

# Intersex, Infertility and the Future:

## Early Diagnoses and the Imagined Life Course

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### Key words

Intersex, DSD, infertility, reproduction, time, life course

### Abstract

Infertility is often recognised as a status that is medically identified in adulthood after unsuccessful attempts to conceive. This paper develops existing literature by illustrating how current conceptualisations of infertility do not incorporate a full range of experiences. Drawing on detailed, reflective diaries and in-depth interviews with five participants, I explore how infertility is experienced and understood by women with variations of sex characteristics (VSCs) or intersex traits. I argue that greater consideration needs to be applied to intersex people and the circumstances of an infertility status that may be received in infancy, childhood or adolescence, before or outside of attempts to conceive, and without undergoing fertility treatment.

Through discussions of time and futurity, this paper seeks to explore how visions of the future coalesce with an infertile status that is received in combination with an atypical sex status early in life. The paper indicates that early infertility can hinder some intersex children and young people's

ambitions. However, infertility is not understood to be pathological or consistently prohibitive throughout the lives of everyone affected. Intersex women's conceptions of a potentially childless future are varied, complex, ambivalent, and in some cases transitional throughout the life course.

## Intersex and Fertility

People with intersex traits have bodies that do not fit exclusively into the medical expectations of 'male' or 'female'. These sex categories are defined by several criteria: genitals, chromosomes, hormone levels, secondary sex characteristics, and reproductive organs. The prevalence of intersex variations (also known as disorders/differences of sex development or DSDs) is difficult to quantify, but some estimates report that approximately two per cent of infants are born with genitalia that clinicians may deem 'ambiguous' (Blackless *et al.* 2000). However, sex variations also manifest in other forms or at later stages. Infertility affects many – but not all – intersex people, and some of the associated (and controversial) medical procedures undertaken in their infancy and childhood can also impact reproductive capacity. In most circumstances, Turner syndrome (Karnis 2012), complete androgen insensitivity syndrome (Oakes *et al.* 2008), partial androgen insensitivity syndrome (Hughes *et al.* 2012) and Klinefelter syndrome (Lanfranco *et al.* 2004) affect fertility. For people with intersex characteristics, a status of infertility may be first received in infancy, childhood or adolescence (as well as later), and without first engaging in attempts to conceive or undergoing fertility treatment.

Despite the prevalence and significance of infertility in the lives of many people with intersex variations, sociological literature on (in)fertility and reproduction that acknowledges their presence is scarce. Intersex scholarship in the Social Sciences also tends to put little emphasis on *experiences* of infertility. When addressed, reproduction is usually raised in critical discussions relating to the determinants of medical sex assignment and surgical consultations (Davis 2015, Karkazis 2008, Preves 2008). For example, in her interviews with medical professionals, Davis (2015: 81) illustrates the

prioritisation of reproductive capacity in the process of assigning a sex to patients, and one clinician refers to 'the potential to carry a child' as 'the *holy grail*'. Other scholars have observed that fertility is emphasised in girls' sex assignment, but not in boys' (Karkazis 2008: 4) and illustrated the ways in which reproductive organs are gendered by clinicians (*ibid.*: 112). However, (in)fertility may also play a significant role in intersex people's experiences and identities. For example, medical research involving interviews with 100 women and girls with Turner syndrome confirmed that infertility was participants' greatest concern and 'health issues' associated with the syndrome were considered to be significantly less important (Sutton *et al.* 2005).

For many intersex people who experience infertility, the medical identification of their fertility issues is acquired at the same time as their intersex diagnosis and their inability to conceive is thus positioned as 'a symptom' of their sex variation and subsumed within this. This may take place prior to the individual's own contemplations about fertility or parenthood, from infancy to adolescence or later. For Greil *et al.* (2010: 141), infertility can be recognised as 'the absence of a desired state'; however, infertility in the case of atypical sex is sometimes determined before a 'desire' (or otherwise) for pregnancy or parenthood may be possible or acknowledged, or in childhood, where the desire may be understood differently. In most sociological studies of reproduction, diversity in the timing of infertility diagnoses is unconsidered, omitting the distinct experiences of people whose infertility was identified at an early stage in the life course.

In this literature, infertility is also often identified when individuals present themselves for medical assistance with conception (Greil *et al.* 2010), thus the experience of fertility treatment is characterised as a customary juncture in some women's processes of dealing with infertility (Letherby 2002). It has therefore been observed that there has been a failure to study those who have *not* sought treatment (Greil 1997), which is estimated at around half of those considered infertile worldwide (Greil *et al.* 2010). The tendency to rely upon a biomedical diagnosis, and the lack of consideration towards people who are not help-seeking, has meant that there is an uncertainty about

whether, or how, to identify or define their status as infertile. Accordingly, scholars have highlighted the importance of considering how infertility is understood outside of a medical schema (Bell 2014), as well as how diagnoses of infertility are understood and interpreted differently by those affected (Bell 2014) and the determinants of, and disparities in, medical help-seeking (e.g. White *et al.* 2006).

