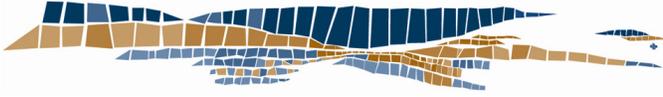


Combined Universities Centre for Rural Health



Intersex and Androgyny and Implications for Provision of Primary Health Care

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Abstract

Issues around intersex, transgenderism, transsexuality and androgyny have been little discussed within the area of primary health care. Indeed, these terms themselves may be variably applied and/or understood. This report investigates the attitudes, beliefs and knowledge amongst primary health care providers of the health needs of those who do not fit the accepted 'male' / 'female' dichotomy, or what may be termed the 'bi-polar social construct.' In this report, this includes those often referred to as 'intersex,' where they genotypically or phenotypically manifest elements of both commonly known sexes. It also includes those who are 'transgender' or 'transsexual,' that is, those that experience some degree of gender dysphoria, or feel they have been born in the 'wrong' physical body to a greater or lesser extent. Such individuals may desire, or have acted, to alter either their physical body or gender role towards one other than that of their birth. Finally, it includes 'androgynous' individuals and all others who may fall outside of the bi-polar social construct. A number of references are included from academic writings to illustrate aspects of the information gained and the importance of being informed.

Semi-structured interviews were conducted with primary health care providers (PHCP) in a regional area of Western Australia in 2006 and 2007, using a set of open ended questions. The interviews were audiotaped and transcribed. Key themes relevant to developing a broad understanding of the extent of knowledge that PHCP have of intersex individuals and androgyny were identified.

Four key findings indicated directions for improving the capacity of primary health care to address aspects of intersex and androgyny. Firstly, there is a need to acknowledge that the bi-polar social construct of sex and gender excludes those who do not identify as either male or female. Secondly, there are distinctions between intersex or androgyny and PHCP need to be better informed about these two terms and how they are differentiated. Thirdly, the professional knowledge base of a PHCP in relation to intersex and androgyny may affect their ability to both identify an individual's status and provide appropriate treatment. Finally, full disclosure of an individual's sex/gender status is paramount to the provision of appropriate treatment; therefore circumstances need to be created for an intersex or androgynous individual to disclose.

The researchers (and indeed the interviewees) hope this report will prompt discourse and research into the concerns facing both the affected person and health care providers in order to improve the primary health care of all.

Intersex and Androgyny and Implications for Provision of Primary Health Care

Introduction

The research conducted for this report sought to explore the attitudes, knowledge and perceptions of Primary Health Care Providers to intersex and androgyny. This was based on the principal researcher's concern that a lack of understanding of intersex by PHCP may lead to a failure to appropriately diagnose or treat general health conditions in a primary care setting.

The report draws on key themes identified from analysis of previous writings about these issues. These themes are: how the bi-polar construct (of sex and gender) is viewed by PHCP; how PHCP define intersex and androgyny; the professional knowledge base of PHCP in relation to intersex and androgyny; and, the importance of disclosure within a treatment setting.

The terms generally used to describe those born sexually or gender variant to the majority of the population are in three main groupings, often described in medical and other literature as sex and gender anomalies. Common terminology includes:

- 1) Androgynous [1]
- 2) Intersex [2]
- 3) Variations of Sexual Development [3].

In general terms, the person who is intersex is an individual whose sex and/or gender may not be easily defined based upon their physical and or genetic make up and where it cannot be categorically stated that they are either *male* or *female*. Intersex may also be used interchangeably with variations of sexual development. Androgyny is more a generic term that refers to people who are gay, lesbian, bisexual, transgender and transsexual and other, but may include those who are intersex.

The principal researcher has reflected on participants' responses using a context of the 'bi-polar social construct' – that is, the broad social expectation that individuals are either male or female and that there are only two sexes and/or genders that populate the world. This is a simplistic concept which is based on power, the status quo and the inability to look beyond the horizon of life and is a disavowal of those deemed different (Somers xxy, C. 1999).

The bi-polar social construct, or the way in which both sex and gender as being 'either / or 'male' or 'female,' is generally accepted by society. As Kipnis and Diamond (1998) note:

...The conceptual distinction between male and female persons (men/women, boys/girls, ladies/gentlemen, etc.) is standard cognitive equipment in culture, deeply implicated in self-identification and social ideology. Particularly in the West, it is taken for granted that

humanity comes in two mutually exclusive sexes, that these are readily distinguishable at birth by the presence or absence of a penis which, in turn, signals a vast array of other permanent physiological and behavioural variations, both present and in the developmental future. Most of us check off the M or the F box and choose the corresponding clothing, hair removal patterns, rest rooms, careers, urination positions, intimate partners, and underarm deodorants.

Intersexuality -- biologically variant sexuality -- disturbs the conventional: both our institutional practices and our ways of thinking and behaving....

Therefore, similar assumptions regarding the basis of what is a 'male' or 'female,' are discussed, together with how PHCP define intersex and androgyny, the extent of their professional knowledge and how they might determine an individual's sex/gender status within their professional practice.

The report concludes with a brief discussion on potential impacts on health care provision.

