

An abstract painting featuring two profiles of faces. The left profile is a solid, dark blue silhouette. The right profile is a more complex, layered composition of colors including purple, blue, and yellow, with some areas appearing to be layered or overlapping. The background is a mix of warm, golden-yellow and cool, purple-blue tones.

From Erasure to Agency

The Power and Significance of
Self-Created Intersex Representations

Svet Sol

In collaboration with Marisela Montenegro
Joan Pujol & Lucas Platero



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"Intersex – New Interdisciplinary Approaches" (INIA)

Report

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The Power and Significance of Self-Created Intersex Representations

Intersex – New Interdisciplinary Approaches (INIA)

Marie Skłodowska-Curie Actions Innovative Training Network Project No. 859869

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About this report

"From Erasure to Agency: The Power and Significance of Self-Created Intersex Representations" emerges from the Marie Skłodowska-Curie project "Intersex – New Interdisciplinary Approaches" (INIA), supported by grant agreement No. 859869 under the European Union's Horizon 2020 research and innovation programme. Conducted between 2021 and 2023, this research on intersex representations entailed comprehensive fieldwork in Spain and England, hosted by the Autonomous University of Barcelona and University of Huddersfield, respectively, and supported by INIA Principal Researchers in place, namely Marisela Montenegro, Joan Pujol, Lucas Platero, and Surya Monro. This report delves into the transformative role of self-created representations in the intersex community. It draws from contemporary Spanish and English contexts and critically analyses select portrayals crafted by intersex people and allied authors. The report is structured into four main chapters, each offering a distinct perspective on the topic.

The introduction sets the stage for the subsequent exploration. It provides an overview of the main concepts we use in this report, such as cultural representation, the impact of representations on a person's or collective's lived experiences, and their role in challenging or reinforcing dominant societal discourses. The introduction underlines the importance of intersex self-created representations¹ in fostering a more nuanced understanding of the intersex experience, moving beyond medical and sensationalised depictions.

Chapter two describes the methodological approach adopted for this study. This chapter, rooted in narrative inquiry and critical ethnography, elucidates the qualitative research methodology employed. The narrative analysis focuses on personal narratives to understand human experiences, while critical ethnography offers insights into the broader socio-cultural structures influencing these experiences. This chapter also details the sample and procedures, highlighting the multi-method approach that

¹ By "self-created", we mean those cultural products/representations created by intersex people and allied activists.

encompasses both case studies and interviews, and outlines ethical considerations undertaken during the research process.

The third chapter, "Findings and Analysis", is divided into two main sections. The first, titled "Navigating life with(out) intersex representations as an intersex person", delves into the lived experiences of intersex people in relation to cultural representations. This section sheds light on the impact of medical silence and secrecy surrounding intersex variations and how this has shaped the personal journeys of intersex people we interviewed. The narratives offer a vivid picture of the challenges, stigmas, and societal taboos faced by intersex people. The second section, "Engaging in creating intersex representations", focuses on the processes and motivations behind the creation of intersex representations. This section offers a comprehensive examination of the creative endeavours of intersex people and allies, exploring the nuances of their artistic expressions and the impact of their work on broader societal perceptions.

Finally, the fourth chapter, "Conclusions and Good Practices", finishes the report. This chapter synthesises the findings into a set of recommended best practices for creating respectful and accurate intersex representations. It serves as a guide for those looking to engage in the creation or promotion of accurate and empowering intersex representations.

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Index

About this report	2
1. Introduction	5
2. Methodology	8
2.1 Sample and Procedures.....	9
2.2 Data Analysis.....	10
2.3 Ethics.....	11
3. Results and findings	13
3.1. Navigating life with(out) intersex representations as an intersex person.....	13
3.1.1. "Silence is prescribed" - Medical Silence and Secrecy in Families.....	13
3.1.2. Impact of Misrepresentations & General Lack of Intersex Representation.	16
3.1.3. Self-Understanding and Affirmation. Learning about Intersex.....	19
3.1.4. Future of Intersex Representation: Aspirations, Desires, and the Work Ahead.....	23
3.2. Engaging in Creating Intersex Representations.....	27
3.2.1. "Tilindula: Memorias de una Mujer Invisible" (Madrid, March of 2022).....	28
3.2.2. "Soy Lola y Soy Intersex" and "Solo Apto Para Bichas Raras"	33
3.2.3. "Alexina B." -Opera, Liceu, Barcelona, March 2023.....	36
3.2.4. "The Well of Silence"	39
3.2.5. "Un Secreto Pelirrojo"	43
3.2.6. Intersex in Comedy and Stand-up shows.....	47
3.3. Reflection on Intersex Representations.....	50
4. Conclusions and Good Practices	53
References	56

