

Intersex Euphoria!

Positive experiences of intersex variations

Tiffany Jones

People with intersex variations are mostly framed within conservative psycho-medical research, or critical empowerment Intersex Studies literature. In both literatures their framing has negative aspects either negating their bodies, identities, health or function; or positioning within discriminatory contexts. Resisting deficit-based framings, this article uses the concept ‘euphoria’ to investigate when, why and how 272 Australian online survey participants (aged 16-87yrs) had positive experiences of their intersex variations. Upon diagnosis under one fifth described what this piece calls Category Validation, Difference Legitimation, Knowledge Integration, Medical Sense-making or Sudden Hope euphorias. Post-diagnosis euphorias were more common; most often Body Positivity euphoria. Also, Acceptance, Autonomous Control, Relative Gains or Fitness Edge euphorias emerged. Euphorias had different feelings, stimuli, processes and impacts. Body Positivity euphoria was most connected and conducive to other euphorias, and has external stimuli which could be invested in further.

Introduction

Intersex is an umbrella term for the over 1.7% of people born with atypical sex characteristics; including over 40 variations to chromosomes, hormones or hormone sensitivity, and/or anatomy (Huang *et al.* 2010; Jones *et al.*, 2016). This article explores people’s positive experiences of their intersex variations. It firstly provides some background on how people with intersex variations are framed in the literature. It secondly draws on the concept of ‘euphoria’ to frame for examination of positive experiences and feelings. It then thirdly reports the methods, results and implications of an online survey of 272 Australians with intersex variations.

Background

Most research literature on people with intersex variations is from the American-Canadian region (Davis 2015; Holmes 2009; Sanders *et al.* 2021); Asia-Pacific (Bromdal *et al.* 2021; Ediati *et al.* 2015) and European-led work (Lundberg *et al.* 2021; Lux *et al.* 2009). There is also work from Africa (Ekenze *et al.* 2015) and the Middle East (Gül *et al.* 2015). People with intersex variations were historically largely framed within traditional institutional expert-centred psycho-medical lenses, constructing them as disordered and requiring “normalizing” hormonal or surgical corrections without their consent (Ediati *et al.* 2015; Ekenze *et al.* 2015).

Contrastingly, recent community-centred Critical Intersex Studies sociological survey work and Bioethical Narrative Inquiry work (Bromdal *et al.* 2021; Carpenter 2018; Holmes 2009; Jones *et al.*, 2016). framed people with intersex variations as marginalised within discriminatory contexts (or medical and education institutions). These works argue for reforms involving people with intersex variations agentively and aligning with rights-based consensus statements (AISSGA *et al.* 2017). However,

the need for more accounts of positive experiences is underlined by intersex organisations (AISSGA *et al* 2017, 8). To build more positive accounts into Critical Intersex Studies, this paper explores peoples' positive experiences of intersex variations, using the concept of 'euphoria'.

1. Theory

"Euphoria" as a concept is poorly established in theoretical or empirical literature (Beischel *et al.* 2021; Bradford *et al.* 2019). Its etymology draws on medical Latin for the effectiveness of medicine on patients (1680s); and *feeling healthy and comfortable within a context of being sick or experiencing discomfort* (1720s) from the Greek euphoros "bearing well" (Simpson, Weiner 2021). It suggests "pleasure" within, even due to, broader "difficulties". Thus, "euphoria" is especially used for positive identity experiences in communities where sex, gender or embodiment are problematised within illnesses, dysphorias, disorders or discriminatory contexts. A non-academic book '*Gender Euphoria*' included people with intersex variations (e.g., Mari Wrobi) in 19 people's euphoric stories of moving from a birth-assigned gender (Dale 2021). It describes euphoria in relation to "dysphoria". A *DSM-V* sub-section "Gender dysphoria with a disorder of sex development" claims individuals in the cohort may experience «*uncertainty about their gender, as opposed to developing a firm conviction that they are of another gender*» as they become aware of «*their condition and medical history*» (American Psychiatric Association 2013, 517). Some people with intersex variations may find recounting dysphoria enables access to interventions or describes disruption to identities from enforced treatments; and studies estimate 8.5–20% of the cohort experience it (Furtado *et al.* 2012). Euphoria lacks the validated status of dysphoria, and is unexamined for prevalence in people with intersex variations.

Academic euphoria studies are recent, Western (from the US, Canada and Australia), sociological and focussed on TGD populations rarely including people with intersex variations (Beischel *et al.* 2021; Benestad 2010; Bradford *et al.* 2019; Lester 2004; McKinney 2021). In some individuals discuss euphoria. One therapist noted their gender therapy aims at congruence between the individuals' sense of gendered or non-gendered self, and external perceptions of them, towards belonging and euphoria (Benestad 2010). Lester explored how disruption of socially constructed gender codes in drag and painting work provides opportunities for positive experiences of self (Lester 2004). Larger studies included an online qualitative survey of 47 transgender, cisgender, and/or nonbinary participants who answered open-ended questions (Beischel *et al.* 2021). They defined gender euphoria as:

1. a joyful feeling of rightness in one's gender/sex,
2. external, internal, and/or social experiences,
3. originating in and circulating in online and in-person gender/sex minority communities,
4. oppositional to dysphoria in nature, and
5. having a complex relationship to dysphoria.

In-depth semi-structured interviews with 13 TGD participants suggested gender euphoric desires were filtered through cis-normative cultural lenses, resulting in dysphoria (McKinney 2021). Without socio-cultural redress only the linear journey

from one cisgender category to the other was given to participants as a material solution to socio-cultural problems; and euphoric self-imaginings. A US online survey of 281 transfeminine adults found associations for hair removal with both gender euphoria and dysphoria; including decreased distress, and increased well-being (Bradford *et al.* 2019). Thus, more elements to euphorias include:

6. medicalisation/disordering of identity and medical changes,
7. material/embodied expressions of identity and material/social change,
8. difficult mental health around identity and wellbeing,
9. idealisations versus embodied realities, and
10. problematising socio-cultural contexts.

An affirming sociological study solely exploring people with intersex variations' experiences of euphoria was needed, to overcome research gaps and explore such elements. The present study considers:

1. What are the euphoric (happy or comfortable) experiences of people with intersex variations like?
2. Why do people with intersex variations experience euphorias (what do these relate to)?
3. How do the euphorias of people with intersex variations change over time?

2. Methods

2.1 Online Survey

An anonymous online survey was used to collect the data on people with intersex variations aged 16yrs+. The researcher formed a reference group of individual representatives from the Androgyn Insensitivity Syndrome Support Group Australia (AISSGA); Organisation Intersex International (OII) and the Australian National LGBTI Health Network, who commented on some completed drafts of the survey design, recruitment ideas and reporting. They advised on language sensitivity. The survey contained both forced-choice (quantitative) and open-ended (qualitative) questions developed by the researcher and advised on by the reference group. It had 10 pages and 61 questions, and completion times varied greatly (between 15min-2hrs). It was hosted by Survey Monkey hosted on a UNE Australia site, and by a URL that included the term 'ausvariations'. Ethical approval was obtained for this project from the UNE Human Research Ethics Committee.

Participants self-selected to join the research, and had the right not to answer any question. The younger participants (aged 16-17) were not required to seek parental approval for their participation, in recognition of anecdotal reports of discrimination or abuse. The survey also supplied links to related help lines and support groups. It opened in May 2015, and closed after two months. It was distributed by AISSGA, OII and the Australian National LGBTI Health Network groups and networks online. It was also promoted by health services, newspapers, private intersex networking sites and e-lists, advocates and word-of-mouth.

