maturation and testicular abnormalities, concluded that whilst the condition had little impact in childhood, the men in older age groups reported a higher level of negative effect (Berenbaum, Bryk, Duck, & Resnick, 2004). The disparate findings probably owe a great deal to the neglect of process factors, resulting in inadequate question formulation to tighten study designs.

In terms of differences in well-being between diagnostic groups, in the Danish report, women with complete androgen insensitivity syndrome (CAIS) and gonadal dysgenesis reported better quality of life scores compared to women with virilised 46,XY and 46,XX conditions (Johannsen et al., 2006). Likewise, a study with 22 women with CAIS concluded that the research participants were similar to non-DSD women in terms of self-esteem, psychological well-being, gender identity, sexual orientation and gender role behaviour in childhood and adulthood, marital status, personality traits that show sex differences and hand preferences (Hines, Ahmed, & Hughes, 2003). Narratives from peer forums suggest that there is an acute need for psychological interventions at critical moments, but these difficulties appear to be poorly captured in many studies, which may well have been driven by diverse aims and unclear agendas.

Bean, Mazur, and Robinson (2009) analysed the extant literature on sexuality, psychological effects and quality of life in MRKH published from 1955 to 2007. They suggested that the professional language used in discussing MRKH may positively or negatively influence a woman's experience of the diagnosis. This resonates with Holt and Slade (2003) who reported that contact with medical services actually enhanced feelings of uncertainty and isolation in women with MRKH. Bean et al. (2009) also noted that although

psychological counselling was often claimed to be vital, there was no elaboration on type, timing or resources.

Wisniewski and Mazur's review (2009) focused on XY-female conditions such as androgen insensitivity syndrome (AIS). As in other recent studies, these authors reiterated the fact that most psychological studies in DSD have focused on gender identity, gender role and sexual orientation and that few have focused on other aspects of health and well-being, or how a diagnosis and related treatment may impact on quality of life – a topic of great importance to patients and families. They reviewed 35 studies that included health information for individuals with AIS, 5-alpha reductase deficiency and 17-beta hydroxysteroid dehydrogenase deficiency. Reported psychological well-being appeared to vary greatly in the literature, probably due to the small and possibly unrepresentative samples, the use of different tools, the lack of accounting for developmental stages and the potential impact of medical and surgical procedures associated with those stages. Data pertaining to individual adjustment to the various diagnoses could not be identified. They concluded, 'We have a long way to go before we have a full appreciation of the mental, physical, social and spiritual domains that contribute to quality of life of people affected by XY intersex/DSD' (p. 5).

The need for nuanced psychological research

At present, what can be said is that psychosocial functioning in DSD populations is neither categorically negative nor categorically positive – a non-specific observation of no use to psychological care providers. We are a long way from understanding what enables a person with a certain diagnosis to do well and what does not, so that meaningful and targeted assistance could be designed, implemented and evaluated. Can quality of life research fill the gap?

Few outcome studies on the adaptation to and the well-being of individuals with intersex diagnoses have been conducted, and it is difficult to draw useful conclusions from those studies because of the small sample sizes and wide variation in methodology. Moreover, existing outcome studies have overwhelmingly focused on gender identity, surgical outcomes, and sexual orientation, rather than on broader quality-of-life issues, partially because physicians and researchers have viewed "correct" gender assignment and genital surgery as the most important aspects of treatment. (Karkazis, 2008, pp. 217–218)

Karkazis (2008) and others may have reacted to the unquestioned privileging of brain gender research – something of academic interest to some psychologists, by appealing for more clinically relevant psychosocial research. Stout, Litvak, Robbins, and Sandberg (2010), for example, reported that out of the 98 CAH studies employing psychological endpoints between 1955 and 2009, by far, the majority were focused upon causal relationships between prenatal androgen exposure and 'masculinised' development in females. By contrast, applied psychological studies that can contribute to the overall health of children and adults are conspicuous by absence. Simplistic quality of life research has now become a hindrance to their development.

