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The Power of Phenomenology

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Abstract: Hermeneutic phenomenology's aim is to bring forth that which needs to be thought about. It is an invitation to think. To articulate thinking, one needs to listen in the corners and the shadows of the lived experience(s) of the phenomenon being investigated. The method simultaneously holds numerous perspectives and adopts an embodied approach to embracing experiential knowledge. This paper explores the power of hermeneutical phenomenology, as a methodological approach for understanding what it means to be intersex. Intersex people have bodies that are born different to typical male-female ones. Intersex is an umbrella term that includes more than thirty ways the human body may differ according to its sex characteristics (i.e., genitalia, hormones, chromosomes, sex organs). From interviews with intersex people, we confirm that employing a hermeneutic phenomenological approach did not just answer our research questions, but also became a powerful and empowering means through which some participants were effectively able to navigate, share and 'own' their personal story. Indeed, the method's person-centred and ethical underpinnings permitted some to engage in the research in ways that became empowering and transformational.

Keywords: intersex; lived experience; sharing stories; other; knowledge of self; empower; hermeneutic phenomenology

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1. Introduction

This paper draws on data that were gathered from the stories people shared with the authors as part of the study Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy. This was an exploratory study and the first of its kind in Ireland. As noted in the study title, we intended to 'map' what it means to be intersex in Ireland. Using hermeneutical phenomenology as our methodological approach, this study sought to understand the lived experience of what it means to be intersex from the perspectives of three distinct groups: (1) intersex people, (2) their families and partners and (3) healthcare professionals who work in this field. Data from these three groups generated the lay and professional knowledge we expected to use to inform the development of appropriate law and policy in Ireland to ensure the rights of the intersex community are protected and upheld in Irish society. This paper emanates from our experiences of doing hermeneutic phenomenology with our intersex respondents. The phenomenon in question is the experience of being intersex. We were interested in how intersex people experience living their lives. This paper does not seek to examine the legal and policy aspects of the Mapping Study, but rather is focused on the experience of doing and using the methodology.[1] Prior to discussing the power of hermeneutic phenomenology in enabling people to reveal their experience of a particular phenomenon, we consider it necessary to explore what intersex might mean as the use of language to describe intersex is a very important issue within the intersex community (Lundberg et al. 2018; Davis 2014).

Intersex is an umbrella term that includes more than thirty ways the human body differs according to its sex characteristics—specifically, its chromosomes, hormones, genitalia and sex organs. Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies (United Nations for LGBT Equality n.d.). Sometimes, this is referred to as having Variation(s) of Sex Characteristics (VSC) or Atypical Sex Characteristics. Many medical and health professionals are familiar with the term Disorders of Sex Development (DSD) (Lee et al. 2006). Before we proceed, we believe the intersex nomenclature merits brief discussion.

Debate abounds within the medical community, and beyond, and even within the intersex community itself, about the use of terminology and what ought to be considered under the 'intersex' umbrella (Monro et al. 2017; Reis 2007). Historically, the word hermaphrodite was used to describe an intersex person, but this is considered by some to be a harmful slur, "outdated and pejorative" (van Lisdonk 2014, p. 15), demeaning (Reis 2007) and offensive (Rubin 2015).

The umbrella term intersex is widely used and accepted internationally (Bauer et al. 2020). In fact, two significant calendar days use this word: Intersex Awareness Day (October 26th) and Intersex Solidarity Day (November 8th). While the word intersex is not without criticism, the general consensus is that intersex is widely accepted globally and is more favourable than other more medical terms, such as Disorders of Sex Development (DSD) (Davis et al. 2016)—the latter being problematic because it pathologises bodily differences (Monro et al. 2017), is stigmatising (Cresti et al. 2018) and has the potential to imply that different or disordered bodies need to be fixed or repaired (Reis 2007; Carpenter 2018a). To counter the pathologising effects of the word 'disorder', Reis (2007) advocated for the use of Divergence of Sex Development. Another variant is Difference(s) of Sex Development. Still, some medics find it best to use the term Atypical Gonadal/Genital Development (AGD) given the "confusion and discomfort" associated with previous terminology (Gorduza et al. 2018, p.45).

Not all people, including those who are intersex, use the term intersex. Significant variation exists among those who are intersex in terms of how they use terminology. Van Lisdonk's research demonstrates that

> interviews with active members of patient organisations and persons with intersex/dsd revealed that they mostly do not use either term themselves. Instead, they generally tend to use the condition-specific term, such as 'men with Klinefelter syndrome' or 'women with x y chromosomes'. Some of those interviewed were actually found to be entirely unfamiliar with the terms intersex and dsd. (van Lisdonk 2014, p. 25)

Greater general acceptance exists around the fact that a person's choice of terminology ought to be respected. Some intersex people, such as Rose (2020), argue for intersex to be understood as a broad and inclusive spectrum that will permit acceptance of multiple and diverse experiences and such a belief sits within our hermeneutical phenomenological approach where the person and their lived experience are front and centre. We are in full agreement with Rose (2020), and we appreciate Lundberg et al.'s comment "that the debate on terminology is not yet settled" (Lundberg et al. 2018, p. 163), and so, for the remainder of this article, we use the word intersex as an umbrella term. This is in keeping with the use of the word by the EU Agency for Fundamental Rights in their 2015 focus paper on human rights for intersex people (European Union Agency for Fundamental Rights 2015) and subsequent report on LGBTI equality (European Union Agency for Fundamental Rights 2020).