How the bi-polar construct (of sex and gender) is viewed by PHCP

Of the nine PHCP interviewed, all except one confirmed their general understanding of the bi-polar social construct, although they may not have come across the actual term. All respondents thought there needed to be a greater understanding of those who are born differently and acknowledged the difficulties that intersex and androgynous people may face. Responding to a hypothetical scenario of a previously unknown patient arriving in their surgery with a non-gender specific name, one respondent's reply typically indicated how reliance on the bi-polar construct of sex and gender can present a challenge to the PHCP. In this scenario, the patient has not indicated in gender or sex boxes their specific identity and neither looks 'male' nor 'female'. The respondent acknowledged that would likely cause them a degree of confusion through having to confront their uncertainties of the unknown, a respondent saying:

I have got to basically confront my own doubts in order to do my job.

(GP # 1 P85)

This reinforces that in normal discourse with a patient there may be challenges, not only in dealing with a concern about recognition of their patient's gender, but also in how the PHCP themselves may think about sex and gender; and how this affects their ability to recognise deviation from that which is considered the norm within most of society, where male and female are the dominant interpretations or, as referred to here, as the bi-polar social construct.

Classifying patients is a common and accepted practice in the health field. When asked about classifications, and the boxes found on most official forms where identification of sex or gender is required, one respondent noted:

You can tick 'male' or a 'female'... the health department loves boxes and categories... even I have trouble trying to fit people into a category that the system wants you to say when you are seeing someone with a whole lot of issues, but I still have to find a category

to fit into that box; and that's how the whole health department works...our data system works like that.

(Social Worker. P59)

Another respondent emphasized the need for full knowledge about their patients, to serve the interests of their health and well being, saying:

I would want to know because it impacts on the psyche and their psyche impacts on their physical health. There's no boundary in between. It's not something that... I have views or beliefs [about], it is just when I am treating people, I need to have access to the things that are important to them in their life in order to fit that into the jig saw and put the picture together, so I can treat them as a whole person. And, at the same time... be it issues you know of sexuality, sexual orientation or whatever, I respect the patients, the patient's privacy... what I hope happens through time is that they become comfortable enough with me as their doctor, to allow me to see into those parts of their life in which they felt they needed to keep the door closed most of the time.

(GP .#1. P77)

Incomplete information regarding an individual's status, therefore, may disadvantage a health care practitioner's capacity to provide appropriate care. As the above quote highlights, there are immediate barriers to understanding the 'whole' patient when the identification of sex/gender remains bi-polar.

Another respondent reinforced this concern; particularly in relation to medications an intersexed patient might be prescribed:

...until recently I haven't really had cause to think about it and it was never brought up in my training. You know now, in retrospect, I look back and think that may have a huge effect on the medications we would give her for various things and no it was never brought up in our training. All that I learnt was that there is such a thing as intersex and that was it really.

(Rural Clinical Nurse. P 27)

Recognition of different constructions of a person's sex/gender identity beyond the bi-polar construct can be considered as paramount to the health and wellbeing of any individual who is classified as intersexed and/or androgynous. A respondent explained this perspective as follows:

I suppose we have such an idea about kids growing up and such a bi-polar idea about males and females and what we expect physically from them, and that I can say it would be pretty tough if we had...a male with Klinefelter who had breasts as they were growing up; that would be very difficult not to do anything.

(Public Health Doctor P7.)

And further the same respondent raised the following:

[I]n terms of gender are you male or female? Who you will have relationship with, and things that go along with that, marriage ..., you can't marry if you are neither male nor female, [other] issues, within society in terms of different role models ... use of toilets... , I suppose all sorts of other areas where you have to categorise such as the Olympics... and jobs, and specific places where you may or may not fit into one of those categories. And I think also, having to deal with other people's ignorance and lack of understanding.

(Public Health Doctor P8)

Another respondent also provides an insight into the potential difficulties of being born intersex and or androgynous, saying:

I haven't been in that situation or wouldn't even pretend to know what it is like; so I would probably acknowledge there's a difficult place or if that is how they want to live their life and don't want to make a decision about being a particular sex that's okay as well, but some of the challenges are: is that you often have to tick a box are you a male or a female there's nothing else, there's only two boxes, our society's geared towards you being either a male or a female. What does that mean to that person, what would it mean to their relations to them, are they gay, or are they bi or are they you know, how would it describe their relationship, how would they identify their sexuality in terms of relating to other people and forming relationships; so trying to help the person try to make sense, if that is what they want to do.

(Social Worker. P53)

When the interviewer asked a respondent whether, in their opinion, is it viable to raise a child as neither a boy or a girl, the response was:

No, I don't think so, unfortunately because the way our society is I think it would be very difficult to... I think it would be very harmful to bring up a child who feels more feminine as a boy. Equally vice versa; but I think it might be just as harmful to bring up a child as neither.

(Rural Clinical Nurse P. 25)

Another respondent after being asked what kind of counselling would be offered to an intersex or androgynous person, noted:

You can't just assume because they fall into that category that they have mental health problems. For some issues I may think in the back of my head they might have just social isolation. Isolation from family who are not happy with the way they live their life, not feeling accepted into the community... These are the things, these are the factors that contribute to mental health problems, of people not quite fitting into society, not fitting into their family, or not finding a place where they belong so that is a pretty big factor.