Recent scholarship has also underlined the need to recognise the complexities of non-parenthood (Letherby 2002). For example, a small body of work has challenged the distinctions made by the binary of 'in/voluntary' childlessness (Letherby 2002, Monach 1993, Morrell 1994, Wilson 2014), and emphasised the range of ambivalent feelings that may be experienced by childless women over the life course. In doing so, they have shown the complexity of personal and structural choices and constraints that affect a person's circumstances and compromise the 'in/voluntary' classification. Whilst an infertile status is often understood to be an *unwanted* physical barrier to parenthood (i.e. one of the reasons people may be 'involuntarily' childless), 'voluntary' childlessness is recognised as an agentic status given to someone who – for a variety of reasons – has declined parenthood. Thus, different degrees and ways of enacting agency and control have been explored, posing a challenge to the stereotype of infertility as wholly passive (e.g. Bell and Hetterly 2014, Letherby 2002). Other valuable work has emphasised how viewpoints, expectations and aspirations of people experiencing infertility may shift significantly over time (Becker 2000, Hudson *et al.* 2016, Parry 2005, Throsby 2004, Wilson 2014).

Letherby (2002) notes that ambivalence is often considered to be an inappropriate response to infertility, especially within a biomedical framework which presents infertility as a hurdle to overcome (e.g. Donchin 1996). This positions eventual parenthood as the only reasonable route or objective when struggling to conceive, whilst coming to terms with childlessness, or other possibilities (e.g. adoption, fostering) are viewed as unviable or undesirable options (Franklin 1997, Pfeffer 1987). This is in part due to the cultural emphasis placed upon the supremacy of 'natural' and/or 'biological' parenting, and the corresponding pronatalist narratives that associate success and contentment with

motherhood. For example, research into the ways infertility is experienced as a 'biographical disruption' (Becker 1994, Ulrich and Weatherall 2000) demonstrates how motherhood is 'constituted as compulsory, normal and natural' (Woollett and Boyle 2000: 309), affirming an ideology that implicitly links a woman's social value and gender identity with her ability to procreate (Earle and Letherby 2007, Parry 2005, Pfeffer 1987, Ulrich and Weatherall 2000). Infertility can thus impact friendships, intimate and family relationships (Greil 1988, 1991, Hudson *et al.* 2016, Ulrich and Weatherall 2000), and produce a sense of discontinuity and uncertainty about the future (Becker 1994, Ulrich and Weatherall 2000).

Greil *et al.* (1988) indicate that due to social factors, infertility may be experienced in a fundamentally different way by men than by women, and various studies have revealed that infertility may be a more stressful (Slade *et al.* 2007) and stigmatising experience for women. Greil (1991: 53), for example, notes that women in his study described themselves as having 'not only imperfect bodies but also spoiled *identities*' and Woollett and Boyle (2000: 309) illustrate how infertile women continue to be positioned as 'empty and deficient'. However, Annandale and Clark (1996) underline the danger of sociologists replicating a biomedical approach by positioning the reproductive capacities/struggles of women as exceptional or intrinsic. Despite the specific cultural dialogues that construct experiences of, and attitudes towards, infertility as gendered, sociological research should recognise genders outside of/between this binary, and reproduction should not be assumed to be central to the lives of all women or insignificant to men. This is reflected in the diverse attitudes of women in this study, and infertility literature that has turned towards men's experiences, developing an understanding of the connections sometimes made between a 'stable' masculine gender identity and fertility (Barnes 2014, Mason 1993).

Whilst concerns have been raised regarding the limited focus of some infertility scholarship, including necessary critiques of the centring of white, heterosexual and affluent women's experiences (Bell 2014, Nsiah-Jefferson and Hall 1989), the exclusion of people with intersex traits from infertility

literature is yet to be highlighted. This paper seeks to address significant gaps in infertility research by considering intersex narratives, which may in some cases complicate understandings of infertility as a status that is necessarily linked, or equivalent, to an unfulfilled aspiration towards conception.

Furthermore, I consider the significance of temporality in infertility diagnosis narratives by reflecting on 'early' diagnoses of infertility, which – in contrast to 'typical' infertility accounts – may significantly shape childhood/adolescent conceptualisations of parenthood and reproductive ambitions, and may not necessarily be perceived as a 'problem' when first ascertained (or later in the life course).