Finally, it is important to note that such bodily variations are not to be confused with a person's sexual/gender identity, which is why some previously used terms, such as intersexual and intersexuality, are deemed "socially undesirable" (van Lisdonk 2014, p. 25). While the 'I' in LGBTQI+ represents intersex, only some intersex people identify under the LGBTQI+ umbrella.

2. Methodology

Intersex people have long been the object of scientific research (Raz 2024). The literature reveals that the impact of research has been negative, and that intersex people report feeling 'objectified' by researchers (Preves 2003; Kessler 1998; Fausto-Sterling 1993). This sense of objectification is further compounded as intersex people articulate that they are not believed when they report their experiences. Carpenter draws on Fricker's (Fricker 2007) concept of testimonial injustice to argue that "the credibility of intersex voices is diminished, even where they speak about personal lived experience, and even though contrary perspectives lack evidence" (Carpenter 2018b, p. 459). Charlebois goes further, arguing that intersex people are, thus, hermeneutically marginalised (Charlebois 2017). She eloquently summarises the difficult process of overcoming obstacles of objectivity to claim their own agency. Facilitating the emergence of subject-actors requires a reimagining of how research is undertaken.

To allow intersex voices to join the community of thinkers, and thus gain full humanity, it will be necessary to reflect not only on the conditions of knowledge production, but also on the modes of assessment and the validation criteria used (Charlebois 2017).

In keeping with the legitimacy of foregrounding the voices of intersex people, we chose hermeneutic phenomenology as our methodological approach. We sought to understand the lived experience of intersex people in a manner which returned to them their agency and power over how the research and interviewing process would proceed. In so doing, we discovered that those who shared their stories with us had a lot to say about both their lives and the experience of being interviewed in this manner. This paper reports those insights.

Through interviews, the voices of intersex people can be heard, offering us an insight into their "ideas, thoughts and memories in their own words rather than in the words of the researcher" (Reinharz 1992, p. 9). In doing this, we seek the meaning(s) and understandings(s) that participants gave to their experiences. Hermeneutic phenomenology aims to bring forth that which needs to be thought about. As Charlebois notes, it is the epistemological injustice inherent in the systemic structures surrounding intersex which subjugates intersex people such that it is difficult for them to come to a knowing of themselves (Charlebois 2017). This methodology creates a space for unencumbered reflection. It is an invitation to think. To articulate thinking, one needs to listen in the corners and the shadows of the lived experience(s) of the phenomenon being investigated. The method "embraces multi-perspectival, embodied and experiential ways of knowing" (Dibley et al. 2020, p. 7). Smythe et al. articulate that there are no set of steps or a step-by-step guide, rather each hermeneutic phenomenological researcher enacts a process that centres on reflection, writing, re-writing and thinking (Smythe et al. 2008).

Meanings and understandings are social products, which are not created in isolation; they are products of interpretations of the actions through a process of reflecting on the actions. Individuals give meaning to the situation in which they find themselves; this is informed by both cultural norms and expectations. Therefore, a similar interaction in a different culture may lead to different meanings (Cuff et al. 2006).

Giorgi (2005) suggests that the goal of phenomenological analysis is centred on the clarification of the meanings given to a phenomenon. By voicing their experiences, participants give clarity to their lived state, which can lead to change, as there can be a discrepancy between what we think we live and/or how we experience life, and the reality of the actual living and/or experience. "A discovery of this difference and its correction can lead to more authentic living and interaction with others and thus a better world" (Giorgi 2005, p. 77). By articulating their lived experience of being intersex, our participants gain a deeper understanding of their lived experience, which can change their reality and their understanding of what it means to be human. Phenomenological studies recognise that in any culture, multiple realities of the same phenomena may exist, and that groups and/or communities share in these realities. It facilitates the position that a number of simultaneous meanings can be given to the same experience. These meanings may or may not be shared by others.

Ethical approval was granted for the study by the DCU Research Ethics Committee (REC) in 2019. The COVID-19 pandemic restrictions meant we had to conduct interviews online using zoom and/or telephone. Our submission to the DCU REC for an amendment to facilitate this was approved in May 2020. We knew our intersex sample were a vulnerable group. We also knew our interviews could have a trigger effect and cause upset in our participants. In order to safeguard our participants' welfare, we established a follow-up procedure. We engaged with a counsellor who had expertise in working with sexual minority clients. This counsellor had also completed master's-level research on the subject of intersex lives. We had business/contact cards printed with the counsellor's details on them. These would be given to participants at the end of each interview. The study paid for the first two sessions that any participant chose to attend. When face-to-face interviews were impossible to conduct due to COVID-19-related restrictions, we provided the counsellor's contact details to participants in an email. We can confirm the counsellor's services were used following interviews, but preserving patient confidentiality, we were not informed which participants availed themselves of this follow-up procedure.