2.2 Data analysis

Final survey quantitative data were downloaded from the Survey Monkey site and then transposed into quantitative computer programs (SPSS v10, Excel). The data were screened and cleansed, those survey participants that did not fit the target group

were excluded (those who had did the survey by mistake, abusive attempts and so on). Descriptive statistical analyses were undertaken for the participants with intersex variations, and grounded thematic analyses of their written responses. There were no significant test results by age, sex or location for the data reported here.

Initial codes were developed from the survey written responses around euphoria using Grounded Theory. Two fluid coding stages placed a focus on emergent categories/strategies (Charmaz, Bryant 2011). The automated content analysis programme Leximancer, historically used in sociology and psychology studies (e.g. Cretchley Rooney, Gallois 2010) was firstly applied to analyse participants' comments on two questions where they explained why they felt "good" or "very good" about their intersex variations on diagnosis when taking the survey (post-diagnosis). All positive answers for each question were collated into PDFs, and uploaded to Leximancer. Leximancer uses word occurrence and co-occurrence counts to identify dominant themes and their sub-concepts, and how they relate. It was applied to ensure dominant thematic concepts and their "typical" quote samples were identified and examined systematically based on data representativeness. Reproducible concept maps evidence how participant comments' over-arching themes and sub-concepts related, as auto-generated by Leximancer, with theme titles named for the dominant sub-concept in each cluster. Equivalent concepts in different tense or quantity, were merged in concept-editing stages (e.g. "feel" and "felt", "person" and "people"). Map settings were kept at "100% visibility" so all sub-concepts Leximancer uncovered were visible, and "50% theme size" to show common theme overlaps. Leximancer algorithms are detailed and verified by Smith and Humphreys (2006); for "showing" (not imposing biases in "searching for") concept relations.

All Leximancer-identified themes were secondly elevated for theoretical sampling, tracing euphorias' feelings, stimuli, processes and outcomes. Open coding processes included line-by-line coding, so different euphorias within a single story were separated out for cross-checking of concept-level and individual-level "meanings". Finally, the researcher engaged in coding actions to expose implicit and explicit connections between euphorias.

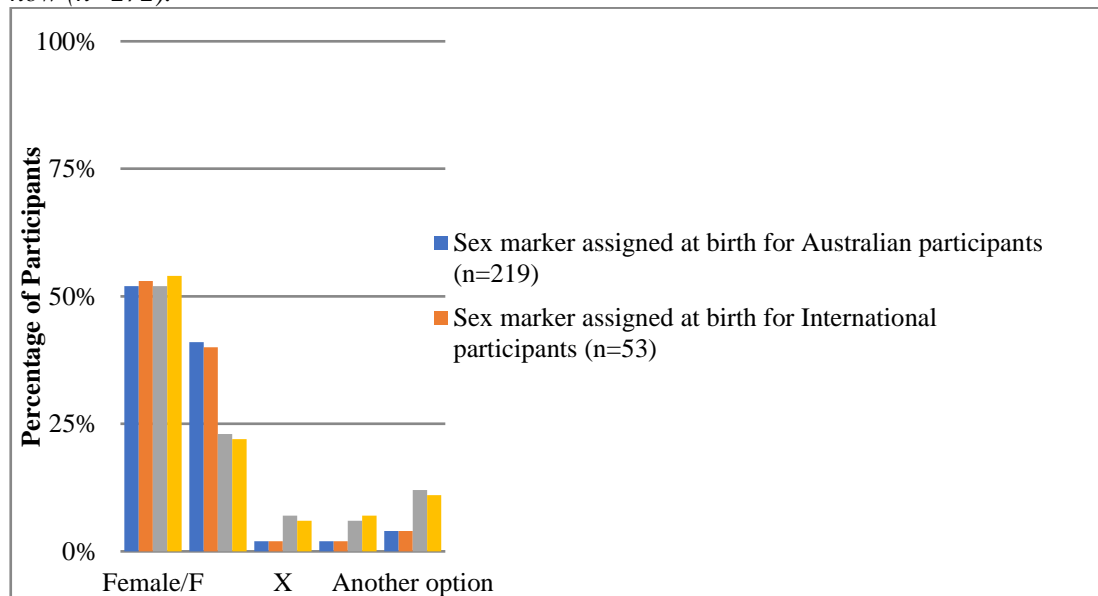
3. Results

3.1 Demographics

Overall, 272 people with intersex variations aged 16-87yrs completed the survey, with the average age 36yrs. All Australian states were proportionately represented in the study, and 4% of these participants were Aboriginal or Torres Strait Islander. One fifth of participants currently lived internationally – mainly the USA and UK. In total 52% of the participants were allocated a female sex at birth and the same portion used that marker now; however 41% were allocated a male sex at birth yet only 23% used that marker now (see Figure 1). The decrease in the use of male sex markers since birth allocation was explained by an increase in identification as alternative sex options later in life (X, unsure, another option). However, only 8% of participants identified as being transgender; changes in sex marker use mainly related to individuals' fundamental disagreement with medical practitioners' assessment of their physical sex characteristics (not gender identity). Whilst 27% of the group had disabilities (including some related to intersex variations e.g. anosmia, motor skill

development delay, movement impairments, osteoporosis etc.); only 12 individuals reported diagnoses of gender dysphoria.

Figure 1. Comparing people with intersex variations' sex marker assigned at birth and used now (n=272).



Over half the participants had experienced two medical treatment interventions related to their intersex variation, commonly reported interventions were hormonal treatments and genital surgeries delivered to participants when aged under 18yrs. The majority had experienced at least one negative impact from surgery (from scarring, to decreased genital sensation, depression/anxiety/PTSD, to life-threatening septicaemia). Participants were asked to select any variations that they were born with from an alphabetised list of over 30 options from 5-alpha reductase deficiency (5-ARD) to XY-Turner's Syndrome, including 'unknown' and 'another option'. On average, the 272 participants reported two variations (see Table 1). The most strongly represented were Androgen Insensitivities; Hyperandrogenism from Polycystic Ovary Syndrome (PCOS); XXY/47 and Klinefelter's Syndrome (the latter two in combination) – these variations have greater prevalence and support groups via which the survey was promoted.

Table 1. Variations experienced by participants (n=272)

Answer Choices Responses	Responses
5-alpha reductase deficiency (5-ARD)	2
17-beta-hydroxysteroid dehydrogenase deficiency	3
Aphallia	1
Bladder exstrophy	4
Clitoromegaly (large clitoris)	14

Classic Congenital Adrenal Hyperplasia (Classic CAH)	10
Complete Androgen Insensitivity Syndrome (CAIS)	20
Cryptorchidism (undescended testicle/s)	17
De la Chapelle (XX Male Syndrome)	4
Epispadias	1
Fraser Syndrome	2
Gonadal dysgenesis (partial or complete)	8
Hypospadias	12
Jacobs/ XYY Syndrome	2
Kallmann Syndrome	4
Klinefelter Syndrome	25
Late Onset Congenital Adrenal Hyperplasia (late onset CAH)	2
Leydig Cell Hypoplasia	1
Micropenis	21
Mosaicism involving 'sex' chromosomes	7
MRKH (Mullerian agenesis; vaginal agenesis; congenital absence of vagina)	6
Mullerian (Duct) Aplasia	1
Ovo-testes (formerly "true hermaphroditism")	16
Partial Androgen Insensitivity Syndrome (PAIS)	24
Persistent Mullerian Duct Syndrome	0
Polycystic Ovary Syndrome (PCOS)/ Hyperandrogenism	38
Progestin Induced Virilization	1
Swyer Syndrome	4
Turner's Syndrome (TS, one X chromosome)	10
Triple-X Syndrome (XXX)	1
XXY/ 47	31
XY/XO Mosaics	8
XY-Turner's Syndrome	2
Unknown	22
Another variation	29