## Methods

The themes of this article arose from a larger qualitative study undertaken between October 2013 and October 2014, which explored the social and medical experiences of people with variations of sex characteristics (VSCs) or intersex traits in the UK, focussing in particular on the realisation of identities and interpersonal relationships. Ethical approval was granted by the University of Sheffield Research Ethics Committee, and participants' names and other identifiable information have been anonymised.

Undertaking a two-tiered process of solicited diaries followed by in-depth interviews (Zimmerman and Wieder 1977), five intersex women, two intersex men, and two parents of intersex children initially wrote about their experiences in unstructured, reflective diaries over a period of two months. The same cohort of nine participants were then invited to in-depth interviews to build on the themes observed in the diaries. Interviews were one-to-one, in-person and largely unstructured, taking place in areas local to participants across the UK. A short list of key themes informed all interviews, but participants' diary content was used as the primary resource for shaping their respective meetings. Questions were unscripted, and the interviews were informal and partially participant-led in order to share control over the direction of the conversations, which resulted in some variation in the topics discussed. Interviews ranged between 90-145 minutes (128 minutes on average) and diary submissions were between 800-9,700 words.

Diaries and interview transcripts were categorised into a coding scheme and separated thematically. This was followed by content analysis (Holsti 1969) to systematically identify key features and themes. The interviews and diaries included a range of topics, but infertility was particularly salient in contributions from intersex women and largely omitted by men, whose fertility statuses are unknown. This paper therefore draws on the experiences of five women with VSCs who participated in this research and spoke of their inability to conceive as anticipated. Following valuable sociological studies centred on a small number of participants (e.g. Cornwell 1984, Mogensen and Mason 2015, Whyte 1955), the in-depth interviews and rich, expository diaries provide large volumes of high quality data based on personal accounts, which allowed for detailed narratives and a more rounded sense of the individuals involved in the research, like a series of case studies rather than a more general overview. Nevertheless, this research is explorative and indicative, and does not attempt to present large-scale, wholly generalisable findings (for further discussion, see Jones 2016, Davis 2015).

The women in this paper were aged between 22-35 and those who discussed their sexual orientations explicitly (two of five) were non-heterosexual. Whilst they were not asked to describe their racial identity, all had the appearance of being white. A greater racial diversity amongst participants would have been preferable, however the active/visible 'intersex community' is known to be an especially 'white space' (Pagonis 2016) consisting predominantly of people privileged by race and class (Davis 2015). Whilst both Davis (2015) and Pagonis (2016) rightly discuss the need to proactively work towards increasing the diversity of the global intersex community, its current state in the UK is not dissimilar to my sample. Class and educational backgrounds were more diverse. Participants worked in a range of occupations with various income levels. Whilst not all participants' careers required degree qualifications, many mentioned attending university education. Participants had been given a range of diagnoses: Turner syndrome, complete and partial androgen insensitivity syndrome, and Swyer syndrome. In all cases, the diagnosis of infertility was ascertained before/outside of attempts to conceive and none of the participants had sought assistance from reproductive technologies (ARTs)

or other routes into parenthood. Participants were recruited through a range of online sources: internet forums for intersex people, support group emailing lists and Facebook groups designed for discussion of intersex issues.

## Findings

### Imagined futures

Anticipated visions of the future were discussed by all participants when recalling their initial reaction to receiving an infertile status, revealing how attitudes towards parenthood were forming from an early age. One participant, 22-year-old Pandora, reflected in her diary that 'one of the facts about AIS [androgen insensitivity syndrome] that struck me hardest at first was the fact that I couldn't have children'. She described her history in which, at 11 years old, an assumed motherhood was forestalled by the discovery of her status:

Before finding out that I was intersex, I adored children and always imagined that I would be a mother to a lot of children. I am part of a large family and loved being so, and I wanted to carry that on with my own breed. When I found out, it was almost as if I had lost a child, albeit only an imaginary future one.

Pandora's description of her upbringing positioned parenthood as a normal, natural and inevitable life event, in which infertility acted as a critical disruption (Becker 1994, Hudson *et al.* 2016), illustrating Ulrich and Weatherall's (2000) conceptualisation of infertility as an unanticipated life course disturbance. Reflecting Pandora's account, Becker (1994: 384) observes that women in her research often described their experience of infertility as being 'like a death'. Here, the compulsory logics of pronatalism and straight time (Freeman 2007) may impose an attitude in which 'natural' conception and genetic parenthood are necessary for a happy, fulfilling and successful life.



Pandora equated the loss of her anticipated child with the loss of her prospects, writing in her diary that 'I also lost my future in some senses, as the path I had hoped to follow was now resolutely closed, and a big empty space remained to be filled, but all I could feel I wanted to fill it with was the thing I couldn't'. The omission of parenthood came with a loss of certainty and ambition for Pandora. Becker (1994: 392) considers how an infertile status, often considered 'the death of the baby', also 'removes hope' (Becker 1994: 393). Consistent with Becker's work, the hope and reliability of Pandora's future was tied to her reproductive ambitions.