A total of seven intersex people participated in the interviews. The small sample size is typical of this type of hermeneutic phenomenological investigation (Dibley et al. 2020). At interview, participants were simply asked to talk about their experience of (being) intersex. This open approach is deliberately designed to give all control of the interview and the direction of the conversation to the interviewee. It does not demand of the participant responses to particular questions, rather, the comfortability of the participant is always reflected in the richness of the story that emerges (Dibley et al. 2020). Further questions arose from the interviewees' responses, giving rise to the prompt or probe questions, which invited clarity where necessary. Interviews ranged in duration from 60 min to 150 min, although some participants requested more than one interview to enable them to tell their story in full. This was a unique aspect of the study which was not anticipated at the outset. Being human in the world of intersex experience is complex and the telling of their story was never a short conversation. Rather, it was a profoundly reflective practice whereby the participant unravelled their story in their own time. Indeed, some participants re-engaged with us for second and third interviews to clarify aspects of their original telling of their story or to share more about themselves. This suggests that the first interview may have been used to establish trust between the storyteller and listener. The storytellers came to understand that they could trust us to hold their stories and honour their lives. Trust was not sought but freely given. Three members of the research team, the authors and our post-doctoral researcher on the project, conducted interviews. Interviews were recorded, then transcribed using pseudonyms, which are the names attributed to storytellers reported throughout this article.

The Mapping Study was designed with participants from the intersex community, thus fulfilling an engaged research approach. The authors of this paper are both Irish and cisgender, one heterosexual, the other a lesbian, ranging in age from the 40s to 60s and both are parents. Thus, the study established a steering committee to ensure that intersex inclusion remained at its centre. The steering committee was made up of national and international members who are either academics, activists or both from the intersex community, thus adhering to the intersex community principle of "nothing about us, without us". As researchers, we constructed ourselves as "researchers in the middle" (Breen 2007, p. 163). The researchers own positions in this research are as follows: (1) being lesbian, through her academic work and own lived experience understanding the nuances of marginalisation by society, and (2) through her earlier work with intersex people having gained an understanding of the institutions of society and how they knowingly or unknowingly are the cause of oppression.

This paper seeks to articulate the power of hermeneutic phenomenology in affording a space where the self and the experience of the self can be revealed. Hermeneutic phenomenology is underpinned by the philosophy of Heidegger (1962), as he was concerned with being *in* the world.[2] The essence of Heidegger's hermeneutic phenomenology is

'Dasein', which he explains as the human being in the world. "The 'essence' of Dasein lies in its existence" (Heidegger 1962, p. 67). The human being is always involved in the world as they experience it. Johnson suggests that Heidegger views the human being as "always involved in the practical world of experience" (Johnson 2000, p. 136). Heidegger indicates that "Being-in-the-world is a basic state of Dasein" (Heidegger 1962, p. 86). Relating this to the participants in this study, being-in-the-world (Dasein) as intersex people can be seen as active participation in that world, creating meaning and understanding to being themselves in a world that may not recognise or speak to them. This paper explores the stories of intersex people as being in the world of intersex experiences. As researchers using hermeneutic phenomenology, we seek to understand the meaning that participants give to their experiences.

Hermeneutic phenomenology is both a philosophy and a methodology that many balk at as it appears to have no criteria or steps to completion. From the outside looking in, this might appear to be so, but hermeneutic phenomenology does have avenues towards completion, albeit in non-conventional ways. Crowther et al. state that hermeneutic phenomenology "challenges pre-determined rules and research procedures" (Crowther et al. 2016, p. 827) resulting in the researcher being liberated from the conventional ideas of what is the "right" and "wrong" way of doing things. It is both a philosophy and methodology centred on the task of thinking.

> We come to know what it means to think when we ourselves try to think. If the attempt is to be successful, we must be ready to learn thinking. (Heidegger 1976, p. 3)

Our participants' observations reflect Heidegger's remarks that thinking creates a road of discovery of who we are as well as the nature of our Being (Gray 1976). This is in keeping with the method as it requires us to think, to uncover and to bring forth that which needs to be thought about. Through the interviews, thinking brings forth shared meaning(s) and understanding(s) of how the phenomenon of being intersex emerges from the participants' evolving knowing. A few participants in our study returned to their story a second and a third time. In returning to the story, the participant reflected upon what they had shared and, in some cases, sought to clarify, adding to their story. The going back and forth of the participants is akin to Heidegger's hermeneutic circle. While the hermeneutic circle is commonly articulated as the method chosen as

> analysis [it] is a continuous circular and reflexive process where themes emerge, and the researcher returns to the data and starts to re-read it. (Dibley et al. 2020, p. 127)

3. Story Telling

At the heart of our study was an invitation to people to tell us their story of being intersex. We ask one question: Can you please tell me your experience of being intersex? This is the creation of a space by which the person is free to tell their story about being them. There are no preconceived ideas or notions entailed in the question. There are no questions that we seek or require to be answered. It is a free canvas through which the storyteller paints their own picture—their reality for the listener. For many of us, we are never really asked: Who are you? Tell me about yourself? We may indeed be familiar with the question: Who do you think you are? But to be genuinely interested in the person as they present themselves to us is the central aspect of hermeneutic phenomenology. Grey states

> For him [Heidegger] the spoken word is greatly superior to the written. (Gray 1976, p. vi)

It is within the spoken word that the nuances of life are articulated. The listener is welcomed into the life of the storyteller, where the hidden is revealed precisely through the way it is spoken. The listener, that is the interviewer, navigates the teller's journey with the teller, traversing the highways and byways of their life. As researchers, we immerse ourselves in the story as told of the lived experience of the phenomena under

investigation. Later, the interviewer will reflect upon the story and transform it for wider public consumption while remaining true to the storyteller.