3.2 Feelings Upon Diagnosis

Most participants (64%) learned of their variation for the first time at under 18yrs, a third as adults, and a small number were unsure of the finer details of their variation. To investigate participants' feelings about their intersex variations over time, the survey asked participants how they felt about their intersex variations when they first found out they had them. From the range of options provided 7% selected 'Very Good', 12% 'Good', 33% 'Neutral', 20% 'Bad' and 28% 'Very Bad' (see Figure 2, n=270). Euphoria was thus possible but uncommon on diagnosis: 19% of participants felt positively about their variations on diagnosis. Participants negative feelings on diagnoses are reported elsewhere in detail (Jones *et al.* 2016). Of the 51 participants who had positive feelings on diagnosis (19 who felt very good and 32 who felt good), six had reported experiencing gender dysphoria. Almost all (n=50) those who had positive feelings provided comments on these feelings. Leximancer found five themes in these responses: felt, different, knew, medical and due (Figure 3).

Figure 2: Comparing how participants felt about their intersex variation/s when they first learned of them, compared to how they felt about their intersex variation/s now (n=270)

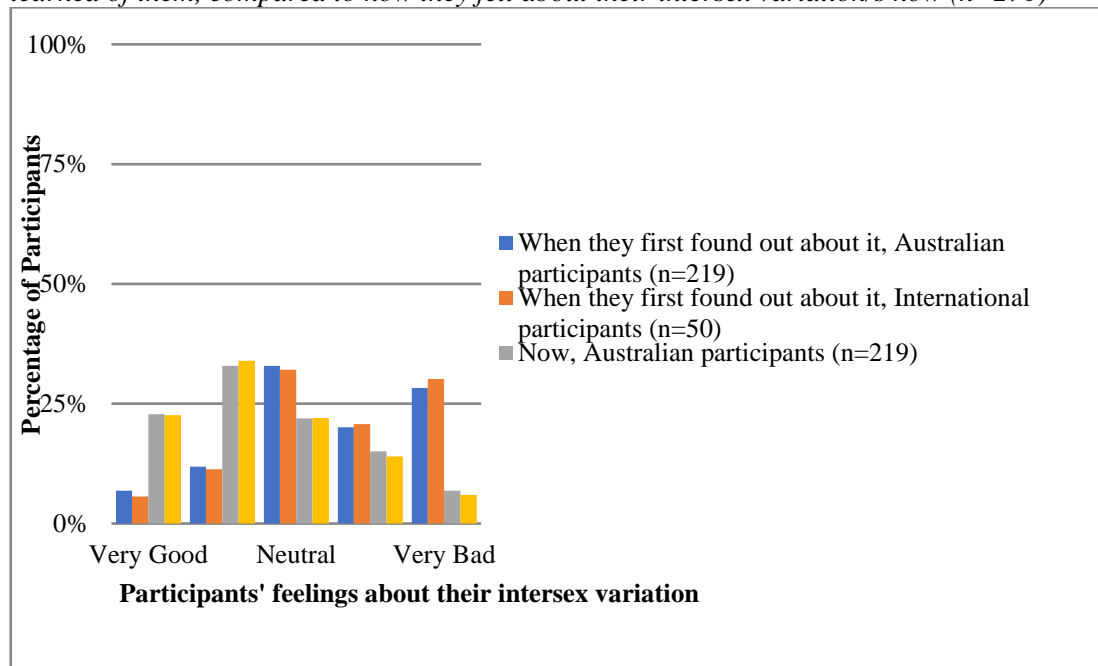
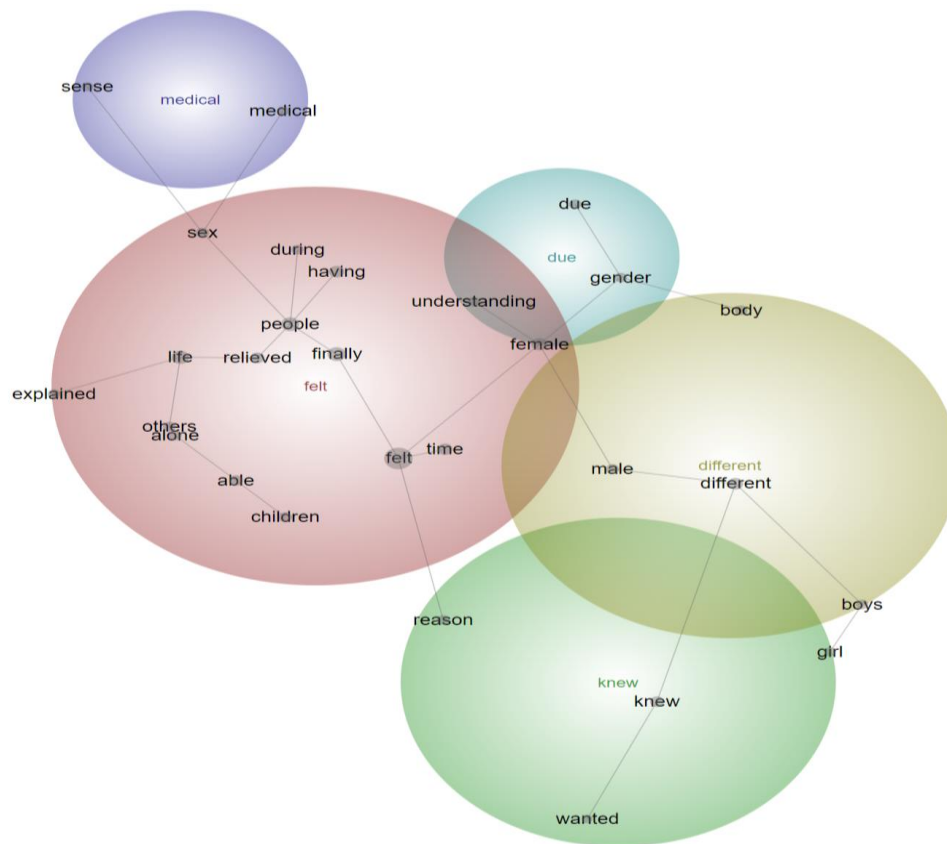


Figure 3: Leximancer map for themes in participants’ comments on why they felt “good” or ‘very good’ about their intersex variations upon first learning of them (n=50).



Theme	Hits
felt	27
different	10
knew	7
medical	3
due	3

“Felt”: Category Validation euphoria

The largest Leximancer-identified theme was “felt” (27 hits, 100% relationality to – meaning consistent co-occurrence with – all other concepts). This theme focussed on participants’ elation and relief upon finally having a category or group they belonged to and feeling less alone (combining the sub-concepts: felt, finally, people, life, female, having, time, relieved, able, children, sex, alone). Zoe (intersex woman with CAIS, 53yrs) felt good learning about her intersex variation: «I was relieved to understand why my body was the way it was». It helped her feel part of and connect to a social group, and she commented: «I had felt very alone with it for a long time, so it was good to put the pieces of the puzzle together and then to be able to meet others

with AIS was a huge relief». Dylan (man with intersex variations PAIS and Hypospadias, 24yrs) had described having periods of suicidal ideation and confusion about his gender and sex prior to diagnosis, when he finally felt “very good”, described as relief and elation:

«I have had difficulties with knowing who I am; knowing I am intersex was a big break through. It was entirely life affirming and so brilliant to have the truth out and to know why I am how I am (...) why I felt like I could be female sometimes. I had thought I was crazy. I am not crazy. I am intersex!»