(Social Worker. P55)

The estrangement of individuals from the normal social discourse of sex and gender then has the potential to place them at risk of receiving inappropriate health care, as becomes apparent in this report. This may not only impact upon the patient's health, but also their trust in other people and their ability to disclose their status to a PHCP whether or not the health care giver is sympathetic or indifferent. As one respondent noted:

...because maybe they don't make that connection between the, for me, needing to see issues that affect the way they perceive the rest of the world and the way they are perceived by the world, as being a part of their whole physical and mental well being; which as a [PHCP] I am supposed to be looking after.

(GP #1. P77)

Therefore, while respondents in this study conceded that the bi-polar construct does have an impact on the way they view sex and gender in their professional practice, this is not an issue they had necessarily considered before participating in this research.

How PHCP define intersex and androgyny

Overall the transcripts revealed that different PHCP have varying interpretations, definitions and understanding of intersex and androgyny. There was evidence of confusion in some respondents' conceptualisation. Most of the respondents needed prompting as to who might be considered intersexed or androgynous and what the differences are between them. One PHCP, a general practitioner, had very little knowledge of common intersexed conditions.

In an interview, when asked about the meaning and differences between intersex and androgyny, a respondent said:

Respondent: I kind of see them as two different words. I don't know the definite definitions of them, but intersex I see as someone who may be either male or female or they're one sex but choose to be another sex. Androgynous I see as, where you hear about the XXY or the one with the extra chromosome and where there is a bit of a mixture between the male and female gender and it's, and it is not a clear line between whether the person is male or female.

Interviewer: Do you know of any of the conditions that might result in ambiguous genitalia?

Respondent: No.

(Physiotherapist. P.92.)

In this instance, the respondent, in outlining their belief that the two words (intersex and androgynous) are different, confuses the two terms, stating: *'Intersex I see as someone who may be either male or female or.'* The same respondent above, when asked about their understanding of other variations of intersex including Congenital Adrenal Hyperplasia (CAH) and Androgen Insensitivity (AIS), and if they knew anything about them, replied 'no.'

In fact, an intersexed person is neither 'male' or 'female' per se; they are *neither* fully one or the other of the assumed sexes but a mix. Dreger (2002) points out that there is a difference between those who are transgendered and those whom are born intersex individuals while also acknowledging that some intersexed persons may be transsexuals saying:

It's important to also be clear that intersex is different from transgender in that a person with intersex is born with mixed sex anatomy, where as a person who is transgendered is

a person who feels himself or herself to be a gender different than the one he or she was assigned at birth. Some people who are transgendered were born intersexed, but most were born with 'standard' male or female anatomy.

Other respondents had similar and consistent difficulties with providing accurate definitions or interpretations, some of which were based upon language used as well as potential cultural interpretations and their own personal understanding and acceptances of difference [4] in various societies [5]. Others were conversant with differences within the varying cultural domains, such as found in Saudi Arabia. This was evident where a PHCP, who had worked in the Middle East for several years. [6] Nihoul-Fekete et al. (2006) noted that in some cultures parents favour boys partly due to maintaining the wealth of the family, therefore an intersexed child would be assigned male where it was possible to do so and consent of the individual concerned never came into the equation:

Primarily [in] the culture was there where a lot of wealthy families who like boys – boys are seen to be they have a higher position I guess within the family structure and they are perceived in their educational and their positions in life and the girls are more subservient in the opportunities made available for them. So obviously given a choice of having the child we find the boy and that is what they primarily did and my recollection was most of these children were reassigned as boys.

(Rural Clinical Nurse # 2. P110)

Another respondent when asked about their understanding of the two words, 'intersex' and 'androgynous,' also replied as though the two words were interchangeable:

Interviewer: So how would you draw a line in-between a word like intersex and a word like androgyny. Would you separate the two?

Respondent: Probably, intersex is someone who wants to change their sex and for example like a male who wants to live like a female, dress like a female and look like a female, whereas androgynous might be a male who dresses like a male but also looks a bit feminine. Or a woman who is a woman but she's got short hair and wears masculine clothing.

Interviewer: So you would say that intersex has got more to do with someone making a conscious decision around their gender presentation while androgynous would be or naturally are...?

Respondent: Well they choose to be ambiguous (Interviewer: They choose to be ambiguous?) Sexually ambiguous.

Interviewer: That could be androgynous as well?

Respondent: Yes a lot of artists are... they play around with that image of androgyny, um so some people make a conscious decision to be androgynous and some people just are. Yeah. Their behaviour, the way they look.

(Social Worker. P48.)

These examples indicate that there are a number of conflicting interpretations among those interviewed as to who may or may not be intersex or androgynous. This has implications for intersex or androgynous individuals, and suggests that effective treatment for general health conditions may be compromised without a more certain understanding of variations of sexual development.

How PHCP define intersex and androgyny prompts the question of the extent to which knowledge is provided during education, training and ongoing professional development.

The professional knowledge base of PHCP in relation to intersex and androgyny

The extent of the knowledge base of PHCP in relation to intersex and androgyny was another aspect discussed during interviews. This was considered within the context of both medical knowledge and the psycho-social implications for individuals who are intersexed. Knowledge ranged from those who knew a reasonable amount about the subject, even though they had little or no personal experience of treating intersex or androgynous individuals (as far as they were aware), to those who had no knowledge. For example, a respondent says in reference to an intersex patient:

I had no knowledge of how being intersexed or androgynous would effect any other body systems, so it didn't seem to affect the way the doctor treated her either.'