In her diary, 27-year-old Siân recalled the moment her parents explained 'the full implications' of her Turner syndrome diagnosis when she was 10 years old:

As well as the injections it was explained that I would need hormone replacement therapy to induce puberty and that because of TS [Turner syndrome] I wouldn't be able to have children naturally. I suppose in a way because my growth hormone injections had helped with my height so although I was short I wasn't that much noticeably shorter than my shorter peers so hadn't really felt like there was anything different about me up until that point but here was something that made me significantly different that I couldn't ignore. I think the best word to describe how I felt at the time was lost. Aged 10 you have no idea what the future holds and what you want to be when you grow up changes on a daily basis but for me I simply just wanted to be a Mum. All the games I played as a child were around families and family life.

After the discovery that conception would not be possible for Siân in the way she anticipated, she noted in her diary that 'at this point my attitude towards TS changed. Instead of it being something I was happy to talk about [...] it then became something that I was embarrassed about and didn't really

want people knowing'. Siân's discovery of her infertile status, like Pandora's, was a significant disturbance to her hopes and desires for the future. Siân identified motherhood as singular in this regard, acknowledging that during childhood the future felt unknown in many respects, but aspirations towards motherhood were a fixed and stable ideal embedded in her everyday subjectivity from an early age. In accordance with many women who learn about their infertility later in life (Ulrich and Weatherall, 2000), Siân struggled with the presumption that fertility and parenthood were universal and 'normal'. She also drew a connection between the new feelings directed towards her Turner syndrome diagnosis – shame, a reluctance to disclose – and the discovery of her infertility. Siân not only expressed a personal disappointment in her inability to conceive as expected, but also felt self-conscious about how her infertility, and therefore her Turner syndrome diagnosis, were perceived by others. Prior to discovering her infertility, cultural narratives of motherhood may have offered a channel of gendered 'normality' for Siân, helping her to accept the Turner syndrome diagnosis and navigate associated stigma. Thus, infertility could have a potentially cumulative impact on the lives of those with pre-existing diagnoses such as VSCs or other experiences that may pose a challenge to perceived gender or sex legitimacy.

Siân and Pandora employed spatial metaphors to express the disorientation they felt following their discovery. Siân described feeling 'lost' and Pandora depicted the 'path' she hoped to follow as 'resolutely closed'. Earle and Letherby (2007: 236) outline the tendency for life narratives to be interpreted as 'a simple unidirectional journey' from birth to death rather than an uneven route filled with unanticipated interruption and revisions. This narrative, bound by straight time, presumes a simple, direct pathway and contributes to the normalisation of conception, pregnancy and parenthood as fixed events in the life course. Becker (1994: 396), too, notes how infertile women in her research expressed defeat because 'the future could not be foreseen'. These narratives can be written into our social lives from the earliest stage; by 10 and 11 years old Siân and Pandora had already developed a clear vision of their reproductive ambitions. Thus, their imagined futures were

disrupted significantly and both participants were required to re-think their 'self-concept' (Bury 1982: 171). In particular, the identity of 'mother' was understood to be no longer attainable, and at this early stage they believed it needed to be abandoned.

For others, their younger age meant they were already comfortable with a potentially undetermined future. Sophie, who was 24 years old, became aware of her fertility issues when she received a diagnosis of Swyer syndrome at 15 years old. In contrast to Siân and Pandora, Sophie described the benefits of learning her status when her future still felt pliable and open:

To just suddenly be told at like thirty/forty, like I think I'd find that really hard. Because I've always known, it's like you grow as a person as a teenager anyway, so it just becomes part of that growth. [...] If you're a grown adult you feel you're sorted with your own life, and then something random happens.

Whilst Siân and Pandora's accounts illustrate that an early infertility diagnosis can be received as a significant life course disruption and lead ambitions and identities to be revised entirely from a young age, Sophie's viewpoint demonstrates that a more amenable outlook on the future can also be enabled by receiving this information early.

### Timing of diagnosis

Infertility literature largely overlooks the possibility that fertility issues may become evident prior to adulthood or identified before/outside of unsuccessful attempts to conceive. The implications of variations in the timing of a diagnosis are therefore rarely considered. However, all participants in this article raised the significance of the timing of their discovery of infertility. This was often positioned in terms of the level of difficulty they encountered in dealing with or accepting their status, and an imagined notion of how an earlier/later discovery would transform the experience. Impressions of

'earliness' and 'lateness' were contingent and diverse. Siân underlined the social and psychological import of receiving a diagnosis at an 'early' age. She commented that

we're in quite a *unique* position in knowing from such a young *age* as well.