Dylan also described a recurrent euphoric experience of participating in the survey and affirming his identity category as “intersex”, reporting that this was “energizing”. Similarly, Jamie (X intersex individual with CAH/21 hydroxalase deficiency, 39yrs) was raised male but came to frame themselves within an ‘X’ category, and intersex. Upon diagnosis, Jamie felt relief and hope to join a category and act within it:

«I was very relieved for a number of reasons. First, there were others, though only two I found, recorded and like me, so I was not alone. Secondly, it explained to me why I was like I was, most of my issues are common with my condition, it was like a breath of hope. Finally, I am able, if I get help, to live a somewhat normal life and not have to be something I’m not anymore».

Cary (intersex woman with Classic CAH and Clitoromegaly, 19yrs) felt ‘good’ when she learned about her variations; she described being elated and amused with her girlfriend about her difference, and said the diagnosis aided her use of more categories; «Sometimes queer when I feel like I am genderqueer or feeling more like a boy. Baby butch is ok too». She commented on her gleeful feelings over the “serious” diagnoses time: «It seemed right. It was sort of funny and sort of our joke, and then it was more serious but it was not a problem, it made sense. I think having my girlfriend there makes things special and sort of something we are doing together, it is tied to our sex life...».

Though her doctor had recently recommended reducing the size of her clitoris; Cary rejected this: «if anything I feel a bigger clit would be more fun». Similarly, Clara (trans-woman with intersex variation Klinefelter’s Syndrome/47 XXY, 21yrs) was overjoyed when she learned of her Klinefelter’s Syndrome diagnosis. Like Cary she wanted to explore the positives of her diagnosis for identity categories. She said: «I felt that I now had a reason for how I felt growing up, I have always felt more like a girl than a boy».

Karma (transgender non-binary intersex person with PCOS/Hyperandrogenism, 25yrs) said they felt “good” about having PCOS/Hyperandrogenism because it helped them identify as non-binary; «I never identified as female, and was relieved that I did not develop wide hips or breasts». Similarly, Celine (woman with XXY/47, 50yrs) felt “very good” in the moment of diagnosis and «related that I finally had a confirmation my gender was genetically different to anything “standard”». She resisted the suggestion from medical professionals that most people with XXY/47 relate to a male sex; living as female and feeling her karyotype further validated this category. The *Category Validation euphoria* identified within the “felt” theme was overall the most central euphoria uncovered by Leximancer in participants’ comments on diagnosis. It had strong connections to the “medical” and “knew” themes, and visible overlaps with comments in the “due” and “different” themes.

“Different”: Difference Legitimation euphoria

The second largest Leximancer-identified theme was “different” (10 hits, 35% relationality to other concepts). This theme describes feeling legitimised as unique or special in the moment of learning of one’s intersex variation/s, and the theme was especially associated with people who were allocated a ‘Male/ M’ sex on their birth certificate and celebrated having a differentiation from typical male bodies or identities (combining the sub-concepts: different, male). Ahmed (intersex man with micropenis, 29yrs) said he felt good about his diagnosis because: «I suppose it was a combination of being different and legitimised. I also think it’s very interesting (...) Part of me also likes that T [testosterone therapy] enhances my erections rather than being responsible for growth». Selma (intersex woman with 47XXY, 24yrs) felt good about the difference implied by her diagnosis, because up until that moment she too had been unduly cast as male. Male identity was something her diagnosis released her from, legitimising her feelings of difference: «It felt good since I knew something was different and I related more to girls than boys as a child. So given that I had learned in school that girls are xx and boys xy. This was kind of a proof to why I felt like such an outsider».

Jordan (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) also said diagnosis legitimised his sense of difference from other boys. He noted that it: «Merely confirmed my androgynous, non-sexual sense of self. Had known I was different to the other boys since early childhood, but didn’t have an explanation why. Knew I wasn’t gay, but didn’t have the language to describe what I was».

For several participants whose comments fell under this theme, the initial joy at difference was not lasting. Bailey (intersex non-binary individual with Klinefelter’s and ovo-testes, 25yrs) found being diagnosed with their intersex variations made them feel “very good”, commenting «it was a relief to me to learn that I was neither male nor female, or that perhaps I was both or something in between». However later Bailey went through difficulties with being pressured by parents and doctors to be more masculine, and phases of competing with others at school or hiding their difference. Similarly, Angelina (intersex female with PAIS, 35yrs) said she initially felt “very good” and commented that on diagnosis: «I felt really good about it, because it explained so much. It was like everything in my life finally clicked». Her family «accepted it without question». However, the initial euphoria later left; «once it sunk in I was Intersex, I got depressed for nearly two months». Scarlet (female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs) said that she felt “very good” about not being male in a traditional sense, but nonetheless her euphoria was complicated since her diagnosis included fertility issues «it was bad enough having a female gender identity and consequent Gender Dysphoria due to a male body, but to have a “defective” one with very limited fertility seemed very unfair». Scarlet’s euphoria over differentiation from male identity was at times complicated by dysphoria or other factors and was not a permanent state. Noreen (transgender intersex woman with Cryptorchidism, 61yrs) also reported feeling “good” about her variation on diagnosis later in life, because it explained her feelings of difference. However, her variation also had created difficult past impacts (contributing to her past divorce), and the diagnosis brought up hard memories. So, her euphoric feelings came with anger, bitterness and mixed sensations. She said:

«It was a bittersweet revelation as I didn't know whether to be angry or to have a good cry. It was good though to finally know why I'd always felt like a fish out of water all my life. After years of my young life spent blaming myself as I grew up for not being able to measure up as a male, I now knew the reason why».

The *Difference Legitimation euphoria* in the “different” theme had overlaps with the *Category Validation euphoria* seen in the “felt” theme and other euphorias. It especially overlapped where several participants had “always felt” different.

“Knew”: Knowledge Integration euphoria

The third largest Leximancer-identified theme, and largest stand-alone theme (without sub-concepts) was “knew” (7 hits, 30% relationality). This covered the pleasure of having a kind of pre-existing subliminal knowledge about one's intersex variations confirmed on diagnosis. It was mostly coupled with a wish to have had the direct knowledge earlier, and so constituted both pleasure and yearning. Victor (man with Kallman's Syndrome, 28yrs) felt “good” in the moment of diagnosis because it confirmed an indistinct ‘inner knowing’. He said: «I knew there was something about me, but I did not know what it was. Knowing you have KS helps and I wish I had known earlier. It sounded weird to other people but it did not sound weird to me as it fit so many parts of me».

Nadine (woman with intersex variations Clitoromegaly/ Classic CAH, 53yrs) said she was feeling “good” in her moment of diagnosis because it fit what she knew already.

«I was glad to find an explanation of why I looked and felt different to other girls I knew. I was in a good supportive relationship with a loving girl who found my body sexy, as the two boys had before her, and my body had never been treated as anything but fit and attractive on the dating scene. So there was no fear of rejection or concern about my health. It just felt like a useful revelation that put words to feelings and answered questions, and made sense of memories like the hospital visits, and the pills conversation».

She was pleased she had avoided genital surgery and declined hormone pills; «I loved my lean body while lots of my girlfriends were fatter and had big baggy breasts slowing them down. Mine were cute and perky».