Pre- and post quality of life assessments may make sense as part of the evaluation of a specific, usually non-curative treatment (e.g. growth hormone regimes). But what psychological insight can arise from a snapshot quality of life measure with affected adults? Psychology is concerned with processes that differentiate outcome. For example, if the outcome were to be adherence to steroidal treatment, the question may be to what extent is it

predicted by knowledge, beliefs and feelings about the diagnosis, by treatment expectancy or by relationship with the team?

The vast array of psychometric tests can be seductive and distracting. There was a time when psychologists had to undergo prolonged training in the development, application and interpretation of psychometrics. Registration to use certain tests was based on a sound understanding of the limitations and theoretical knowledge to interrogate the results. Some of the safeguarding principles appear to be lost. Commercial funding (e.g. from the pharmaceutical industry) for scale development may even subject the process to undue partisan influence. Above all, a contentious issue common to most psychometrics is that of locating problems in the individual (e.g. 'low self-esteem', 'high neuroticism'). Such a project, especially when applied to classify people into categories, will subtly nurture an ethos of patient-blaming and even patient self-blame, as in, 'I am socially isolated because I have low self-esteem'. It will render clinicians complacent about the extrinsic factors upon which the individual's experience and choice are contingent.

Psychologists should question the routinisation of psychometrics, and of 'methodolatry' (Chamberlain, 2000) more generally. Instead of selecting the most appropriate and feasible method to answer a research question, there is sometimes an unhelpful attachment to a particular method or type of measurement. The process of opportunistically fitting people into a pre-determined set of instruments without a clear rationale is becoming evident in psychosocial endpoint research in DSD. Some of even the most recent research reflects limited psychological understanding. Sample differences in social and economic power alone can explain differential findings in quality of life, but socio-economic status is often not assessed (e.g. Reisch et al., 2011). Other potential explanatory variables include uptake of psychological treatment, degree of stigmatisation, social support and many more. Rarity of certain diagnoses is a barrier to high-quality work. A detailed analysis of psychological difficulties and needs involving men and women may need to take place across collaborative centres that share comparable health care infrastructures and linguistic resources. The work needs to be psychology-led for the results and interpretations to be informative and relevant.

Our final criticism of recent psychosocial endpoint studies concerns the issue of social inclusiveness. It is unacceptable to make generalised truth claims from studies that do not report response rates, have not assessed the social, economic and ethnic composition of their samples, have restricted participation with user-unfriendly methods, and have recruited only regular clinic attendees residing in urban areas. In doing so, the realities of many affected individuals and communities are obliterated.

Developing and evaluating educational interventions

Irrespective of gender of rearing, Migeon et al. (2002) reported that almost half of their sample of intersexed men and women were poorly informed about their medical and surgical history. Furthermore, 66% of the 41 women and 38% of the 34 men were not satisfied with their level of information. A study with a small sample of CAIS patients likewise identified poor understanding of the diagnosis in more than half of the sample, and a desire to improve understanding in the majority (Wisniewski et al., 2000). This was echoed by a Dutch study with XY women (Slijper et al., 2000). These findings are consistent with the doctor-patient discordance identified and replicated by researchers in the field of 'doctor-patient communication' that thrived between the 1970s and 1990s (see Waitzkin, 1984), a field that supported the subsequent development of communication training for doctors.

Psycho-education may be more appropriate than the ‘top-down’ didactic information- and advice-giving tradition in medicine. In psycho-education, the task is not just to input into the recipient as if he or she is an empty box waiting to be filled. Instead, it takes for granted that people have their own thoughts and feelings, and selectively process new or contradictory information as they negotiate their own truth. Therefore, repeat opportunities for questions and discussions are needed. Furthermore, the recipient is also encouraged to give expression to his or her reactions, to process meanings and implications and explore solutions with significant others.