Whereas, y'know, a lot of people would discover it at sort of our age [27 years old] when they start trying for children, so it's more of a – it's a bit of a different scenario.

Due to her early discovery, Siân added that 'I don't really talk to anyone who hasn't got Turner's about it, because [...] I think it's one of those things that you can't really, truly understand until you're in that position'. Siân noted that this timing also meant that she 'wasn't expecting to be told, because I s'pose I didn't *necessarily* realise that you couldn't [...] have children'. For Siân there was a clear division between the experiences of 'conventional' or expected infertility narratives involving diagnoses later in life, and those of women with Turner syndrome. Siân recalled that, despite her emphatic desire for motherhood, for her parents 'it was something that wasn't even on the radar' due to her age. She noted that this meant that her infertility was not openly discussed, and that it was likely her parents would have felt that there were 'a lot of other hurdles we've got to get through before we get to that'. In contrast to women who experience their infertility after attempts to conceive, it was initially framed as inapposite for Siân or her parents to address or further inquire about her infertility. At 27 years old, Siân noted that she still did not discuss this issue with her parents, instead emphasising the importance of peer support she received from other women with Turner syndrome, who were the only people who 'truly understand'. Consistent with reports from others experiencing infertility (Greil *et al.* 1988), there was a barrier that prevented identification with those Siân considered to be outside of her circle of experience. However, for people with VSCs, further marginalisation and isolation may be felt due to the multiple facets of their diagnoses and the differing timing, which can prevent identification with 'conventional' infertility narratives.

One participant, 35-year-old Paula, described holding a limited understanding of her intersex variation up until around 18 years old when she discovered her precise diagnosis inadvertently, reading a story in a magazine about someone with AIS. She was frustrated to uncover later that in her medical notes her karyotype was confirmed as 46,XY at two years old and she was given a label of AIS at the age of three. Her parents had told her since that they were also not fully informed. In her diary, Paula recalled that she was taught three characteristics about her status in childhood:

that I wouldn't have periods

that I wouldn't have babies

that I was special.

She reflected that it was 'kind of the same spiel every time'. Growing up, Paula's infertility typified her difference. Sophie also identified infertility as the most significant and challenging aspect of her intersex experience. However, she believed that it was 'so much easier' to become aware of her diagnosis of Swyer syndrome at 15 years old rather than later in life. She noted that she was lucky to have discovered her infertility this early,

...because I've always known. Before I ever had the urge to want children I've known so it's not a big deal. I mean, maybe when I'm 30, like older and really want children, when all my friends are having children, it might be worse, I don't know. But it means you can come to terms with it a lot easier and you don't get that big surprise later in life.

Sophie explained that receiving her diagnosis in adolescence 'means that I have to tell my boyfriend right at the beginning because he was my friend for years anyway, like... and everyone who knows me knows that kind of thing'. This meant that Sophie felt her infertility had never been a secret or a surprise for her or anyone else. For the many people who encounter issues with fertility for the first

time when trying to conceive with a partner, relationships can be put under strain. In Hudson *et al.*'s (2016) study on infertility, some women suggested to their partners that they should leave in case they could not have children. The authors argue that infertility can impact women's perceived ability to perform 'dominant gender scripts associate[d] with being a wife or girlfriend' (Hudson *et al.* 2016). In Sophie's experience, this tension may have been alleviated by two parties happily entering the relationship with a shared knowledge, in part due to her earlier diagnosis and younger age.

In contrast to Sophie's views, Pandora expressed frustration that her parents waited until she was 11 years old to disclose her reproductive (and intersex) status to her despite her parents receiving the medical diagnosis in Pandora's infancy. She remarked,

I'd just assumed that that *was* going to be part of my life, so to sort of... that was how I saw my life *to be*, or where it was heading, but then when I found out it was sort of – I almost felt like that was stolen away from me in a way. Like the life that I... sorted of planned, the children that I wanted were sort of taken away from me, whereas if you just grow up knowing, that's not really going to be there for you. Um, I think it would've been easier to... *accept* and form just – form other plans and ideas from being younger. And just not question it quite so much, and just like – if you *always* know that just like from childhood, that 'Oh, I can't have children, that's fine'. 'Cause it's – a bit better having longer to accept it, to not see it as a problem.

At 11 years old, Pandora had already created a vision of parenthood, whilst Sophie understood 15 years old as an age that preceded any reproductive ambition. These differing accounts are illustrative of the diverse ways in which individuals approach reproductive desires, and the different stages at which these desires and decisions may become relevant or important in the life course (if ever). Pronatalist discourses may also be experienced in different ways and to different extents. Sophie

predicted that in the future her experiences may change, suggesting that the confines of a 'straight time' narrative are understood to demand varying degrees of conformity at different life stages.