Cameron (man with XXY/47 and Klinefelter's, 66yrs) said his diagnosis made him feel “good” because it confirmed his knowledge that his body was unique, saying «I knew why I had the lumps and to some extent, I felt special». He found out about the variation in the context of sterility later in life, and so wished he had learned about it earlier because it would have confirmed his suspicion that he had differences in his hormones and could have allowed him more testosterone therapy options earlier. Mia (intersex woman with clitoromegaly and unknown variation, 24yrs) said she felt “good” upon receiving her diagnosis, because «I knew I was a bit different. I have no desire to be a man but I do not feel or look like a girly girl either». It was pleasurable to confirm what she knew subconsciously. It also helped that she had experienced pre-diagnosis positive exposure to people with intersex variations at LGBTI events including Mardi Gras, where there were intersex people:

«I did not know it at the time, but seeing those intersex people at Mardi Gras meant a lot to me when I was first getting the results and starting to look into this. It was something my girlfriend and I talked

about, those people and how happy they were. The fact they did that, meant I did not feel alone when I found out».

Mia's story showed how some participants both knew, and didn't know, about their intersex variations simultaneously pre-diagnosis.

The "knew" theme overlapped with the "different" theme, through stories like Jordan's (intersex individual with intersex variation 47/XXY/Klinefelter Syndrome, 56yrs) where the participant always knew they were different. The *Knowledge Integration euphoria* identified in the "knew" theme had strong relationships to individuals' past knowledge of or exposures to communities, people or traits related to intersex variations.

"Medical": Medical Sense-making euphoria

The fourth largest Leximancer-identified theme was "medical" (3 hits, 13% relationality). It comprised the joy of sense-making upon medical intersex diagnosis, with few sub-concepts (medical and sense). The "medical" theme also particularly linked to the "felt" theme through stories like Cary's and others', where one or more medical diagnoses made sense of a feeling that the participants already had, that they aligned with a sex category or social cohort different to the one they were assigned at birth. Clara (trans-woman with intersex variation Klinefelter's Syndrome/47 XXY, 21yrs) commented that her diagnosis provided medical sense-making of her sense of self as female: «With the diagnosis I felt I could finally be myself as I now had a medical excuse as to why I felt this way».

Drew (intersex person with Cloacal Exstrophy, 36yrs) commented that their diagnosis gave them a base-line of 'good' feelings about being intersex, because it made sense of their identity. Despite later difficulties and challenges around their identity, they argued that because they had positive support and experiences of care around the initial medical explanations, the initial positive sense-making processes mediated relations with family, and harder times later on, and «due to having two ostomies and other medical complications I was brought up to be resilient and independent». So, participants' comments revealed that *Medical Sense-making euphoria* identified within the "medical" theme potentially had a relationship to positive treatment by medical professionals and family. It also related to *Category Validation euphoria*.

"Due": Sudden Hope euphoria

The smallest Leximancer-identified diagnosis theme was "due" (3 hits, 13% relationality). This stand-alone theme (without sub-concepts) explored sudden hope upon diagnosis for understanding or envisioning a better future occurring *due* to its contrast against preceding negative contexts of confusion or difficulties. Blake (man with XXY/47, 49yrs) described a "good" sudden hope feeling on diagnosis, because it gave him the knowledge to overcome sexual issues he was experiencing with his wife and some context for the bad treatments he had experienced without explanation as a child. Information was hope-inducing for Blake, in the context of having previously had information withheld, since «Knowledge helps us to live well. Research must continue to allow everyone a better quality of life».

Reese (intersex woman with CAIS, 40yrs) described a sudden euphoric “very good” hopeful feeling upon diagnosis:

«I finally felt like I had found the answer I was searching for! There was a name, and other people who had this, and an answer as to why I felt different to other female friends. Definitely shock and confusion at first due to not understanding or knowing of these variations prior to now, however a feeling of finally understanding myself. Lack of support for myself and my family at this time however affected our relationships (...) This new information allowed me to be involved in the (intersex-related community support group) which then gave support...»

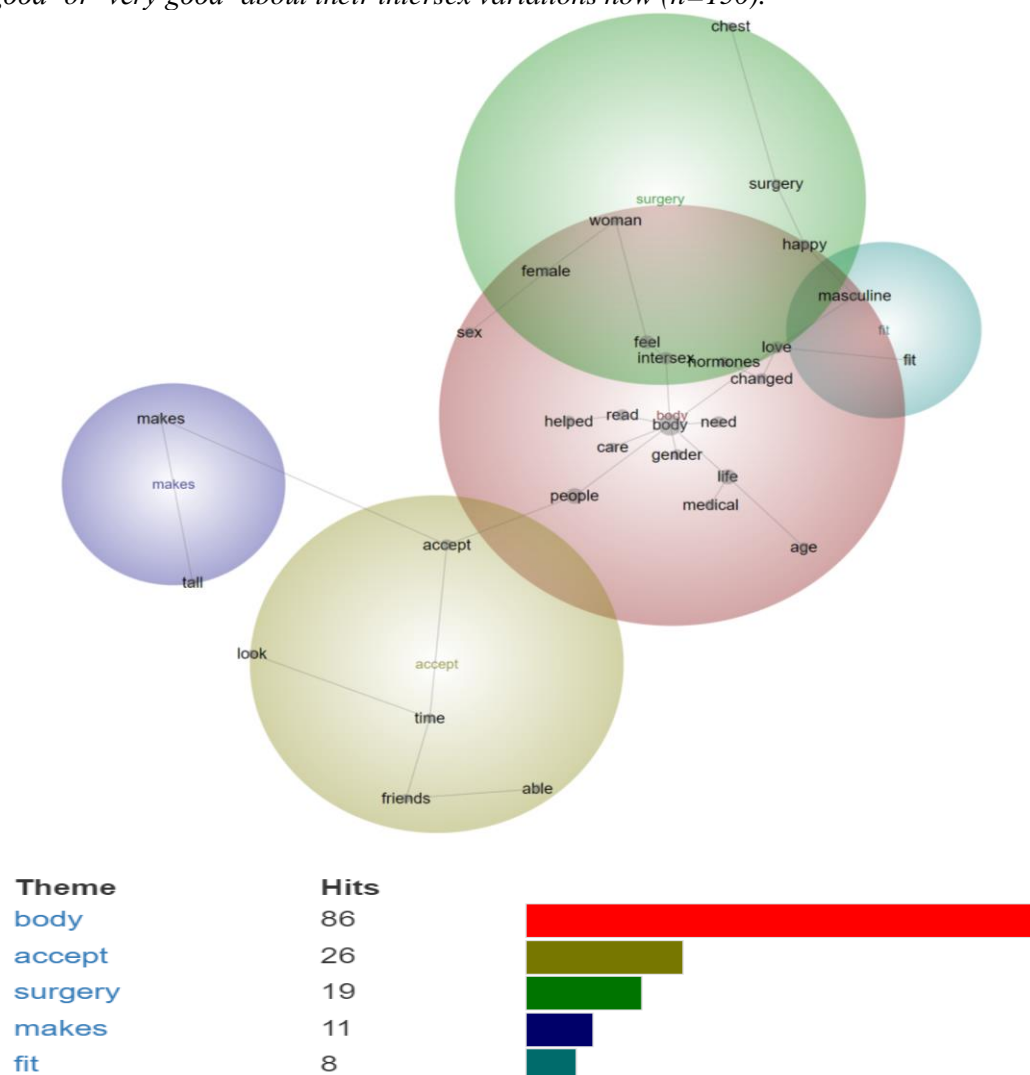
Being diagnosed in a context of negative prior understanding and relationships; meant Reese saw the diagnosis as hopeful and an impetus for seeking understanding and social supports.

The “Due” theme thus suggested that *Sudden Hope euphoria* may occur for some individuals upon diagnosis. It especially was due to a break from prior hopelessness, negativity and/or confusion.