1. Introduction

As the intersex community gains more visibility, self-created^[1] cultural representations of intersex people become increasingly crucial. Cultural representations encompass how various mediums—including literature, film, television, art, and other media—depict particular groups, ideas, or concepts and how they are depicted or portrayed. These representations play a pivotal role in shaping societal perceptions, attitudes, and beliefs about specific groups or topics. For minority groups, cultural representations can significantly influence members' well-being and societal acceptance, fostering understanding, acceptance, and the reduction of prejudice (Wong, Massey, Barbati, Bessarabova, & Banas, 2022; Żerebecki, Oprea, Hofhuis, & Janssen, 2021). Conversely, negative or stereotypical portrayals can perpetuate misconceptions, biases, and discrimination and, ultimately, negatively impact the mental health of minority members (Johnson, 2016; Castañeda, 2018; Rivadeneyra, Ward, & Gordon, 2007; Ross, 2011).

As Hall (1997) argued, cultural representations are not mere depictions of reality; they are complex constructions that shape and are shaped by cultural identities. The meanings communicated through language, discourse, and visual images—serving as 'systems of representations'—have the power to create, reinforce, or challenge social structures and ideologies. As Hall (2019) suggested, cultural identities are historical narratives in constant transformation. The fluidity of identities and community narratives, as performed within specific social and cultural contexts, significantly influences the perceptions and portrayals of intersex people and their lived experiences. Representations in media and society are not passive reflections but active agents in forming and reforming the understanding of intersex experiences.

People of all ages, and specifically teenagers, seek out media with characters similar to themselves for identity development and social identity gratifications, with shows popular among Black and female adolescents more likely to exhibit racial and gender diversity, respectively (Ellithorpe & Bleakly, 2016). In the realm of body positivity, the representation of diverse bodies on platforms like Instagram can either challenge or reinforce societal norms about "acceptable" body types (Griffin, Bailey, &

Lopez, 2022). Chatterjee (2016) discussed how the reductive standards of popular global media regulate perceptions of beauty and body, confining and repressing the self-expression of diverse sexualities and genders, and explores the potential for a postgender representational mode subverting traditional binaries and accommodating sexual/gender diversity.

Turning our attention to intersex people, their representation in arts, popular culture, and media is sparse and often riddled with misconceptions and stereotypes. The cultural and discursive category of 'intersex' has been historically shaped and policed by various social actors, including medical professionals, policymakers, activists, and scholars (Amato, 2016), rendering it “not one but many sites of contested being... hailed by specific and competing interests... whose significance always carries the trace of an agenda from somewhere else” (Holmes, 2009, p. 2).

While it is acknowledged that up to 1.7% of the population are born with intersex traits (UNFE, 2017), intersex people have frequently been erased and silenced, either obscured behind heavily medicalised jargon or predominantly referred to through euphemisms in mainstream media (Kerry, 2011). Unnecessary and 'cosmetic' surgical interventions, usually performed in early childhood, along with the culture of shame that surrounds them, have led to an institutionalised silence around intersex variations and an extreme scarcity of first-hand accounts from intersex people, their parents, and families (Davis & Murphy, 2013; Kerry, 2011; Travis, 2015).

In the absence of these personal narratives, social portrayals of intersex people were dominated by pathologising medical discourse and a scrutinising medical gaze, treating intersex bodies as sites of coercive normalisation or disciplinary 'punishment' (Foucault, 1977) that has stripped intersex people of personal agency and voice (Amato, 2016; Cabral, 2009). A shift occurred at the beginning of the 1990s, marked by the emergence of intersex activism and non-medical scholarly attention to intersex experiences. This shift fuelled debates around the social construction of sexual and gender dichotomies and the ethics of medical 'normalising' treatments performed on intersex bodies (Chase, 1998; Dreger, 1998; Fausto-Sterling, 1993, 2000; Kessler, 1990, 1998; Preves, 2000, 2003). Simultaneously, intersex individuals began to form communities that served as safe platforms to share their stories and find individuals

with similar experiences. The Internet has facilitated first-person intersex narratives, with the potential for intersex visibility, demedicalisation, destigmatisation, and empowerment (Dreger, 1998; Preves, 2003).

While growing, research on the portrayals of intersex individuals is still in its early stages. (e.g., see works of Amato, 2016; Enguix Grau, 2011; Frotscher, 2016; Hart, 2016; Kerry, 2011; Lee, 2011; Martin, 2013; Maya, 2017; Middleton, 2021). A few studies have delved into the representation of intersex characters in literature and film, examining the narratives constructed around them and their impact on societal perceptions. For instance, Amato (2006) critically analysed the portrayal of intersex characters in literature, highlighting the challenges and complexities they face in a predominantly binary-gendered society. Qureshi (2019) explored the representation of intersex individuals in film, emphasising the need for more authentic and informed portrayals that move beyond sensationalism. The recent volume, 'Interdisciplinary and Global Perspectives on Intersex,' edited by Walker (2022), offers a collection of essays from scholars and intersex activists. This work provides an extensive overview of intersex studies, encompassing media portrayals and cultural representations of intersex people.