Fostering positive, pluralistic and fluid identities

Some DSD diagnoses are associated with body differences that are internal (e.g. absent womb), and/or external but concealable (e.g. genital ambiguity), and/or external and visible (e.g. shorter stature, unwanted body hair). Giving explanations about body differences in social and sexual contexts is a major concern for adolescent and adult service users – male (Chadwick, Liao, & Boyle, 2005) or female (Alderson, Madill, & Balen, 2004; Liao, 2003). Furthermore, most DSD diagnoses are also associated with infertility. Extensive qualitative research suggests that infertility can become central to a person’s identity (Olshansky, 1996). It has been argued that emotional responses to infertility should be understood within a bereavement model (Syme, 1997).

Managing a stigmatised identity can be expected to be a central psychological task for people with DSD, and stigmatisation is known to predispose people to poorer mental health. Studies with women diagnosed with primary ovarian insufficiency, for example, have found an association between degrees of stigmatisation and psychological distress (Davis et al., 2010; Slade, O’Neil, Simpson, & Lashen, 2007). Interestingly, distress was negatively associated with goal re-engagement despite continued preoccupation with the loss (Davis et al., 2010). This points towards the importance of skill development and problem-solving interventions to promote goal re-engagement rather than an exclusive focus on reducing distress.

Group work has been shown to reduce psychological distress in a small study on women diagnosed with MRKH (Weijnenborg & Ter Kuile, 2000). A level of professional psychological input combined with ongoing peer support can be helpful for some individuals in the ongoing process of negotiating preferred identities. Insight-based group psychological interventions provide opportunities for diverse identities and positions to be expressed, thereby deconstructing notions of normalcy (Liao, 2003). Skill-based group interventions may focus more on the practice of evidence-based strategies for approaching and managing feared situations.

Service planning needs to take account of the practical barriers in regular attendance brought about by the large geographical spread of tertiary DSD services. As for other health care contexts, telephone and email consultations can be developed and evaluated.

Addressing barriers in relationships and intimacy

The centrality of normative embodiment in DSD care protocols places clinicians at significant risks of heterosexualising their patients, who may identify as bisexual, lesbian, gay, heterosexual or any other sexuality.

Regardless of partner preference and whether or not genital surgery has taken place, sexual difficulties are more common compared to non-clinical populations (Minto, Liao, Conway, & Creighton, 2003; Minto, Liao, Woodhouse, Ransley, & Creighton, 2003). Sex

research however has focused more on women with CAH than any other male or female DSD population. The quality of the data is variable, but parameters of compromised sexual lives are consistently reported to include delayed relationships (Hurtig & Rosenthal, 1987), reduced rates of stable relationships (Johannsen et al., 2006; Kuhnle & Bullinger, 1997; May, Boyle, & Grant, 1996) and reduced homosexual and heterosexual interests (Zucker et al., 1996). Recent research has demonstrated impaired genital sensitivity due to surgery (Crouch, Liao, Woodhouse, Conway, & Creighton, 2008) and poor post-surgical cosmesis (Creighton, Minto, & Steele, 2001). These barriers are thought to be related to the fewer than expected attempts at conception (Ogilvie et al., 2006), though a US study concluded that a major cause for the low fertility rates was an inadequate introitus (Mulaikai, Migeon, & Rock, 1987). Currently, the direction of influence between sexual difficulties, relationship prevalence and attempts at conception is unclear. This further highlights the problem of the low values placed in identifying psychosocial predictors in sex research in DSD.

A more nuanced study compared the sexual experiences of women with CAH and women with insulin-dependent diabetes, who had attended the same paediatric hospital (May et al., 1996). Both conditions are metabolic diseases involving regular medications and hospital visits and are associated with potential sexual difficulties. Compared to the diabetic women, the CAH women were less sexually experienced, were more avoidant of intimate relationships, reported more sexual anxiety and were more likely to engage in sexual activities to test what their surgeons had done. They also reported fewer attempts at problem-solving (e.g. the use of a lubricant to deal with vaginal dryness). The authors interpreted the differences between the CAH and diabetic women in terms of the different ways in which the two childhood conditions had been managed. In contrast to the CAH women, the diabetic women understood their condition, had extensive educational input and could openly discuss difficulties with sexual partners.