3.3 Positive Feelings Now/Post-diagnosis

The survey also asked participants how they felt about their intersex variations at the time of taking the survey/post-diagnosis; 23% selected “Very Good”, 33% “Good”, 22% “Neutral”, 15% “Bad” and 7% “Very Bad” (see figure 3, n=270). Most (56%) participants felt positively about their intersex variations now/post-diagnosis (on average over a decade post-diagnosis); well over twice as many felt good post-diagnosis than on diagnosis. Thus, the quantitative data showed that participants felt better about their variations over time and ultimately appeared to have mostly positive experiences of intersex variations as time went on, despite having felt mostly negatively initially. Of the 56% of participants who had positive feelings post-diagnosis (62 who felt very good and 89 who felt good), nine had reported experiencing gender dysphoria. Almost all of those who had positive feelings post-diagnosis (n=150) provided comments on these feelings. Leximancer found five themes in the comments: body, accept, surgery, makes and fit (Figure 4).

Figure 4: Leximancer map for themes in participants' comments explaining why they felt 'good' or 'very good' about their intersex variations now (n=150).



“Body”: Body Positivity euphoria

The largest Leximancer-identified theme was “body” (86 hits, 100% relationality to – meaning consistent co-occurrence with – all other concepts). It focussed on how participants shifted towards increased experiences of body positivity across their life often after a negative experience of diagnoses (combining the sub-concepts: body, people, life, feel, intersex, love, read, helped, need, changed, gender, hormones, medical, happy, sex, age, care). For some this shift to body positivity occurred when they saw or met other people with intersex variations who provided positive examples. Lily (intersex woman with Mayer Rokintanky Kuster Hauser Syndrome – MRKH/congenital absence of vagina, 31yrs) had “very good” feelings about her intersex variation now, years after “traumatic” medical treatment incidents upon diagnosis in her teens and periods of self-harm. Connecting to other people with intersex variations was life-changing for Lily, creating a positive feeling of connection to her body and to those loved it:

«The intersex community changed my life. Becoming connected and becoming an activist and educator changed everything. I love my intersex body and have found partners that do, too. My fears about being a freak and being rejected simply haven't played out».

Fernanda (female/X with PAIS, 25yrs) also felt “very good” about her intersex variation and body now, and explained that this shift was inspired by intersex community groups that «affirmed intersex body-positive ideas»:

«I spent so much time revising everything they had taught us in school, in the media, in daily life about bodies. I felt so much better about my body knowing it was just one of many possibilities, and one of the many body types that is not accepted or celebrated as it should be (...) more than anything it helped to know some intersex people who loved their bodies and believed I too could love mine.»

Jannali (intersex female with CAIS, 25yrs) also now shifted to feeling “very good” about her body due to online intersex contacts:

«Meeting happy, healthy intersex people online caused a complete and radical shift in my thinking and wellbeing. Seeing that they had come out about being intersex, and that they liked themselves, that some had partners, and that they sometimes even talked about having had and enjoyed various kinds of sex, that they had found all these ways to have children and jobs and lives... BEST. THING. EVER!»

Warren (intersex man with unexplained scarring, 38yrs) he finally felt “good” when «I started to meet other intersex people and find social support» around his body. This aided his positive changes:

«I started to find medical professionals who treated me with respect and care, instead of bullying me into hating my body or doing interventions that I didn't want to do. I take better care of my body and am more likely to seek medical care now when I need help...».

For some participants, euphoria around body positivity was inspired by reading body positive texts. Edwina (woman with intersex variation MRKH Syndrome, 27yrs) had negative schooling and medical experiences which initially made her feel “very bad” about her body when she was younger. However, body positive reading had often created “very good” feelings of validation of her body and:

«...helped me to see the pressure placed on women's bodies (...) The more I read and talk to other people with bodies like me, the more I know the stories we are sold about living up to sex ideals are the stories that make us feel we can not live. I have let those old ideas go now.»

Fernanda also added, «it helped to read about feminism, gender theory».

The *Body Positivity euphoria* evident in the “body” theme was the most central and dominant euphoria in the study. It had relationships to the most euphorias in Leximancer's map overlaps and participants' comments post-diagnosis, showing connections to the “surgery” theme, and visible overlaps with the “fit” and “accept” themes.

“Accept”: Acceptance euphoria

The second largest Leximancer-identified theme was “accept” (26 hits, 31% relationality to other concepts). This theme focused explored increased individual self-acceptance or social acceptance over time (combining the sub-concepts: accept, time,

able, friends, look). Ralph (man with intersex variation 47/XXY/Klinefelter's, 42yrs) had a history of negative experiences, like being bullied, attached to his having low testosterone. However, he increasingly had moments where he felt "good" about himself as he became more self-accepting, and more accepted by family and friends. He stopped using drugs three years and had increasingly disclosed aspects of his identity to people in his life. He said: «I've been able to connect with so many people and share what I am experiencing. Since "coming out" couple years ago to my family and friends about my cross dressing, I have been able to accept who I am today».

Raj (man with 17-beta-hydroxysteroid dehydrogenase deficiency, 26yrs) said he felt 'good' now with increased self-acceptance, because «I am getting the look I want and accept what happened [*to my body*] and why». He also was increasingly more able to discuss his variation or body with his accepting colleagues above other people in his life, «colleagues were better as they did not have anything invested in how I am, they just like to hang out. [...] That kind of acceptance feels good and I like being able to talk to them about it». Jonah (man with XY/XO Mosaics, 63yrs) commented: «I'm content with my body. When I first found out that my XO cell line was responsible for my feminine face (due to micrognathia) I was angry. (...) It took some time, but I grew to accept my body».

Younger people in this theme group especially commented on satisfaction about body parts they accepted. Giana (woman with intersex variation PAIS, 17yrs) commented that she came to accept herself: «I like my body, how I look, how boys like it. Girls get jealous that I am not hairy, and don't have to wax all the time». Vita (intersex woman with Kallman's Syndrome, 18yrs) commented: «I like my little boobies! I am still a bit skinnier than most girls». The *Acceptance euphoria* in the "accept" theme had an overlap with the "body" theme and body positivity in the Leximancer map. It also had a connection to the 'makes' theme.

"Surgery": Autonomous Control euphoria

A third Leximancer-identified theme was "surgery" (19 hits, 19% relationality). It comprised feelings of achievement for those who had experienced increased autonomy and personal choice/control around their identity, information, hormonal and/or surgical treatments (combining the sub-concepts: surgery, woman, female, chest). Sloan (individual with PCOS/hyperandrogenism, 45yrs) had felt "very bad" upon diagnosis but felt 'good' and happy after engaging in a survey at their own direction, with a potential for creating 'very good' feelings in future: Surgery and hormones have changed my body slightly, but I believe living in the appropriate gender for me has made me happier with my body more than medical interventions. I would choose very good, but I need to go to the gym for that».

Sherry (woman with PAIS, 55yrs) also felt "very good" and happy with the level of control she now had over her surgical and hormonal interventions, which had increased. Chris (intersex individual with 47/XXY, 44yrs) felt "Very Bad" about the initial experience of receiving minimal information about their diagnosis as a teen, but had more recently received full access to their medical records on their chromosomes and had greater control over interventions. Chris now felt "Very Good" about their variation, commenting on their recent chest and genital surgeries:

«It cost me a pack of money and the results are ok (...) But frankly I am very happy because these are the changes I wanted and this is the person I am. Finally being able to realise and say who I am, and doing what I wanted to do about that has made a massive difference to every aspect of my life».