However, research addressing cultural representations of intersex people in contemporary Spanish or English contexts remains scarce (Monro, Wall, & Wood, 2023). Furthermore, it is underexplored how intersex individuals or people with variations in sex characteristics view, understand, and negotiate mainstream intersex representations, engaging in dialogue with 'master narratives' of intersex experience and (possibly) producing alternative, 'counter-narratives' of intersex subjectivity. These mainstream intersex representations, as well as the growing body of cultural products created by intersex within the intersex community, can have profound implications on the lived experiences of intersex people and create a social canvas for their life narratives from early childhood through adulthood (Amato, 2016).

2. Methodology

This study employs a qualitative research methodology based on narrative inquiry and critical ethnography to gain knowledge of lived experiences of intersex people regarding intersex cultural representations. It also develops a nuanced understanding of intersex self-created representations across various artistic mediums. Therefore, narrative analysis provides the tools to examine individual experiences, while critical ethnography contextualises these experiences within broader cultural and social structures.

Narrative inquiry, as developed by Riessman (1993, 2008), employs personal narratives as a central method for understanding human experiences. Personal narratives are viewed as integral to identity construction, being deeply embedded within larger cultural narratives and societal structures (Bruner, 1991; Crossley, 2000; Gergen & Gergen, 1984). As a methodology, narrative inquiry recognises narratives as an essential medium for identity formation and the making sense of lived experiences. This methodology facilitates the exploration of subjective processes and provides a rich understanding of individuals' experiences (Riessman, 2008). In the context of this study, narrative inquiry provides a powerful tool for exploring the way intersex individuals use narratives to make sense of their unique experiences and narrate their identities. The narratives are not viewed merely as individual stories but as social texts that reflect and respond to dominant societal discourses about intersex.

Critical ethnography, at its core, is an approach that combines elements of traditional ethnography with a critical theory lens. Rooted in the works of Madison (2005) and Carspecken (1996), it goes beyond the descriptive task of classical ethnography by incorporating a critical dimension that seeks to contextualise individual experiences within broader socio-cultural structures. While classical ethnography aims to describe cultures, communities, and practices from an insider's perspective, critical ethnography assumes a more politicised stance by deliberately and explicitly emphasising change and using knowledge production to challenge dominant discourses and advocate for social justice (Madison, 2005). This methodology draws attention to

the politics of representation and the influence of power structures on the lived experiences of individuals.

2.1 Sample and Procedures

The research encompasses a multi-method approach using both case studies and interviews with participants who are either intersex or allies actively involved in the creation or promotion of intersex representations. Six case studies encompassing children's literature, theatre and performance, and comics were selected as key illustrative examples of intersex self- or ally-produced representations. The selection was based on accessibility, diversity, and an opportunity for direct contact with the creators for an in-depth understanding of the creative process and intention behind each representation.

The study included semi-structured interviews with 14 participants recruited through purposive and snowball sampling (Browne, 2005) due to the small size of the target community and the specific criteria for selection. Nine participants identified as intersex, while the remaining five were considered experts or allies in the field of intersex representations. Participants ranged in age from early twenties to late seventies and were split evenly between Spain and England. Some of these interviews informed the analysis of six case studies (look up chapter 3.2.)

The interview process was conducted both online via Teams and in person. It was designed to foster a deeper understanding of participants' experiences and the processes behind their creation of intersex portrayals, as well as intersex people's experiences of navigating life with(out) different intersex representations.

An invitation letter detailing the study's ethics, objectives, and the research team's contacts was sent to potential participants. In some cases, a preliminary phone call was made to address potential concerns and answer any questions. Informed consent was obtained from all participants prior to the start of the interviews. All participants were also informed of their right to withdraw from the study at any point without facing any repercussions.

The semi-structured interviews ranged from 60 to 150 minutes, with an average duration of 90 minutes. They allowed for the exploration of individual experiences while also covering key topics of research interest. All interviews were audio recorded and later transcribed for analysis. Original audio recordings of interviews were stored on a secure, protected institutional server.

The topics explored during the interviews included, among others, the participants' experiences and challenges in creating and navigating intersex representations, their motivations, the impact of their work on their personal lives and the wider intersex community, their perspectives on the current state of intersex representations, and their vision for the future of intersex representations.