In psycho-sexual counselling, a defocus from 'normal sex' and an increased emphasis on sensuality and pleasure can encourage people to become more open to opportunities for good-enough sexual enjoyment and relating (Liao, 2007). Therapeutic exploration might focus on expanding awareness of variations in male and female sexualities and increasing interaction skills in social and sexual situations.

Facilitating informed choice in elective procedures

Where a gender boundary is blurred by characteristics deemed to belong to the 'opposite' sex, individuals can become extremely preoccupied with fixing the problem. Many women with DSD diagnoses speak of feeling like outsiders and un-entitled to relationships (Boyle, Smith, & Liao, 2005). When adults seek elective surgery, they may well be seeking 'normality' in identity, relationships and sexual practices. However, Bean et al. (2009) reported that the surgical or non-surgical creation of a neovagina per se does not ensure a successful psychological outcome in women with MRKH. This conclusion was advanced in an interview study with XY women after vaginoplasty (Boyle et al., 2005).

Grabham (2007) saw as a key issue 'the continued location of life-changing decisions about intersex embodiment and subjectivity within the medical sphere' (p. 44). Given the complexities, decisions relating to (further) surgery are best pre-empted by a psychological 'work-up' to facilitate informed consent. In particular, it is important to offer a cool-off period in which individuals can explore their current well-being, their knowledge of their medical and treatment history, their understanding of the intervention proposed, including evidence of potential risks, benefits and limitations (see also Tamar-Mattis et al., *in press*).

Boosting health and well-being

Adolescence is the time when the child begins the process of assuming responsibility for accessing the health care system as an independent young adult. Transition from paediatric to adult care is a key indicator of service quality, and poor transition has been implicated in being lost to follow-up (Viner, 2008). In DSD, there has been little attempt to systematise transitional care (Liao, Tacconelli, Wood, Conway, & Creighton, 2010). Unmanaged negative impact on identity, self-evaluation and emotional well-being may rebound on the young persons' behavioural responses that could increase their long-term health risks (e.g. osteoporosis). Psychosocial issues are at the centre of transition and psychologists have a key responsibility in designing care protocols that improve adherence to medically necessary treatments.

Interventions developed in *behavioural medicine* can be advanced to benefit DSD patients. A protocol developed by clinical psychologists (Liao, Doyle, Crouch, & Creighton, 2006) has enabled most women with CAIS and MRKH without a surgical history to avoid vaginal surgery by following a dilation regime (Ismail-Pratt, Bikoo, Liao, Conway, & Creighton, 2007). Since dilation is often required even with surgery, the same protocol also has the potential to boost surgical impact. A urological study of bowel vaginoplasty – the most invasive and high-risk treatment for vaginal agenesis – as first-line treatment for the same diagnostic groups, published at about the same time (Hensle, Shabsigh, Shabsigh, Reiley, & Meyer-Bahlburg, 2006), could make interesting comparisons in health economics, if nothing else.

Brief and structured evidence-based psychological interventions need to be increasingly and methodically introduced to DSD (see for example Chadwick, Smythe, & Liao, *in press*). We have known for some time that psychological preparatory interventions can aid coping and recovery from surgery and reduce complications (Raich, 1999; Ridgeway & Mathews, 1982), but promising work has, by and large, been neglected, though not just in DSD. There is also increasing evidence that low-cost psychological interventions can promote wound healing (e.g. Broadbent et al., 2012). Cost-effective stress reduction programmes have been tried and tested in many areas of medicine, yet they have not been introduced to CAH, despite a clear psycho-physiological rationale concerning stress mechanisms (Merke, Chrousos, & Eisenhoger, 2000; Weise, Mehlinger, & Drinkard, 2004).