Paula, who was eleven years older, mentioned the difficulty of watching most of her friends become pregnant.

Siân and Pandora's perceptions of their discoveries as 'late' may also need to be framed relative to their doctors' and parents' knowledge of their intersex variations. The details of Siân and Pandora's infertility were temporarily withheld and not shared with them until several years after their diagnoses had first been established by doctors, whereas Sophie discovered her status alongside her initial medical label of Swyer syndrome in adolescence. The withdrawal or late admittance of information from intersex patients has been widely critiqued in recent literature (Davis 2015, Preves 2008, Reis 2009).

## Embodied intimacies

Becker (1994) underlines the way in which an inability to conceive is an 'embodied' disruption, as well one which is social, psychological and biographical. She discusses the gendered nature of embodied knowledge, whereby infertility 'unravelling basic understandings [women] had of themselves' and challenged their 'fundamental bodily knowledge' (*ibid.*: 394). Pandora's reflections on her gender identity in her diary were shaped by the absence of a uterus, which she regarded as a manifestation of her infertility:

I don't have a uterus... no periods, no chance of children. In a lot of ancient cultures, the image of a woman is a symbol of fertility, the central part of which is the womb. So the lack of this female organ saddens me hugely and again questions my female mind. I suppose there's a disparity for me between mind and body: my mind is female, my body is not.

Embodied disruption, and a perception that their bodies (and genders) were under question and scrutiny, were already dominant in participants' accounts due to their atypical sex diagnoses and resulting medical encounters. However, for some this was a former struggle rather than a current concern. Pandora felt that the absence of a womb brought substantive physical consequences, which also raised ontological and epistemological questions. She acknowledged explicitly that she would not apply the same essentialist logic to dispute other people's (e.g. a trans woman's) gender authenticity; instead the embodied and gendered disruption caused by infertility was tied intimately to her own intersex status.

Consistent with past research (Greil 1988, 1991, Ulrich and Weatherall 2000), infertility also affected Pandora's approach to relationships. She recalled that 'when I found out that I couldn't [conceive as anticipated] *that* was quite devastating. And it, to *me*, that also felt like... if I can't have *kids* then no one's going to want to *be* with me and so it sort of stamped *aloneness* to me'. Pandora's feelings about infertility have changed over time; she described feeling 'more at peace' with her status now and noted that she has 'sort of accepted' it. However, she suggested this could change later. As with her intersex status, Pandora had not spoken to any intimate partners about her infertility, but she reported feeling confident about raising it in future. Whilst Pandora wished that she had been aware of her diagnosis earlier in life, she narrated a significant change in perspective over the ten years since she had been told: from her initial belief that intimate relationships of any kind would not be available, to now asserting the confidence and self-assurance to 'hold her own' if, or when, she discloses her status to a partner. This confidence, Pandora explained, was due to her own growing acceptance of her infertility.

Infertility also imposed barriers for Siân which have prevented her committing to partnerships. She indicated that infertility is 'probably the thing [about Turner syndrome] that bothers me most', so she has chosen not to share her status with others. In her diary, Siân's concerns around disclosure and the



potentially stigmatising consequences of an infertile status were the main reasons she said she had not established an intimate relationship:

Because of all this I have never been able to form or have any kind of physical relationship. I have tried various avenues of trying to meet people but the thought of having to lay bear [sic] my infertility issues and fear of having to adapt to such a big change in how I would live my life should anything develop into something more serious has always meant that nothing has ever come of any attempt I have made.

Siân upheld that her infertility would definitely 'be an issue' in a relationship. Siân's aversion to disclosure and the 'big change' engendered by a relationship have led her to remove herself from the possibility of intimate relations altogether, attempting to prevent (or mitigate) the anticipated disruption her infertility could create during her adult life. Receiving a diagnosis at a young age, prior to forming any intimate relationships, may have contributed further to the uncertainty Siân felt about the impact of infertility and the response it could receive by a potential partner.

## Other futures

Points of resistance to, and frustration with, social expectations and the normalisation of parenthood were evident. Following Parry's (2005) research illustrating women's evolving interests and desires after experiencing infertility, participants' conceptions of a potentially childless future were often transitional and uneven. In some cases, their stories were in staunch opposition to stereotypical accounts of childless women as forlorn. In contrast to her previous struggles with infertility, Pandora spoke about the appeal of exploring different experiences outside of parenthood:

Over a long period I sort of realised that there's more to life than children [laughter]. And there is... and *now* I kind of *don't mind* not having kids, like

I've seen a couple of friends my age having kids and like, oh God, I wouldn't want that! [*laughter*] So, you know, I can try and see the benefits of it now and that doesn't really upset me that much anymore. [...] I s'pose it's *more* since I went to uni and more careers have opened and there's a lot to *life* and there's – I s'pose it, again, 'cause it's, at the time I didn't really have that many friends around me, so I know now it doesn't mean I have to be *alone*.