4. Invitation to Speak

We received an email from a participant at a conference on a presentation about this methodology relating to intersex experiences. We had raised the question 'What is it like to be human?'. Commenting on their own life, they wrote

> This has been one of the challenges for me; how to express what it's like to be me. [correspondent]

In the context of being human, the correspondent continues

> Throughout my life including my encounters with the medical world I was never asked, "How do you feel?" or "Tell me about yourself ". It seems almost too obvious to miss this critical question because our inner world is as important as our physical outer world. [correspondent]

Indeed, few are asked in a medical setting to reveal who they are from their perspective. In other settings, we may upon greeting someone ask them: How are you? If the person begins to respond, they may have broken the social norms of greeting. The response in an Irish setting may be to say, "I am doing fine" or "Great, thank you" but never revealing the true nature of how we are. But a detailed response is not what is socially expected. We have social cues for interaction. There are some settings where these cues are not relevant; for example, when a doctor asks, "How are you?", there is an expectation that the patient/client will respond relating to the reason why they are in a consultation in the first place. Heidegger regarded language

> As that sphere in which man can dwell alright and make clear to himself who he is. (Heidegger (1962), in Gray 1976, p. vii)

It is through language that we articulate who we are. The correspondent suggests that they were never invited in a healthcare setting, or indeed any other setting, to articulate who they were. Through this, the self is never revealed to the other, but more importantly, as Heidegger (1962) suggests that it is in the articulation that we come to know ourselves, neither is the self ever revealed to oneself. It is the negation or the unrevealing of the self when it really matters that leads to a hiddenness of the truth of who we are to both ourselves and others. Indeed, in a healthcare setting, when the healthcare provider does not ask how the patient experiences the condition that they are presenting with, it removes the possibility for the healthcare provider to review, reflect, and, through thinking, make changes in how they as professionals engage with intersex people or indeed any other person they encounter in their practice. This level of engagement is something that our correspondent would have welcomed.

5. Participant's Engagement

We suggest that some participants in our study engaged in their own hermeneutic circle through a reflective process, returning to their story, further sharing their understanding(s) and meaning(s) with us. They dwelled with the story they had shared to add illumination later. For example, Darcy returned to their story twice with a few emails in between. Prior to the ending of the third interview, they were asked if there was anything else they wished to further explore. They stated:

> No, I can't really think of anything. I think I am good. I have covered everything. But that really is everything now. I don't think there is anymore that I can possibly tell you but if there is I will come back to you and tell you but thank you for giving me the opportunity to come back and tell more of it. [Darcy]

It is in the dwelling with the story of the self that Darcy could make clear to themselves who they are. This experience reflects Charlebois' point that intersex people are required to negotiate the tension between the impact of non-consensual medical interventions and the

subsequent internalisation of a deficient vision of oneself in order to become active subjects with full agency (Charlebois 2017). In the telling of Darcy's story, the reflective process opened up avenues through which the self was explored and shared. It gave meaning and understanding to their life as an intersex person; meaning and understanding as they had come to know it through the articulation of this life.

While Darcy had come to tell their story in their own way and in parts, there was also an underlying reason why they felt they could come back

> Part of the reason why I am committed to doing this and doing it so fully is because I appreciate the fact that you guys want to do it for fully and you are being led by intersex people. I have never done a research study that is so led by intersex people like myself and that is why I am happy to do it. [Darcy]

Participants returning to the story reflected the trust that was placed in us to reveal their story to others in ways that were true to their meanings and understandings. We are in effect "bearing witness to their stories" (Crowther et al. 2016, p. 2) through the opportunity to "review, reflect and inspire new thinking" (Crowther et al. 2016, p. 2).

6. Building Trust Leads to Understanding

The study was developed through partnership and built with the intersex community in the development of the research programme. This led to trust relationships being built with participants prior to our meeting.

> Being aware of one's population is very important; being sensitive to the concerns of others and listening to their fears, needs and desires for their own personal safety emanates from an ethical standpoint. (Dibley et al. 2020, p. 81)

Being comfortable with the process and subsequent interview lends itself to the revealing of the self by the participants. Alan reflected on his experience of being different during his teenage years:

> I would probably answer by asking you the question, how does a teenager hide a variation in genital anatomy in a compulsory shower with 20 other fellas after PE? My answer to that is you could only hide by being in plain sight. There was no option of hiding. [Alan]

Saving oneself from the gaze of the Other as a teenager can be difficult at the best of times. The taken-for-granted situation of the communal shower amongst boys is the expectation of the 'sameness' of bodies. It is here that Alan discovers his difference or rather comes to the knowing that Others can expose his difference. In this situation, Alan found that one can hide in plain sight. He further states:

> No, again that is before the age of the internet and before the age of, I don't believe, I didn't have access and no one else would have access to pictures, descriptions, diagrams, terminology etc either. That anyone else could pick it up readily. I do remember the PE teacher looking but never went as far as saying anything. So, the obvious thing for me was as quickly as possible to shower without ever drawing attention to myself. Cause there was another chap in the class like that was even more self-conscious than I was and he became a target. So the two together was the absolute proof that you do not be visible by being, the best way to be invisible to be completely visible. By showing no signs, showing nothing. [Alan]

Even though Alan's PE teacher may have noticed his difference, nothing was said. He, the PE teacher, was the external observer of Alan's body. The non-recognition of his status led to the reinforcements that silence prevailed about his body. This reflects Sartre's notion of the body, that it is through the body that I experience myself but also it is through the body that I experience the Other (Moran 2000). There were silence and unknowables as access to information about bodies like Alan's was unavailable. Alan responded by not drawing attention to himself. Alan's experience of the showers was a situation that

"threatens the integrity of the self" (Giddens 1992, p. 54). Whatever mechanisms that were built over time to protect the self were dismantled, and the validity of himself was never questioned but cast aside by that one look.

Being self-conscious could lead to being 'targeted' and Alan did not bring that attention to himself. Not drawing attention to himself became a strategy for his life:

> Very good at hiding in plain sight but I spent my life hiding. [Alan]

Alan had learnt how to act, react and behave to exist within the spaces he found himself in, which was crafted and became a way of life during his teenage years. In Goffman's terms, Alan made himself "into something that others can read and predict from" (Goffman 1971, p. 11). Every time he had PE, Alan is confronted with himself, the reality that he is different from other boys. He exists within the reality of what a normative male body 'looks' like and knows that he does not fit. Alan never reveals the truth of his situation, neither did he develop trust relations with others as he spent all his life hiding in plain sight. Giddens suggests that an individual will have a stable sense of self-identity if there is:

> a feeling of biographical continuity which she is able to grasp reflexively and, to a greater or lesser degree, communicate to others. That person also, through early trust relations, has established a protective cocoon which 'filters out', in the practical conduct of day-to-day life, many of the dangers which in principle threaten the integrity of the self. Finally, the individual is able to accept that integrity as worthwhile. (Giddens 1991, p. 54)

Alan did not communicate to others who he was, which led to the fact that acceptance of himself as a worthwhile human being was never realised to his satisfaction. His worth, value and understanding of who he was in the world was undermined as, Giddens (1991) suggests, by necessity these traits are developed through early trust relations, which were not available to Alan. Alan's "every-day skill of coping" (Draucker 1999, p. 361) was hiding. In effect, Alan became a shadow. He was not casting a shadow as we all do in twilight, which gives a sense of self. I can see myself through my shadow and I know I exist. Casting a shadow is something my body does, but to be cast as a shadow is to have something thrust upon you by the Other. Alan's image of the shadow does not denote positivity, rather, it casts him into darkness, a shadow in the corner, whereby the Other does not acknowledge his existence, as he does not exist within their realm of normative bodies. Alan cannot be seen or is not seen, which he recognises. This is very different from Sartre's suggestion of:

> My possibility of hiding in the corner becomes the fact that the Other can surpass it towards the possibility of pulling me out of concealment, of identifying me, of arresting me. (Sartre 1969, p. 264)

From a Sartrean perspective, the possibility of hiding in the corner is my choosing of concealing myself. However, Alan was placed in the corner by the Other through non-recognition. He has no possibility of being discovered, as the Other does not recognise his existence. He has become the outsider (Becker 1963), looking in but with no say in what is happening. He is alienated from the world as Alan knows it and from himself through the actions of the Other. Alan's own possibility becomes the possibility of the Other to declare who he is: a non-entity.

7. Hiding Loss, Hiding Pain

This study revealed lives that were deeply entangled in mistrust, unknowns and unknowables, but centred on the vision that others had of what bodies should be and the consequences for not having that desired body. What our study revealed was the power of parents, teachers and medical personnel to make pronouncements and claims about the body, thus imputing meanings and understandings on the body. The study also exposed

how power was used from the perspective of the power holder, rather than the person who experienced the inferences of the power holder.

> It is in the reality of everyday life that the Other appears to us, and his probability refers to everyday reality. (Sartre 1969, p. 253)

People living with intersex bodies confront the reality of being intersex in the most unexpected places. They exist within a world with normative bodily expectations. Institutions, such as family, education, hospitals and GP services, not only reflect this normalisation but have no perception of bodies outside of that norm.

The truth of their situation (intersex people) may be hidden from them, and coming to the understanding of their difference may be a difficult experience, as revealed by Frankie:

> I was 12 that is when I realised there was something different about me because like all kids went through the change of life and I stayed the same of when I was like a child. [Frankie]

Through her friendships, Frankie realised that there was something different about her. This difference was centred in and on her body—her body was not similar to other girls' bodies; unlike her friends' bodies, Frankie's body was not changing. As she traversed her teenage years, there were many interactions with doctors to unravel why she was not developing in accordance with what is expected as she made the journey from childhood to teenagerhood to adulthood.