Auditing and researching for patient benefits

Davis (2011) argued that the terminology shift from 'intersex' to 'disorders of sex development' 'allows medical professionals to reassert their authority and reclaim jurisdiction over intersexuality in light of intersex activism that was successfully framing intersexuality as a social rather than biological problem' (pp. 155–156). Her observations are justified by the exponentially accelerated bio-medicalisation of DSD. Paediatric endocrinologists, in particular, have been building bio-molecular projects (<http://www.eurodsd.eu/en/publications-1.php> and <http://www.eurodsd.eu/en/the-project.php>), said to represent a 'quiet revolution' that has taken DSD to 'the high altar of medical practice' since Chicago (Hughes, 2010, p. 161). This line of inquiry, sometimes dubbed 'frontier medicine', is of course not unique to DSD, and there are instances of potential clinical utility (see Conway, *in press*). However, nuanced and theoretically accountable psychological research for patient benefits continues to be marginalised:

In recent years, international collaboration in the field of DSD is increasing, although so far most of the studies focus on medical aspects. If psychological and social aspects would also be included in such collaborative studies, mental health professionals would no longer have to base their work merely on clinical intuition. (Cohen-Kettenis, 2010, p. 328)

Roen (2004, 2008) argues for the need of psychological research to engage across clinical and non-clinical spheres to negotiate the epistemological rift between those that assert the need for medicalisation and those who interrogate the imperative of normative embodiment (see also Roen & Pasterski, *in press*). Closer collaborations between clinical and research psychologists and service users are a good place to start. Endpoint psychometrics, whilst selectively useful, can be delimiting, even falsely reassuring in the absence of reflexivity. Process research should be prioritised. Robust national psychological needs analyses targeting males and females across age, diagnostic, social and ethnic groups are urgently needed. Investigations of the effects of low-cost psychological interventions on self-evaluation, stress and distress, relationship and sexual experiences and adherence to medically essential treatments and health-protective lifestyle changes, are critically important in the DSD field.

Clinical psychologists who converse with affected individuals and families daily could develop PAR methodology in DSD. The words of Reason and Bradbury (2001) suggest interesting parallels between PAR and some therapeutic orientations:

It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities. (p. 1)

PAR aims to engage socially excluded minorities (Daley et al., 2012; Ganann, 2013) in the art of knowledge production. As an example, people affected by DSD especially wish to know about disclosure patterns and their effects, and PAR provides a useful framework of inquiry for this topic.

Life expectancy for many diagnostic groups is as yet unknown, due to the relatively recent availability of some medical treatments (e.g. the availability of effective steroidal management for CAH from the 1950s). However, more and more people known to have DSD conditions are reaching old age and little is known about their clinical and non-clinical trajectories. High-quality psychological research with older adults living with DSD has not begun.

Raising awareness

Having carried out a survey on how intersex was taught in higher education, activist Emi Koyama (2003) took feminist and gender scholars to task for deploying intersex in their theoretical expositions of sex and gender without addressing the problems faced by affected people:

Intersex people are reduced to their peculiar organs, then are further diminished into a pure theoretical device, the exhibit A in the case against essentialism and for social constructionism. In other words, people's bodies were used to support abstract theories, rather than social theories being used to support the people. (p. 1)

Koyama collaborated with like-minded academics and activists to produce guidance for teachers, including psychologists.

In her book, Suzanne Kessler talked about research into the views of non-affected student populations on intersex issues. It is a great pity that this work has been so little developed. In our respective roles, we meet with regular requests to facilitate psychosocial research in DSD. It is peculiar that academics, journalists and programme makers alike should assume that the only way to understand DSD is via research on affected people. It is as if the non-DSD world has nothing to do with how DSD is experienced. Public engagement via research and interventions with non-affected populations should become a key psychosocial focus in future.

Conclusions

A mature and productive health care psychology that diligently tackles, at multiple levels, the psychosocial issues raised by people affected by DSD is possible. It would require its practitioners and researchers to be explicit about the theories and values that define their professional priorities, methods, transactions and goals, as they actively navigate conflicting agendas and embedded assumptions. A number of clinical documents including the Chicago consensus statement offer encouraging signs that a level of psychological care will be integrated into clinical management at major centres. However, in order to forge effective contributions informed by psychological values and principles, and by direct and indirect evidence, psychologists working in DSD cannot remain complacent and satisfied with lip service to the psychosocial realm. Significant systemic barriers have yet to be overcome.

Notes on contributors

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