Pandora's realisation that there were other potential sources of pleasure in her future, which '[don't] have to revolve around family' demonstrates how the desire (and pressure) to live a life centred on motherhood, whilst persistent, can undergo transformations.

Consistent with other research (Becker 2000, Parry 2005, Wilson 2014), Pandora acknowledged the potential for routes outside of parenthood to be enjoyable, not just endured. In contrast to some studies (Becker 2000, Throsby 2004), the reshaping of her aspirations occurred without undergoing unsuccessful infertility treatment (see also Czarnecki 2015). Pandora described a process where, by revising the value she placed on life options outside of parenthood, she re-discovered feelings of hope and optimism about her future. She also developed a more critical understanding of parenthood. For example, in her diary Pandora reflected,

As sensitive as I am to my body image maybe it's good that such a process won't come along to change my body. In a trusting relationship I don't have to worry about condoms or the pill or the chance that my life will change radically with an unexpected pregnancy. [...] I can continue to live a life of relative freedom without the burden of children. [...] I have to look at the positives, even though they sound so selfish, or the future can look gloomy.

Pandora's retreat from motherhood was nevertheless haunted by a concern that she would be judged negatively by others. In challenging the desirability of pregnancy and parenting, Pandora's self-

portrayal moved away from the image of an 'empty and deficient infertile' woman, and towards the 'selfish, childless and career' driven woman (Woollett and Boyle 2000: 309), who prioritises other life goals. Both models operate in opposition to the image of the 'warm, caring and 'good' mother'. These cultural discourses seeped into Pandora's reflections, even whilst she spoke about taking a more affirmative approach to alternatives to parenthood.

Natalie, 32 years old, received a diagnosis of complete androgen insensitivity syndrome (CAIS) at 21 years old and was the only woman in this study to say that infertility had never caused her any distress. In her diary, she commented that she was 'NOT broody around baby's [sic]' and 'struggle[s] to see what's [sic] so special about the whole thing'. Natalie believed that it was her indifferent disposition towards infertility that led her not to raise an alarm about her absent periods during adolescence:

'Cause I didn't start my periods, I thought I'm just one of the lucky women who doesn't have them! Bingo! You know, I didn't think that... I mean, obviously when I was younger my mother told me to go to the doctors and I wasn't that fussed about it. I just thought 'Oh well, I don't have them'. [...] I just thought – I don't have 'em. Y'know, just leave it at that. I'm not interested in having kids. Can't *stand* kids. Can't... even picture myself being a mother of any kind or anything, and I thought 'Oh well, it doesn't matter', but then you don't think about... well, if you're not having periods that means there *is* something wrong. [...] So, I thought this was working out perfect for me, you know, 'cause I don't *want* children! So yeah, bonus! And then they're like, 'No, no, no, it doesn't mean that, that everything's all y'know, cushty, you just gotta... be investigated'.

The characterisation of infertility as a state whereby individuals ‘define their inability to have children *as a problem*’ (Greil *et al.* 2010: 141, my own emphasis) may be due to an assumption that infertility would only be discovered during attempts to conceive and thus inevitably experienced by people who perceive parenthood as desirable (*ibid*). However, Natalie exhibited gratification towards the ‘symptoms’ and consequences of her inability to conceive. As Natalie had not engaged in vaginal-penile intercourse, enjoyed an exemption from menstrual periods, had no ambitions towards parenthood, and did not feel a sense of ‘desperation’ (Pfeffer 1987), she was, in many ways, entirely removed from the exemplary ‘infertile woman’.

Natalie discussed an imagined notion of who she might be without a diagnosis of CAIS. She noted that ‘if I *was* without [CAIS] anyway, I’d probably have had a hysterectomy’ because ‘I’d like to think that even if I didn’t have the CAIS I wouldn’t have had children anyway, and I wouldn’t have been interested’. When Natalie discovered her infertility, she did not withstand a ‘fundamental re-thinking of [her] biography and self-concept’ (Bury, 1982: 169), as described in other infertility studies preceding this. Instead, Natalie constructed an ordered and stable narrative in which parenthood was such an undesirable route that, without a diagnosis of CAIS, Natalie still believed (or hoped) she would have followed the same trajectory.