(Rural Clinical Nurse #1 P26.)

For PHCP who had treated intersex and or androgynous individuals, this had been in both overseas and Australian settings.

As a midwife I had seen two babies with ambiguous genitalia while they were being born. I had also visited the islands and knew a person who functioned as a woman... but she had ambiguous genitalia as well.'

(Rural Clinical Nurse . # 1. P15)

Most respondents identified the need for an awareness of those born differently to most, recognising their lack of knowledge and understanding of the intersex and or androgynous peoples amongst the overall population. When interviewed a number of PHCP were adamant about the lack of knowledge both within the community and also within their own professions. For example, one respondent said:

Oh, absolutely, I think you know some people have no idea. You know about what to do, how to respond or you know what's appropriate what's not appropriate. My advice with those people is just to be honest. Because invariably honesty is the best policy and if you and I have found that myself if you go to that patient and say: 'look, I've got no idea about this, but I am going to find out and then that's sincere and they appreciate it.

(Clinical Nurse # 2. P. 118)

The interviews generally indicated that little information concerning intersex and androgyny was provided during their training. A registered nurse expressed concern about how medications may affect these individuals. Since women and men may react differently to certain pharmaceutical preparations, it could be equally possible that others who are intersex and or androgynous might do so too.

You know now, in retrospect I look back and think that may have a huge effect on the medications we would give [a patient] for various things, but no it was never brought up in our training. All that I learnt was that, you know, that there is such a thing as intersex and that was it really.

(Clinical Nurse. #1 P27.)

Analysis revealed that respondents were interested in becoming more knowledgeable about intersex and androgyny, its probable impacts on diagnosis and treatment and how they may be able to be better informed. A number demonstrated concern at the potential for intersex and/or androgynous people to 'slip through the net,' thereby being at an increased health risk, in relation to, for example, different or unknown gonads, osteoporosis or breast cancer. One respondent remarked, after learning of a person who was intersex and had great difficulty in being accepted by the breast screening van because they looked 'male' rather than 'female', said:

Respondent: Yes, I mean that's part of health promotion I suppose you need to get people's attention but at the same time it tends to isolate or alienate certain people who don't fit into that group. I was reading about men who had breast cancer, one in one hundred with breast cancer, are actually men. We don't hear about them because breast cancers research and breast cancer information is all about bras and pink ribbons and girlie things, so they again they feel isolated and they are less likely to go and have a screening.

Interviewer: So there's something just about being part of a minority per se which actually makes you disregarded?

Respondent: Yes exactly.

(Social Worker. P. 59.)

Another respondent reinforced this, saying:

Yes,... with osteoporosis there is a risk of fractures, falls we do a lot of work with that...if you have got low oestrogen that can affect the elasticity of your muscle fibers so that can have an affect. So I mean I guess that these are things that I need to know about. It is a very unknown field.

(Physiotherapist. P93.)

It was evident from the analysis that the potential for significant difficulties was present as a result of non-disclosure by individuals of their intersex status, an aspect that is discussed in the next section. However, this situation may not only be the result of a PHCP being unaware that individuals may withhold this information but also that individuals may not themselves know they are intersex. Therefore, unless the patient presented for an unrelated area of concern where a karyotype or other assessment was required, their status might not come to light. For example, a respondent explained in reference to a hypothetical scenario where a person's karyotype may indicate infertility:

Knowing what your genetic make up or your chromosomal make up is this... it's saying who you are, this is, just pieces of chromosome it has the implications on the fertility or whatever, but, this piece of paper doesn't alter who you are; but it may impact on the way that you feel about yourself. (GP #1. P87)

However, there are a number of more recognisable indicators of intersex at birth, such as Congenital Adrenal Hyperplasia (CAH), where a person is 46 XX but is likely to have an enlarged or hypertrophic clitoris:

If a girl has a hypertrophic clitoris everyone will worry... What is it? So that is why females are easy to pick up, if they have ambiguous genitalia. And the medical issues in that situation would be first of all do they have congenital adrenal hyperplasia. An abnormality of the adrenal glands... And in that situation they are at risk of collapsing any time, there are certain types of adrenal hyperplasia where you lose your salt, you lose your sodium... you can go into hypovolemic shock and you die. So that's the medical emergency we need to quickly find out about if that is due to... adrenal hyperplasia, so we check quickly sodium, potassium, glucose.

(Paediatrician. P36.)

The same respondent, in reference to the person who has had their clitoris reduced, also said:

You have already done irreversible surgery so you can't go backward, and at the same time you have made somebody a boy and then she thinks she could have been better off as a girl, you can't go back. That's why they say that the best approach and in my opinion and that within society is you do minimal surgery and give that gender assignment in childhood and then wait until the child himself is between sixteen to eighteen where other issues one needs to think about and he also or she ought to think about is what is the best functional sex for them. Are they better off female, functionally there'll be better sexually functionally females or better functionally sexually functionally males. And when you think making somebody female you have to think about fertility as well. One day will they be able to produce, reproduce otherwise female is not complete and that will cause psychological problems. So those are the issues and at the moment it is not clear cut, everyone has his own opinion.