> And then when I was older, I kept going to the doctors to find out why I wasn't growing, and they said, well, when you are 13 we are going to try medication because if you are on medication you should go through the changes of life. [Frankie]

Healthcare provision was not an option for Frankie as her father refused to pay for it. However, later, through the discovery of a Rainbow Resource Centre, Frankie did discover what was blocking her developing. When a member of the centre asked her if she understood her medical papers, her reply affirms how she perceived herself:

> I just know that I was born a mistake. [Frankie]

Through her interaction with family and the medical professionals, Frankie had learnt that she was a "mistake", but that "fact" had never been unpacked for her. Her difference was flaunted in front of her by family members as not being the "norm" of social expectation. Her body was examined by others and declarations were made on who she was:

> And he [doctor] checked me in the same way that my dad would check me or whatever and he was like 'I can't believe how she didn't grow properly' and he [father] was like 'well what does this mean?' And the doctor said 'well, it is kind of like she is trans but she is not'. 'Well can it have kids? Because that is the only thing that I want' [father] and the doctor said 'no, she can't have kids'. And he [father] was like 'well what use is she to me then?' And he's [doctor] like 'she can adopt kids', 'and like what, she can have two people that are mentally retarded in the house? No thanks.' [father]

For Frankie, no opportunity was provided by the medical personnel or her father to discuss the truth of her situation with them. Medical examination was carried out on her without her consent and the revelations announced without discussion. Frankie found herself within a

> Context of discourse and interaction position persons in systems of evaluation and expectations which often implicate their embodied being; the person experiences herself as looked at in certain ways, described in her physical being in certain ways, she experiences the bodily reactions of others to her, and she reacts to them. (Young 2005, p. 17)

Frankie was placed into systems of evaluation and interaction through her body being different by being examined by a healthcare professional who could make judgements about her. While doctors do evaluate, assess and care for patients, Frankie experienced the revelation of the kind of being she was, being evaluated and assessed and rendered without care. The revelation was unfinished and unsatisfactory. Frankie was left with the understanding that she was different, incomplete, a non-trans, trans-like person; thus, she was unfinished and unsatisfactory. There was nothing to be done, she was not the emerging woman that the medical profession expected her to be or that society expected as the declarations by her father made clear to her. What Frankie did not expect, in the examination of her body, was that the totality of the self was exposed for Others to see and evaluate, in accordance with the values and belief systems of those caring for her within the culture within which she resided. The truth of herself was mediated by Others (Sartre 1969). Heidegger suggests that

> To every being as such there belongs identity, the unity with itself. (Heidegger 1969, p. 26)

Through the declarations of others in her life, Frankie's 'unity of the self' became unravelled and unknown to her as she did not fit what was thought of as an emerging adolescent and later adult woman. She was rendered with no identity.

From a Giddens' point of view, one could suggest that Frankie could not develop a biographical continuity whereby she could recount her life story and recognise the self in that story (Giddens 1991). To achieve a biographical continuity Frankie would first have to be able to communicate to herself who she is before she could communicate it to Others. Like Frankie, Alan also experienced this never happening as he chose to live his life on his own as the sharing of that life is too painful for him. The development of trust relationships whereby people can be themselves with themselves and Others, thus establishing a comfort in their life, can be difficult to achieve for intersex people.

Frankie is devalued as a human being. Her worth, value and understandings of who she is in the world were undermined:

> It is only through being object that we can be given a value, assigned a worth, some "thing" that can be assessed. (Howard 2002, p. 59)

She is not measured in accordance with her own bodily integrity but measured against the general expectation of the integrity of certain genitalia that belong or are assigned to either female or male bodies, by the community of the assessor, that is the healthcare provider. Within this measurement, she becomes a non-entity and is, according to her father, a being of 'no use'.

Sartre suggests that "shame of self; it is the recognition of the fact that I am indeed that object which the Other is looking at and judging" (Sartre 1969, p. 261). It disrupts the sense of self, the taken-for-granted knowledge of knowing who I am. In Frankie's case, that knowing was negative.

> So, I grew up thinking that everybody was supposed to hate me. [Frankie]

She became the object of this judgement. The world within which Frankie lives is alien to her; she was alienated from that world and, by extension, alienated from herself. Frankie discovered the two-fold result of the uncovering of the truth of the self; she was alienated from the self and there was no possibility of self-recovery either now or in the future. Once you uncovered and acknowledged your difference, there was no belonging, no safe space, no feeling of being one with the Other. Were you really the person you were before you discovered who you are? You cannot undo what you now know, but equally you cannot accept the definition of who you are as being told by others who do not want to know who you really are. Frankie sat in the midst of power relations as a child to a father, as a patient to a healthcare provider, as a worker to an employer and as a road user to those who did not want the person she is to be in that space. Power shaped her perception of herself and her place in the world.

8. Conclusions

The power of hermeneutic phenomenology is that through interviews, we bear witness to the experiences of people sharing their stories, in this case, their experiences of being intersex. Through listening to their stories being told, we sometimes hear about a life that has been hidden or supressed. Crucially, their stories expose to us the damaging or destroying effect of being unseen as a whole person. Alan's story reveals how others, namely, his family, hid the reality of who he was from him and how that affected his education and, later, his life. In the telling of her story, Frankie reveals how her father viewed having a female child. Her value and worth to him was solely as the provider of the next generation. But not being what he wanted, she was rendered useless and less than human and, indeed, less than woman. The power and perception of her body communicated by the medical professionals reinforced this perspective.