Dana (woman with XXXY chromosomes, 45yrs) felt “good” and satisfied due to her increased information about her variation and control over her identity and body. She said: «initially, I was gendered female, then they sealed that and made it look as if no previous record had existed. I have now been able to get the original with the original registration date reinstated». She reflects that now she increasingly feels self-love after controlling her surgeries: «You just learn to love yourself, made it a lot easier after recent surgery to undo damage done». Andy (intersex man with Jacobs/ XYY Syndrome, 34yrs) felt “Very Bad” upon diagnosis as a teen, because he said he did not know exactly “what” he was. He reflected that after this exposure to intersex support groups online he now feels “Very Good” about his variation and has more information and treatment control: «When you know what you are, you can learn to live with it». Elaine (trans intersex woman with Klinefelter’s Syndrome, 31yrs) had gone from feeling “bad” upon her diagnosis to “good” now. She was initially raised as male, and transitioned to female later in life and was forced to divorce, lost her mortgaged home and was estranged from family and couch-surfing. However, her control over some interventions now made her experience poignant moments of being «happier than ever». Nina (intersex woman with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) now felt “good” but had experienced many difficulties when younger. She felt much happier and more ‘in control’, despite pressure, since being able to control her interventions:

«I feel like being female is what my body was naturally trying to do... maybe I did not need all the procedures but I feel it all works. I have a designer vagina! Very perfect body, my friends say. My regrets are just that it needs to be perfect. You never stop being seen as intersex or trans (...) So I feel more pressure...»

The *Autonomous Control euphoria* evident in the “surgery” theme overlapped with other types of euphorias identified for the “body” and “fit” themes through several stories, as seen in the Leximancer map. This suggested relationships to *Body Positivity* and *Fitness Edge euphorias*.

“Makes”: Relative Gains euphoria

A fourth Leximancer-identified theme was “makes” (11 hits, 19% relationality). It includes positive feelings on relative gains people had around having intersex variations compared to endosex (non-intersex) people or their own or others’ varied experiences of intersex variations (combining the sub-concepts: makes, tall). Gains could be to one’s height, strength, uniqueness or social differentiations in positive ways. Some participants experienced relative positive feelings in comparison to other peoples’ bodies or experiences. Gabriel (man with intersex variation XY/XO Mosaics, 19yrs) used to find being shorter than others difficult, but now he feels “good” about being intersex, as it «makes you stick out». Stewart (man with intersex variation Klinefelter’s/XXY, 39yrs) said HRT helped him to look masculine and he felt it gave him advantages his brother did not have that made him feel “Very Good”. He commented: «Like being tall, like being on T. My brother did not have this. He’s not

as good looking ;»). Siobhan (girl with intersex variation TS or “TS butterfly”, 16yrs) described a special feeling around giving a speech at her school on her Turner’s Syndrome, when the students gave her a standing ovation: «It makes me feel so much more special». She also liked getting taller; «I’m growing a bit! It is exciting». Vincent (man with intersex variation XXY/47, 49yrs) enjoyed feeling “Very Good” now when realising he was more interesting than other people, or than if he had been endosex: «It is now a point about me I find interesting and unusual. There is not much else about me that makes me unique».

Some participants experienced relatively happier feelings in comparison to their own earlier or compartmentalised feelings or experiences. Marcia (intersex woman with Turner’s Syndrome, 27yrs) said that she got «happier as I get older». Barbara (trans intersex woman with PAIS, 40yrs) had felt “Very Bad” about her intersex variation growing up due to poor socialising, but now felt “Very Good” as «Hormones and hair removal have made a huge difference». Gordon (man with intersex variation Klinefelter’s Syndrome/47 XXY and micropenis, 21yrs) often felt “good” about his height and that contrasted against unhappy feelings around other aspects of his body: «Being tall makes up for so much. Unhappy about my teeth». Briony (woman with Turner’s Syndrome/One X Chromosome, 30yrs) had felt bad early but now felt “Very Good” about her gains from TS: «Very good about the body, I am old enough to know you only get one and everyone has some complaint or another. My complaint is the infertility, TS itself just makes me special and more open-minded. I think it made me stronger».

The “makes” theme had a link to the “accept” theme and sub-concept. This suggests connection between *Relative Gains* and *Acceptance euphorias*.

“Fit”: *Fitness Edge euphoria*

The smallest Leximancer-identified theme was “fit” (8 hits, 14% relationality). It comprised positive feelings some participants had around how their intersex variations enhanced fitness, litness, muscle-tone or masculinity (combining the sub-concepts: fit, masculine). Kelly (intersex woman with clitoromegaly and Congenital Adrenal Hyperplasia, 19yrs) felt “very good” about their fit body and masculinity, saying: «I’m happy with it, I am fit and strong. I like sex a lot and would not want to wreck that. I don’t have big boobs or anything so I look androgynous which is what I like and what my partner finds attractive».

Nina’s (intersex woman with 3beta hydroxysteroid dehydrogenase deficiency, 32yrs) story was partially coded into this theme by Leximancer, including the efforts she made to be «very pretty, very fit, very easy on the eye» and her descriptions of joy at the gym. Sherry (woman with PAIS, 55yrs) felt masculinity aided her looks: «I love that even middle-aged I have remained fit and lean. My chest is not sagging, my hips are not large, I have no stretched belly having carried no children. It is ironic that the ideal woman is like a man».

Marnie (intersex woman with gonadal dysgenesis, 58yrs) felt “good” having realised that: «Overall I am fit and healthy and there are people with much more significant and incapacitating conditions so I count my blessings». Tina (woman with 17-beta-hydroxysteroid dehydrogenase deficiency, 33yrs) sometimes felt “very good” now, based on advantages from being intersex: «I have some masculine traits within my

personality that are a real gift – they contribute to my success at work, and in my personal relationships».

The *Fitness Edge euphoria* seen within the “fit” theme had an overlap with the “body” theme and *Body Positivity euphoria*, and “surgery” theme and *Autonomous Control euphoria*. This was visible in the Leximancer map and overlapping stories.

4. Discussion

4.1 What euphorias are like for people with intersex variations

This study uncovered several intersex diagnosis euphorias, involving different experiences and feelings:

- *Category Validation euphoria*: a sense of validation within a category, relief, elation and/or humour;
- *Difference Legitimation euphoria*: a sense of prior or new knowledge confirmation, release from certain identity categories, anger, and/or bitterness;
- *Knowledge Integration euphoria*: pleasure in integration of direct or indirect prior knowledge or exposure reminiscences with diagnoses, yearning for more earlier knowledge, and feeling special and/or self-satisfied and/or unconcerned;
- *Medical Sense-making euphoria*: increased understanding or justification based on scientific sense-making within a medical context; and
- *Sudden Hope euphoria*: sudden hope for understanding and the future, contrasted against past negativity or co-occurrent confusion, shock, negativity.

Category Validation, *Difference Legitimation* and *Knowledge Integration euphorias* were most dominant on diagnosis. *Category Validation euphoria* most reflected a joyful feeling of rightness in existing studies; whilst *Difference Legitimation euphoria* most reflected relationships to identity struggles and dysphoria (Beischel *et al.* 2021; Dale 2021).

There were also several intersex post-diagnosis euphorias:

- *Body Positivity euphoria*: love and care for one’s body and bodily diversity;
- *Acceptance euphoria*: self-acceptance and being accepted, partial body satisfaction or contentedness;
- *Autonomous Control euphoria*: happiness and sense of being in control of one’s body, identity, medical information and/or treatments etc.;
- *Relative Gains euphoria*: relative happiness and excitement; and
- *Fitness Edge euphoria*: a sense of having an edge to one’s fitness, personal traits, happiness and/or success.