(Paediatrician. P39)

A midwife had a similar view about sexual reassignment through surgical intervention [7,8]:

Surgical intervention... I don't think that should be done. I would not think that would be an immediate priority. ... The problem with surgical intervention is once it's done, you can't change your mind 12 years later, when this child suddenly shows far more traits of being female and um, well, no probably more the other way, showing far more traits of being male, and you have taken away everything, that could enhance some sort of maleness in this child. So I think personally I would leave surgical, I wouldn't touch surgical not as a child... even if the genetics were all saying 'boy' or all saying 'girl'; I still think that it is something that as an infant, I don't think that is all that important; because it is physical, and it is not going to change the way a baby or a small child is going to be. And it is irreversible and you cannot do anything about it.

(Midwife. P71)

The attitude towards sexual reassignment surgery (SRS) and its consequences was similar among the PHCP and was summed up by a social worker who was concerned about the mental health of the person who is intersexed, saying:

There's been a lot on the media lately and my understanding is that that the medical profession does not do gender reassignment surgery on young babies anymore because of the adverse affects it has had on adults...adults who have been raised as a particular gender and they could not identify with their gender often ended up with committing suicide or having you know..., very sort of intense mental health problems as a result,... um my guess, you know you, my job is to support people given options, and mini choices, like giving information, um, but I will tend to say well you know, it's a very difficult decision to make, to support them... because it's and once you hit the good, bad, ultimately it's the child who should decide what they want to be when they get older.

(Social Worker. P52)

PHCPs stressed the importance of knowing a person's sex and gender status and disposition. One respondent reported that when she was working in a small remote community setting she observed that a local woman had ignored reminders for a pap smear. When opportunistically questioned during a visit for another reason, the woman indicated she was an intersexed person. The patient had been born with both a penis and vagina, had her penis removed and lived as a woman. The patient thought that because she had no cervix there was no need for her to have a pap smear.

In retrospect you know I should have thought about that more, that lady was also going to the GP, he had been seeing her. There was never any mention that 'oh you know', the way I would have expected when he was treating her, he should have told us as community nurses, that we need to be considerate about these things, but perhaps he didn't consider it either... I think that may be it is a huge void in the health provision.

(Clinical Nurse. P27)

Another respondent who has had experience in an overseas health setting and knowledge of intersex, demonstrated a clear understanding of the dilemma faced by parents when asked a question about a child born with ambiguous genitalia. The respondent outlined the status of the newborn as presenting a psychological, rather than physiological emergency, for the parents:

This is a sort of psychological emergency as soon as the kid is born. The family was thinking it was a boy or a 'lovely' girl, then suddenly no one can tell them... whether it is a 'boy' or a 'girl' ... so, first of all for health care workers it's an issue that says 'psychological emergency' and there are multiple issues not just one thing.

(Paediatrician. P36)

The respondent further states:

When you cannot determine whether it is a *girl* or a *boy*; another terminology is used, the most commonly being named 'ambiguous' genitalia, which is obvious, it is not clear... in India & Pakistan a very popular word is 'Hijras.'

(Paediatrician. P 33)

Other respondents also raised concerns regarding psycho-social development of the individual as being as important as the physiological manifestations of intersex and/or androgynous individuals. For example, in the future how would they perceive themselves and

their gender identity? This aspect of identity is clearly illustrated by an intersexed person (Noble, 2002):

The intersexed people have been concealed for many decades because they threaten the man-made laws of nature, which dictate that there are two sexes: male and female. Yet nature does not manifest in comfortable, finite boxes. Rather it exists as infinite spectrums of variation. But in our modern scientific mind this variation threatens to unleash chaos. And what drives science? The desire to control nature.

In reference to a child born with no clear gender identity, a PHCP respondent reported giving the following advice:

If [the parents] are thinking about the name think about a neutral name and take time. Say a few weeks or so, a few days to a week; we should be clear about gender assignment at least,. In about a week, once we have got chromosome and once we know internal genitalia, gonads and we have got hormonal assessment done. Then we can give the gender assignment to that child that this is more likely a girl or a boy. And then to plan further for the surgery if necessary for the genitalia, and then obviously later on, there'll be heaps of psychological problems.

(Paediatrician. P38)

Another respondent addressed an interesting point concerning psychological upbringing and disclosure when she said:

I guess to try and make explanations as *early* as possible so that the child doesn't get to eighteen and suddenly find that they are different to everybody else. I think that would be pretty traumatic. It's almost along the lines of any sort of disability... that the child needs to know early on in the piece... so that they just know that they are not better than anyone else and they are not lesser than anyone else, they are just different.

(Midwife. P73).

Knowledge of intersex and androgyny then appears to be dependent on whether the PHCP has had contact with an individual who is clearly identified as intersex or androgynous and experience of providing health care. Knowledge of an individual patient is also dependent on full disclosure by a patient of both their medical history and their (self) identity as being intersex or androgynous.

The importance of disclosure within a treatment setting

The issue of disclosure has been identified above as having a potential impact on the capacity of the primary health care provider to decide on appropriate diagnosis and treatment when undertaking patient assessments. Transcript analysis indicated that the need for disclosure is seen by PHCP to be important. Some respondents were in favour of 'fishing' for information, while others did not agree with this approach. Those who did, saw it as a precursor for a more in depth study of the patient and the ability to fit the *'jigsaw pieces together to get a better*

picture’ or, in other words, a more holistic view of the person under their care, particularly where the knowledge may have a direct bearing upon their overall health and well being.