However, Frankie's story points to the fact that a community did exist whereby she could find acceptance of herself as the whole person she is, a whole person with a particular body and who needs a community (acceptance) to be whole. This, for her, was the Rainbow Resource Centre. Alas, Alan did not find such a community. On the other hand, Darcy informs us that being presented with an opportunity to tell one's story is a way of being oneself in the world.

Through the uncovering of the lived experience, an important contribution to knowledge is made. These stories demonstrate that true expertise of being intersex in the world is held by those who embody intersex experience. Hermeneutic phenomenology, as both a philosophy and a method, highlights how research can be carried out which centres the experiences of the person, empowering them through the sharing of their stories. In this way, they become agents of their own lives rather than being rendered objects of academic curiosity and research.

It is through the non-directed rambling along the highways and byways of their own lives that their stories emerged in a manner that was meaningful for each storyteller. In sharing their stories, as they wished, Darcy, Alan and Frankie came to new insights and understandings of the lives they have experienced. They found the sharing empowering. Through reflection, they were able to review and plan how their next encounter with the Other may enable them to obtain a better outcome. As Alan said:

> They had all the power, I had nothing. I had no information. I had no ground to stand on. All I could do was just react to what was being said to me. I was so much on the back foot I couldn't catch up and that would have been a major part of the difficulty. Again, it goes back to if you don't even know enough of your own story to be able to say it. [Alan]

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Notes

1 Further work by the authors is forthcoming that does examine these aspects of the Mapping Study.

2 The contributions of this author to scholarship in the field of hermeneutic phenomenology are indisputable; however, we do acknowledge the controversy that surrounds Heidegger's engagement with National Socialism. As Wolin notes "It would be foolish to suggest that, as a result of Heidegger's concerted, short-lived engagement on behalf of the Nazi regime, he would somehow forfeit his status as a significant contributor to the legacy of Western thought." (Wolin 1993, p. vii).

References

Bauer, Markus, Daniela Truffer, and Daniela Crocetti. 2020. Intersex Human Rights. *The International Journal of Human Rights* 24: 724–49. [CrossRef]

Becker, Howard Saul. 1963. *Outsiders; Studies in the Sociology of Deviance*. New York: Free Press.

Breen, Lauren. 2007. The Researcher 'in the Middle': Negotiating the Insider/Outsider Dichotomy. *The Australian Community Psychologist* 19: 163–74.

Carpenter, Morgan. 2018a. Intersex Variations, Human Rights, and the International Classification of Diseases. *Health and Human Rights* 20: 205–14. [PubMed]

Carpenter, Morgan. 2018b. The 'Normalisation' of Intersex Bodies and 'Othering' of Intersex Identities. In *The Legal Status of Intersex Persons*. Edited by Anatol Dutta, Jens M. Scherpe and Tobias Helms. Cambridge: Intersentia, pp. 445–514. [CrossRef]

Charlebois, Janik Bastien. 2017. Les sujets intersexes peuvent-ils (se) penser? *Socio. La Nouvelle Revue des Sciences Sociales* 9: 143–62. [CrossRef]

Cresti, Matteo, Elena Nave, and Roberto Lala. 2018. Intersexual Births: The Epistemology of Sex and Ethics of Sex Assignment. *Journal of Bioethical Inquiry* 15: 557–68. [CrossRef] [PubMed]

Crowther, Susan, Pamela M. Ironside, Elizabeth Smythe, and Deborah G. Spence. 2016. Crafting Stories in Hermeneutic Phenomenology Research: A Methodological Device. *Qualitative Health Research* 27: 826–35. [CrossRef] [PubMed]

Cuff, Edward C., Wes W. Sharrock, D. W. Framcis, A. J. Dennis, and Dave W. Francis. 2006. *Perspectives in Sociology*, 5th ed. London: Routledge. [CrossRef]

Davis, Georgiann. 2014. The Power in a Name: Diagnostic Terminology and Diverse Experiences. *Psychology & Sexuality* 5: 15–27. [CrossRef]

Davis, Georgiann, Jodie M. Dewey, and Erin L. Murphy. 2016. Giving Sex: Deconstructing Intersex and Trans Medicalization Practices. *Gender & Society* 30: 490–514. [CrossRef]

Dibley, Lesley, Suzanne Dickerson, Mel Duffy, and Roxanne Vandermause. 2020. *Doing Hermeneutic Phenomenological Research: A Practical Guide/Lesley Dibley, Suzanne Dickerson, Mel Duffy, Roxanne Vandermause*. Los Angeles: SAGE.

Draucker, Claire Burke. 1999. The Critique of Heideggerian Hermeneutical Nursing Research. *Journal of Advanced Nursing* 30: 360–73. [CrossRef] [PubMed]

European Union Agency for Fundamental Rights. 2015. *FRA Focus Paper: The Fundamental Rights Situation of Intersex People*. Vienna: (FRA) European Agency for Fundamental Rights.