Body Positivity and *Acceptance euphorias* were most dominant post-diagnosis. A unique finding was that *Body Positivity euphoria* was the most dominant euphoria for intersex people overall, and post-diagnosis euphorias broadly. Overlaps in Leximancer maps and single participant stories showed that for some people, different euphorias co-occurred, occurred consecutively or intermittently. *Body Positivity euphoria* was most connected and conducive to other euphorias. *Acceptance euphoria* and *Autonomous Control euphoria* reflected McKinney’s (2021) concept of euphoria relating to social redress, extending it to institutional redress.

4.2 *Why people with intersex variations had euphoric experiences*

Intersex diagnosis euphorias occurred for reasons that had inverse relationships to individuals' past negative experiences. This included their past lack of: identification with allocated/mainstream categories; belonging to allocated/mainstream categories; knowledge of or exposures to intersex communities, people or traits; positive treatment by medical professionals and family; and/or hopelessness, negativity and/or confusion. In short all diagnosis euphorias reflected a positive response to the redress of past difficulties around identity formation processes and support. Western cultures privilege adolescents and young adults' 'identity moratoriums' (engagement in exploration of identities) and 'identity achievements' (commitment to identities after exploration); whilst negating a lack of identity achievement as problematic for adult development and intimacy (Erikson 1950; Kroger, Marcia, 2011; Marcia 1980). Ahmed has emphasised that happiness economies are culturally limited for people whose identities and bodies sit outside stage-based ideals and norms (Ahmed 2004, 2010). Within such psycho-social and sociological theories, however, and these data, revisitation of psycho-social development even in adulthood may progress social identity formation and culturally politicised access to happiness opportunities.

Conversely, post-diagnoses euphorias had positive relationships to individuals' more affirming or positive experiences. These included their experiences of: (re) positioning of their body within greater body diversity whether aided by community, reading or experience; changing internal (personal) and/or social (others') responses to their variations, bodies, identities and behaviours; increased control of their identity, medical records/information and/or treatments; physical or social gains around intersex variations in comparison to self or others; and/or increased fitness, strength, attractiveness or gains from their intersex variations or related treatments. Post-diagnoses euphorias reflected the 10 elements behind euphorias in the literature review especially the value of external, internal, social and online experiences; and oppositional or complex relationships to negative wellbeing or dysphoria (Beischel *et al.* 2021). The study uniquely emphasised intersex community and reading/conceptual exposures for body positivity; and identity and body autonomy for intersex euphorias. To understand these latter concepts' importance, consider that many people with intersex variations have had genital surgeries enforced in infancy and/or hormonal interventions imposed in adolescence (Jones *et al.* 2016) – when autonomy, identity formation and intimacy develops (Erikson 1950). Erikson (1950) has argued that such disruption to bodily autonomy (will) and identity formation (fidelity) restricts intimacy and generativity across adulthood; and Ahmed (2004, 2010) emphasises the association of negative emotions onto bodies cast outside of cultural norms and individual control. *Autonomous Control*, *Acceptance* and *Body Positivity euphorias* then – though representing personal experiences – are also highly political expressions over the rights claims to autonomy, bodily acceptance, self- and social- acceptance from the margins. *Relative Gains* and *Fitness Edge euphorias* further represent a radical pleasure in privileging intersex lives and bodies in the face of overly valued normative lives and bodies. Euphoric emotions thus do political work (Ahmed 2004; McKinney 2021). They re-centre the rights and bodies of people with intersex variations from their former positions on the margins of cultural economies of value

and happiness. This reflects the radical impulse at the heart of broader body positivity movements online (Cohen *et al.* 2021); which could be useful in facilitating and holding space for resources supporting Body Positivity euphorias for people with intersex variations.

4.3 How people with intersex variations had euphoric experiences

The study emphasised the volatile temporality of initial intersex diagnosis euphorias. These evolved for some participants as: short-term, longer or recurrent shifts away from pre-existing negative feelings; a sense of confirmation sometimes later followed by depression or mixed emotions; recurrent knowledge and memory integration processes; explanatory identification justification processes that may or may not continue over time; or sudden new outlooks on current conditions and future prospects.

Contrastingly, post-diagnosis euphorias tended towards a slower evolution, building gradually across time, but this only occurred where time was *used*, productively: for the absorption of external ideas and social stimuli; increased positive social reactions to disclosures; increased control over social treatment and medical treatment; changes in bodies and/or perspectives on bodies; and/or developing the perception that one fared well relative to physical, social and workplace ideals. These findings reflected relationships between euphoria and material expressions of identity and possibilities of material change over time, and change in socio-cultural contexts over time, emphasised in TGD literature (Bradford *et al.* 2019; Beischel *et al.* 2021). However, the findings extended the understanding that different euphoria types evolved in different temporal patterns.

The dominance of *Body Positivity euphoria* overall for this intersex cohort, and the ways it was most linked to other euphorias, and evolved as a response to external ideas and social stimuli; highlight it for attention as a euphoria which may be promoted via direct and indirect interventions. Participants reported that body positivity could for example be transferred by example through intersex community social contexts and support group events; by online communities and outreach; and by texts/resources. Such avenues could be an important entry point for government funding and support towards promoting the wellbeing of people with intersex variations; particularly as a reparative strategy given the past allowance of enforced interventions by many governments. Further, since most people with intersex variations learn about their variations through contact with medical health professionals (doctors, hospital teams including therapists and so forth) medical and mental health education programs could fold body positivity messaging into education and training for such professionals in their degree programs so Body Positivity euphoria can be accessed earlier and more often by clients with intersex variations. Supporting such work would demand revisions to psycho-medical texts (e.g. revising the *DSM*'s deficit-based frames for intersex people).

4.4 Other Significance & Limitations

The study showed euphorias were impactful, improving wellbeing as for TGD people (Bradford *et al.* 2019), and actions. Intersex diagnosis euphorias may aid peoples' relationships to sex/gender groups and their alternatives; mediate emotions

and experiences; and knowledge and community seeking behaviors. Post-diagnoses euphorias may aid disclosures, overall contentedness, and positivity in self-accounts or comparisons. *Body Positivity euphoria* may aid people in seeking improved personal treatment of their bodies, supportive medical professionals and sexual/romantic partners.

The study's limitations included that this intersex sample had low rates of dysphoria diagnoses compared to other samples (Furtado *et al.*, 2012); so associations between euphoria and dysphoria may be understated (10 of 12 participants who reported dysphoria, experienced one or more euphorias). There were no endosex participants and international cohorts were mixed; the study thus could not show if intersex peoples' impacts from *Body Positivity* (or other) *euphoria*, differ from broader populations' impacts, or by context.

Conclusion

People with intersex variations' euphorias occurred more after, not at, diagnosis. They aid more affirming feelings, relations, accounts and actions around having intersex variations. Whilst intersex diagnosis euphorias were inspired by an enablement of the personal identity formation processes which had been seized at the moratorium stage, post-diagnoses euphorias had a particular political quality to their radical re-valuing of the rights and bodies of people with intersex valuations in cultural economies of happiness. Given that *Body Positivity euphoria* was most dominant euphoria for this intersex cohort, most linked to other euphorias, and a response to external ideas and social stimuli; it may be promoted. Increased body positivity themed intersex community events and texts; government funding and supports; and messaging in psycho-medical training approaches and texts may aid earlier and wider exposure to *Body Positivity euphoria* and its benefits. Future studies could consider if the types, associations and processes of euphorias seen here, are evident for other cohorts – including those who may become similarly fruitfully engaged with online body positivity movements.

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