Knowing what your genetic make up or your chromosomal make up is this.... and the impact on the way you feel about yourself. Is there anything in this information that perhaps acts as missing piece of jigsaw puzzle in your life?

(GP #1. P86)

The same respondent stated:

I would hope they would see their primary carer as someone who is looking after them and not as a sexual entity or any other issue, but as a person, and so from that point of view, that they actually see primary care as the place they can go, whatever their needs.... how that is going to be perceived must be enormously difficult for someone to approach someone who is a complete stranger with something so intimate to their entire being. I would imagine it would be perceived as *an enormous barrier*.

(GP #1. P80)

Paradoxically though, the same respondent also stated that if they were intersexed or androgynous they would not disclose this to their colleagues, particularly if they wished to change their sex and or gender.

I have colleagues that I am sure if I was in that situation I would not be wanting to present to...some would be very dismissive of... for example, take the gender reassignment issue. There are some people who would not have a bar of that... they would be seeing it as a freak show.

(GP #1. P82)

This highlights the difficulties for those caught in the bi-polar social construct of gender encounter, where the derogatory use of terms such as freaks can alienate an individual, by negating the intersexed or transsexual’s existence as a person of worth. Estrangement of a person from the society in which they belong effectively disenfranchises those who do not fit within the cultural norms of that which is perceived acceptable. The fear that is generated is largely induced through an unwillingness to recognise that there really are differences within nature that defy the ‘binary understanding of sex and gender,’ and thus ‘it generates the potential for social stigma and identity confusion (Preves 1998)’ to the point where the patient becomes reluctant to disclose information to their care givers, even when it may be to their benefit.

Intersex or androgynous individuals who are reluctant to disclose are likely to access primary health care services less often, creating a potential barrier to appropriate treatment. PHCPs need to be aware of this.[9] For example, if an intersexed or androgynous person had internal physical attributes that were unknown to the health care provider, their capacity to make informed treatment decisions would be compromised.

Interviewer: Do you think by not disclosing to their doctor that they had any kind of intersex condition, this will have an impact on their health and how the GP will manage them?

Respondent: I really think this is case by case...If you look at the physical health, then if someone has got ovaries and testes...and then develop abdominal pain, you know in their sixties or something, *we may not do the appropriate ultrasound scan looking for ovarian cancer because we don't know the ovaries are there* So, yes, physically it is going to be a problem; if you have illnesses specific to the fact the person who may have the opposite sex type, that you know will have combination sex types, they may be all the things that you did not think were there...

(GP # 2.. P123; emphasis added)

A PHCP noted that greater knowledge is not only needed among health professionals, but in the population at large:

I will always welcome educational information and I think the community has to know as well, because you know whether they chose to like it or not, or accept or not, these people live in the community and they survive in the community...

(Clinical Nurse # 2. P118)

Presumably, such education of the community may also encourage intersex and androgynous individuals to disclose their status to PHCP, thus avoiding potential problems. From the perspective of the analysis, disclosure, from both the point of view of the patient under care and that of the PHCP, should be made so that the affected child and eventual adult is able to be effectively treated within primary health care, or other health settings. The PHCP interviewed were not able to suggest ways in which circumstances to improve knowledge could be created.

Discussion

The key themes presented above have indicated that there are a number of aspects to understanding intersex and androgyny of which PHCP need to be mindful. Firstly, there is a need to acknowledge that the bi-polar social construct of sex and gender excludes those who do not identify as either male or female. Secondly, there are distinctions between intersex or androgyny and PHCP need to be better informed about these two terms and how they are differentiated. Thirdly, the professional knowledge base of a PHCP in relation to intersex and androgyny may affect their ability to both identify an individual's status and provide appropriate treatment. Finally, full disclosure of an individual's sex/gender status is paramount to the provision of appropriate treatment; therefore circumstances need to be created for an intersex or androgynous individual to disclose.

The biologist Anne Fausto-Sterling in her book '*Sexing the Body*' (2001) acknowledges that sex and gender is culturally defined and that naming only two sexes is not adequate to cover the complex interrelationship between sex and gender, suggesting at least five major variations.

In some cultures there is an acceptance or recognition of those who do not fit the norm of what is usually termed as either male or female. For example a number of cultures do

acknowledge others who do not fit the bi-polar social construct, such as the Navaho and Inuit nations. Similarly, India and Pakistan have a special sect of people known as the Hijras. A PHCP explained:

These people go and dance and entertain people... that is special, everyone knows they don't have a clear sex, so these are a different kind of people. That is, they don't have a very clear gender. Hijras, they're neither male nor female so that is another word used in the sub continent, but it basically means when one has difficulty in declaring the proper gender of the infant or new born that is intersex.

(Paediatrician. P33.)

It was evident in the course of analysing these interviews, however, that a lack of certainty of what comprises intersex and/or androgyny among the PHCP interviewed has implications in the provision of treatment for general health conditions.