European Union Agency for Fundamental Rights. 2020. *A Long Way to Go for LGBTI Equality*. Luxembourg: Publications Office of the European Union.

Fausto-Sterling, Anne. 1993. The Five Sexes: Why Male and Female Are Not Enough. *The Sciences*, 20–25. [CrossRef]

Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Giddens, Anthony. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Oxford: Oxford Polity Press.

Giddens, Anthony. 1992. *The Transformation of Intimacy Sexuality, Love, and Eroticism in Modern Societies*. Oxford: Oxford Polity Press.

Giorgi, Amedeo. 2005. The Phenomenological Movement and Research in the Human Sciences. *Nursing Science Quarterly* 18: 75–82. [CrossRef] [PubMed]

Goffman, Erving. 1971. *The Presentation of Self in Everyday Life*. London: Pelican Books.

Gorduza, Daniela B., Charmian A. Quigley, Anthony A. Caldamone, and Pierre D. E. Mouriquand. 2018. Surgery of Anomalies of Gonadal and Genital Development in the 'Post-Truth Era'. *Urologic Clinics of North America, Pediatric Urology* 45: 659–69. [CrossRef] [PubMed]

Gray, J. Glenn. 1976. Introduction. In Heidegger, Martin. 1976. In *What Is Called Thinking?* Translated by J. Glenn Gray. New York: Harper Perennial, pp. vi–xvi.

Heidegger, Martin. 1962. *Being and Time*. Translated by John Macquarrie, and Edward Robinson. New York: Harper and Row Publishers Incorporated.
Heidegger, Martin. 1969. *Identity and Difference*. New York: Harper and Row Publishers Incorporated.
Heidegger, Martin. 1976. *What Is Called Thinking?* Translated by J. Glenn Gray. New York: Harper Perennial.
Howard, Peggy Ann. 2002. "The Look" in Teacher's Performance Evaluation. In *Writing in the Dark: Phenomenological Studies in Interpretive Inquiry*. Edited by Max van Manen. London, ON: The Althouse Press, pp. 50–60.
Johnson, Mary E. 2000. Heidegger and Meaning: Implications for Phenomenological Research. *Nursing Philosoph* 1: 134–46. [CrossRef]
Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.
Lee, Peter A., Christopher P. Houk, S. Faisal Ahmed, and Ieuan A. Hughes. 2006. Consensus Statement on the Management of Intersex Conditions. *Pediatrics* 118: e488. [CrossRef] [PubMed]
Lundberg, Tove, Peter Hegarty, and Katrina Roen. 2018. Making Sense of 'Intersex' and 'DSD': How Laypeople Understand and Use Terminology. *Psychology & Sexuality* 9: 161–73. [CrossRef]
Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee, Fae Garland, and Mitch Travis. 2017. Intersex, Variations of Sex Characteristics, and DSD: The Need for Change. Huddersfield, UK. Available online: http://eprints.hud.ac.uk/id/eprint/33535/1/Intersex%20Variations%20of%20Sex%20Characteristics%20and%20DSDreportfinal.pdf (accessed on 15 November 2023).
Moran, Demotee. 2000. *Introduction to Phenomenology*. London: Routledge.
Preves, Sharon E. 2003. *Intersex and Identity: The Contested Self*. New Brunswick: Rutgers University Press.
Raz, Michal. 2024. Uncertain Knowledge: The Medicalisation of Intersex People and the Production of Ignorance. *Social Sciences* 13: 385. [CrossRef]
Reinharz, Shulamit. 1992. *Feminist Methods in Social Research*. New York: Oxford University Press.
Reis, Elizabeth. 2007. Divergence or Disorder?: The Politics of Naming Intersex. *Perspectives in Biology and Medicine* 50: 535–43. [CrossRef] [PubMed]
Rose, Maddie. 2020. Is MRKH Intersex? Ask a Different Question Instead. Available online: https://interactadvocates.org/is-mrkh-intersex/ (accessed on 15 November 2023).
Rubin, David A. 2015. Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics. *Frontiers: A Journal of Women Studies* 36: 51–83. [CrossRef]
Sartre, Jean-Paul. 1969. *Being and Nothingness: An Essay on Phenomenological Ontology*. Translated by Hazel E Barnes. London: Routledge.
Smythe, Elizabeth, Pamela M. Ironside, Sharon L. Sims, Melinda M. Swenson, and Deborah G. Spence. 2008. Doing Heideggerian Hermeneutic Research: A Discussion Paper. *International Journal of Nursing Studies* 45: 1389–97. [CrossRef] [PubMed]
United Nations for LGBT Equality. n.d. Fact Sheet Intersex. Available online: https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf (accessed on 15 February 2022).
van Lisdonk, Jantine. 2014. *Living with Intersex/DSD: An Exploratory Study of the Social Situation of Persons with Intersex/DSD*. The Hague: The Netherlands Institute for Social Research.
Wolin, Richard. 1993. *The Heidegger Controversy—A Critical Reader*. Cambridge: The MIT Press.
Young, Iris Marion. 2005. *On Female Body Experience: "Throwing Like a Girl" and Other Essays*. Oxford: Oxford University Press.

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