Natalie’s imagined future did not contain the same ‘fixed bio-social stages’ (Earle and Letherby 2007: 237) described by other participants so she experienced reproductive concerns in a different way. Despite her lack of interest in parenting, Natalie had – and continued to – encounter many challenges, some of which were ‘embodied’ (Becker 1994), and all of which were principally related to the stigmatisation of her intersex status, including issues with disclosure, friendships, sexual relationships and body image. She depicted the impact as substantial, stating that she ‘think[s] somewhere along the line [everything I do and say in life can] always stem back [...] to having this condition’. The complex synthesis between her CAIS diagnosis and her infertility, despite the latter being more warmly received, made them difficult to untangle. This confounds the pathological status given to her

variation, which in many ways has granted considerable benefits as well as difficulties. As an active agent in the process of constructing and defining her experience, Natalie demonstrated alternative interpretations of 'infertility' and intersex outside of medicalisation and unsuccessful aspirations towards conception.

## Conclusions

This article expands on academic conceptualisations of infertility by considering the experiences of people with intersex traits. I have illustrated that infertility may be identified at any time in the life course, including in infancy, and that in some instances this may challenge a desire for 'biological' parenthood when felt at an early age. Thus, my analysis suggests that some childhood and adolescent imaginaries of the future are mapped out and re-drawn according to a revelation of infertility, and identities and broader configurations of future and past selves can also be constructed around this knowledge. Some accounts therefore made a clear distinction between 'conventional' experiences of infertility, and the experiences of women with intersex variations, who often discover their infertile status before conception is feasible, regardless of whether it is desired. In this study, conceptualisations of infertility were inseparable from the experiences of intersex/VSC diagnoses. Social, as well as physical, impediments to parenthood were present in intersex women's accounts, including an ambivalence towards relationships and sex, as well as heightened anxieties around gender/sex identity and body acceptance due to their intersex status, stigma and (often unwanted) medical treatment. This meant that instigating intimate relationships could feel daunting or unappealing in some instances.

However, this article shows that an 'infertile' status is not understood by everyone affected at all stages of their life course to be pathological or prohibitive; nor is it central to the lives of all women who are unable to conceive. Building on the work of previous studies (e.g. Letherby 2002, Monach 1993, Morrell 1994, Wilson 2014), I have shown there is potential to be both infertile and wilfully

childfree: the distinction often made between 'voluntary' and 'involuntary' childlessness presents a false dichotomy and denies the agency of people experiencing infertility (Bell and Hetterly 2014, Letherby 2002). Whilst some participants at times felt disempowered, devastated or restrained by their infertility, there were also ways in which different futures were actively and enthusiastically planned, challenging dominant cultural narratives, and (re-)constructing visions of lives and goals that suited their needs. A 'changing' future was understood to be more comfortable in some cases due to an early diagnosis. Stories shared of a potentially childless future were varied, complex, ambivalent and in some cases transitional throughout the life course. The views participants presented in this paper may also change in the future, and further longitudinal research could therefore be beneficial.

This study illustrates similarities between the experiences of intersex people and those in previous infertility studies; whilst life is never entirely predictable and stable throughout, the 'heavy weight of the cultural model of continuity' (Becker 1994: 402) makes disruptions difficult to encounter and, as unexpected as they often are, we are usually unequipped in ways of 'dealing' with them. However, the time at which discoveries of infertility occurred was depicted by intersex women as significant and determinative in attempts to accept their status and feel optimistic for the future. Infertility was especially 'unexpected' when, for those diagnosed in childhood, they were unaware this was even a possibility. Details of infertility and intersex traits that were initially withheld from participants also contributed to (dis)comfort and perceptions of (un)timeliness, and feelings of helplessness were aggravated by this perceived lack of knowledge of one's own body and diagnosis.

These accounts from five women foreground the importance of considering the various circumstances of intersex diagnoses in discussions of infertility experiences, and thus invite us to reflect on the deficiencies of dominant narratives and pervasive stereotypes of infertility in medical and public discourse. However, this work is limited in some respects, including its size and demographics, participants' reliance upon memory recall for their reflective accounts, and the diversity of topics covered in data collection due to the participants' jurisdiction over content. Further

(in)fertility research addressing intersex experiences is needed, paying attention to stratified reproduction and infertility care, and variations across race, gender, socio-economic status and sexuality, but also considering specific intersex variations which may be impacted differently by barriers of medicalisation and social stigma. Extending themes of reproductive time, further sociological work is also required into parents' and children's increasing engagement with the fertility preservation options available to some people with intersex traits, and the impact of these decisions later in the life course.

## Acknowledgements

I am grateful to the participants for sharing their stories and the ESRC for funding this research.

Thanks also to Kate Reed and the anonymous reviewers for their helpful comments on article drafts.

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