There are a range of variables in the genetic makeup and physical attributes of intersex individuals. For example those whose karyotype may be 46 XY (Androgen Insensitive) or 47 XXY [10] (sometimes known as Klinefelter Syndrome [11]) and its variations, and those who are 46 XX (CAH). Others may have what is known as a micropenis, hypertrophic clitoris, hypospadias. Each individual may identify as either male or female or intersex and others again as transgender or transsexual or other. Some of those who are born differently to others may opt for sexual reassignment surgery (SRS) or other surgical procedures and or hormone replacement therapy (HRT) to either enhance their predispositions or to maintain equilibrium concerning their sex hormone imbalances. Others may reject any surgical or other medical interventions or SRS and HRT outright. Many who are intersex do not have much personal choice in the matter where both parents and medical teams do so for them, unless the medical teams are more cautious and open in their approach to these complex issues.[12] This illustrates the complexity of issues facing PHCP when responding to an intersex patient.

Sexual reassignment surgery was noted to be a complex area, particularly when being considered in relation to a baby. It was noted that this is as much a matter of considering the psychological outcomes for the child related to sex and gender identity.

The ability of individuals to disclose their intersex status is also an area of complexity that relies both on the individual and their confidence in disclosing and the PHCP to acknowledge that ambiguity in a presenting patients sex/gender identity may indicate that the person is intersex or androgynous. This requires building trust in the person to enable them to fully disclose their history. In relation to intersex children, an Australian study on intersex conditions found that disclosure is an issue for intersex individuals. Asking '*is full disclosure always in the best interests of the patient*' the study concludes '*that parents and patients are entitled to the truth, presented to them in a way that they can understand* (Warne and Bhatia 2006, p203).'

As indicated by respondents in this project there is a need for public education initiatives to be instigated to bring about greater awareness of intersex and androgyny. This would serve the interests of both intersex and androgynous individuals and PHCP. Understanding the whole person is important to PHCP in determining how best they can contribute to

maintaining overall health and wellbeing. The capacity to prescribe appropriate medications and treatments are also influenced by full knowledge of a patient's history.

Conclusion

It is clear from this research project that primary health care providers are faced with a complex range of factors when treating intersexed or androgynous individuals. Not the least of these is their own limited understanding of the extent of intersex and androgyn in the population, their knowledge of the medical and psycho-social needs of the intersexed, and whether the intersexed person has confidence to disclose their status.

The PHCP interviewed for this study agreed that important facts might well be lost in developing an appropriate treatment pathway, particularly if they do not know the full history of an intersex or androgynous patient. One general practitioner likened it to being presented with the pieces of a jigsaw puzzle, and another was particularly concerned about hidden aspects where the body may not match that which they had been taught to see. This as a dilemma in so much as the intersex or androgynous person may have a condition that is directly related to their genetic and overall biological, physiological and or psychological makeup but is not immediately apparent to the health care provider without a full patient history.

In conclusion this report illustrates that, among the participants interviewed for this study, there is a dearth of knowledge and understanding of those who are born intersex or androgynous. It is reasonable to assume that this will be reflected in the general primary health care provider population. The PHCP indicated in interviews that that they wished to be more fully inclusive of their patient base, and acknowledged the need for further research.

The PHCP interviewed, despite some of their initial misgivings, appeared adamant that intersex and/or androgynous individuals should be treated with the same respect and dignity as any other person, when in reality they were people like any other regardless of their differences or variations of what it means to be a human being whether they are referred to as Intersex, Androgynous, Variations of Sexual Development or other.

Endnotes

1 'The truths of androgyny ... are too complex to be categorized easily in stereotypical syndromes. Many doctors make the stereotypes true by forcing the "patient" into the normalizing shape of male or female. So do many teachers, without realizing it. Our assumptions concerning a bipolar social construct in Western society are extremely naive. The reality is opposite to the popular belief that to be a person one must either be male or female. We must recognize that gender and sexuality is a complex continuum to be cared for in the mystery of life (Haynes and McKenna 2001, p38).'

2 'Intersex' is a general term used for any form of congenital (inborn) mixed sex anatomy. This doesn't mean that a person with an intersex condition has all the parts of a female and all the parts of a male; that is physiologically impossible. What it does mean is that a person with an intersex condition has some parts usually associated with males and some parts usually associated with females, or that she or he has some parts that appear ambiguous (like a phallus that looks somewhere between a penis and a clitoris, or a divided scrotum that looks more like labia). It's important to understand that intersex doesn't always involve 'ambiguous' or blended external sex anatomy. Sometimes a child or adult who is intersexed can look quite unambiguous sexually, although internally their sex anatomy is mixed (Drager 2002).'

3 <http://adc.bmj.com/cgi/eletters/91/7/554> Diamond, Milton. 27 July 2006. Accessed 11-12-2007

4 'When the child matures and becomes more aware of his history I predict he will likely come to live as a man or in as close to a neuter gender as possible. He will come to recognize that he is intersexed and might or might not openly identify as such (Diamond 2002).'

5 'The existence of people who are neither 'all male' nor 'all female' has long been recognized in many societies and, with the advent of European Societies in the 19th century, effort has been directed at determining the 'true sex' of such individuals (Creighton and Liao 2004, p 659).'

6 The American Urology Association have stated 'cultural differences are crucial in the management of intersex, and should be taken into account for the collection and interpretation of data.'

7 It should be noted that not all transsexuals are willing partners to the act of reassignment such as the infamous case concerning the tragic case and eventual suicide of David Reimer through the late Dr. John Money who was notoriously involved in what could be considered a deception exercise. See the relevant works of both Professor Milton Diamond and colleagues (1998, 2002, 2004, 2005, 2006) and John Colapinto (2000).

8 Dr. John Money an eminent researcher at the John Hopkins Hospital in Baltimore USA whose later works which were largely based on an infamous case known as the John / Joan case, which swayed members of the medical fraternity to modify the sex and gender of a given child by lending support to their assumed right to carry out either or both Hormone Replacement Therapy and Sexual Reassignment Surgery with or without the knowledge of the person concerned and often in collusion of the parents to maintain a code of secrecy while being persuaded that this was the best course of action. This being based on limited knowledge of the real outcomes and inconclusive evidence that nurture changes nature despite the serious missgivings of scientists such as Diamond, M et al who for years were ignored until the catastrophic John Joan case exploded into the public arena and the subject of the case, namely David Reimer became very public. This sanctioned both paediatricians and others within the medical fraternity to carry out treatment and operations that they might not have otherwise carried out, and where surprisingly they did not question the research that Money and associates were espousing to be correct in part through their blatant fabrication of the facts concerning David Reimer (Colapinto, J. 2000). Harper says: '...by allowing Paediatricians to deal with shocked and upset parents who desperately wanted a boy- or as girl-child, but whose infant was intersexed and had ambiguous genitalia. A surgeon could offer a surgical solution to 'fix the problem', and could support that solution with a psychological theory of infant neutrality. The surgeon could cosmetically enhance the appearance of the infant's external genitalia, and propose a way forwards in terms of naming and rearing the child, assuring the parents that this solution was workable and would guarantee a happy child and successful outcome. Understandably the majority of parents chose – continue to choose – an apparently immediate and medically sanctioned 'solution' over an unknowable possible future problem (Harper 2007, p 48).'

Unfortunately a great deal of both secretive, persuasive and unnecessary procedures are still carried out to-day, both here in Australia and globally.

9 Failure to recognise those who are intersexed and / or androgynous leads to, or results in:

Inequity of primary health care provision where, for example, those who may have characteristics of another sex may go undiagnosed when it does matter. Some hospitals, in particular the West Australian public hospitals, for

example have placed four indicators on their emergency department's forms known as MR1 or Emergency Notes:

- 'M' for Male
- 'F' for Female
- 'I' for Indeterminate or Intersex
- 'O' for Other

However, many staff are unaware of the meaning of these designators. They either cover them up with a sticky label bearing the patients address and / or other material, or ignore the requests of those who disclose their status, that is, patients who request that the appropriate box or indicator be ticked and / or circled. The attending nurse taking the history at the triage desk thereby negates the hospital admission forms' gender and sex identity boxes. This disavowal of patients' differences, by blatantly ignoring patients' requests to have their sex and or gender recognised in the space provided, is not only a dereliction of duty but it also places patients at risk. The attending doctors and other medical team members, that is, the primary health care providers, are then possibly locked out of ever knowing, or being aware, that their patients' anatomy may be quite different from what has been assumed. Such an oversight would affect and effect the very taxonomy and physiological and / or psychological dispositions relative to all people who are assumed wrongly to be either totally 'male' or 'female' per se. (extract from a submission by Somers xxy, Chris. 2007. To The Australian Bureau of Statistics, Submission 125 for the proposed WA Human Rights Act and Senator Lyn Alison, endorsed by Professor Milton Diamond PhD of The Pacific Centre for Sex and Society, Hawaii University, Dr. Jeff McMullen AO of The New Journalism, Author and the Host of the ABC's Difference of Opinion and Curtis Hinkle, intersex activist, professional linguist and founder of the Organisation Intersex International, the world's largest intersex site and translated into many languages).

10 There are many variations of sexual development of the 47 XXY and associated karyotypes, some may also present as fertile women who are aside of those whom may be considered male, intersex, variations of sexual development or differences of sexual development. See Thangaraj et al. 1998).

11 Chris invites readers to consider the consequences of viewing themselves as a syndrome, perhaps called the 'Somers Syndrome', Dreger (2002:25) similarly says: I realized recently that I suffer from a genetic condition. Although I have not actually had my genome screened, all the anatomical signs of Double-X-Syndrome are there. And while I could probably handle the myriad physiological disorders associated with my condition- bouts of pain and bleeding coming and going for decades, hair growth patterns that obviously differ from 'normal' people's- the social downsides associated with it are troubling. Even since the passage of the Americans With Disabilities Act, people with Double-X remain more likely to be sexually assaulted, and are legally prohibited from marrying people with the same condition. Some potential parents have even screened fetuses and aborted those with Double-X in an effort to avert the tragic life the syndrome brings. Perhaps you know the Double-X by its more common name: womanhood (cited in Haynes and McKenna, 2001).'

12 'Sexual function could be compromised by clitoral surgery. Debate on the ethics of the use of this surgery in children should be promoted and further multicentre research is needed to ensure representative samples and comprehensive outcome assessment. Meanwhile, parents and patients who consent to clitoral surgery should be fully informed of the potential risks to sexual function (Minto et al. 2003).

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