The interviews ensured that the participants could share their experiences and perspectives freely while maintaining a focus on the research objectives. This method allowed for rich, detailed, and varied data, shedding light on a range of experiences and perspectives related to intersex representation, offering a solid framework for understanding intersex self-representation, foregrounding the value of these narratives, and highlighting their potential to challenge dominant discourses and foster a more nuanced understanding of the intersex experience.

2.2 Data Analysis

Data analysis was informed by Riessman's guidance for narrative methods in the human sciences (Riessman, 2008), with thematic narrative analysis chosen as the most fitting approach. To ensure research rigour, the researcher maintained reflexivity, took written notes during and after each interview, performed peer checking, memo-writing, and constantly revisited the data (Tracy, 2010). The small size of the intersex community and the diversity of positions included in the interviews sustain the saturation of the empirical material.

After transcribing audiotaped interviews and familiarising themselves with the data, the researcher conducted a 'clean up' of the transcripts to facilitate working with information relevant to the research questions. The thematic narrative analysis was then performed. Riessman's approach to narrative analysis emphasises a case-centred

method rather than a population-based one, prioritising participants' unity, personal agency, and coherence of narratives over fragmented data for generalisations. Therefore, entire narratives were examined as a unit of analysis, focusing on the content rather than the linguistic tools of language production in narratives. Themes within each narrative were identified, considering personal, contextual, timely, and spatial factors as constitutive of meanings. Vignettes were used to encapsulate fieldwork findings, offering a glimpse into the narratives and facilitating the reflection of the following analysis (Ely, Vinz, Downing, & Anzul, 1997; Spalding & Phillips, 2007).

The establishment of themes was influenced by “prior and emerging theory, the concrete purpose of an investigation [and] the data themselves” (Riessman, 2008, p. 54). Selected excerpts preserved their narrative sequences to maintain contextualised and nuanced information and narrative integrity. The illustration of themes enabled the identification of overarching concepts and trends across cases, facilitating an evolving analysis and discussion. This approach was applied to all relevant documents and interview materials which together informed the case studies under the Critical Ethnography lens.

The results (chapter 3) were organised according to the major themes analysed. We start by presenting findings from the narrative analysis concerning intersex subjectivities and representations (section 3.1), followed by an exploration of six case studies on intersex self-created representations based on ethnographic data and interviews with the respective authors (section 3.2)

2.3 Ethics

This research project received ethical approval from the Ethical Commission of Universitat Autònoma de Barcelona (Spain) in February 2022. Throughout the study, we remained aware of the power dynamics embedded within data collection and subsequent knowledge production, as emphasised by Woodiwiss, Smith, and Lockwood in 'Feminist Narrative Research' (2017). This resource offered valuable insights into participant recruitment, data collection, researcher positioning, and ethical considerations post-interview while working with vulnerable populations. Complementarily, Ackerly and True's exploration of power and research ethics from a

critical feminist perspective (2008) helped us understand our role in projecting power through knowledge claims.

Respecting the individual agency of participants, we offered two levels of participation: named and anonymous. The inclusion of the named option was particularly appreciated by the vocal activists within the intersex community who wished their names to be known. For those who chose anonymity, rigorous measures were taken to ensure their identities were protected in data storage, analysis, and presentation. Only the research team had access to the audiotaped interviews, with pseudonyms applied to transcripts, unless real-name use was explicitly consented to by participants. Before respecting these requests, we ensured the participants understood the potential risks of identity exposure. In order to safeguard identities further, all potentially identifiable details, such as partners' names, residential neighbourhoods, workplaces, leisure spots, and cities of origin, were erased from the data presented. When a quote contained highly sensitive information, references to pseudonyms were omitted to prevent linkage to the rest of that participant's narrative data.

While ethical considerations are central to research integrity, we also acknowledge the implications of our own positionalities. As qualitative researchers, we recognise that our work is not entirely objective in the positivist sense. Interpretations are inevitably co-created and influenced by our experiences, beliefs, and theoretical positions. As such, our research recognises the shared construction of knowledge, indicative of our interaction with the data and our personal backgrounds (Riessman, 2008).

3. Results and findings

The results are organised according to the major themes analysed. Initially, the chapter presents findings from the narrative analysis concerning intersex subjectivities and representations (section 3.1). This is followed by an exploration of six case studies on intersex self-created representations based on ethnographic data and interviews with the respective authors (section 3.2).

3.1. Navigating life with(out) intersex representations as an intersex person

The thematic analysis of narrative material revealed four primary themes in examining intersex representations:

1. Silence and taboo surrounding intersex life experiences;
2. The subjective impact of media representations, or the absence thereof;
3. The formation and self-affirmation of intersex identity; and
4. Aspirations for the future of intersex representation.

The following sections delve into these themes, presenting extensive excerpts from participants' narratives to respect and amplify the direct voices of intersex people.

3.1.1. "Silence is prescribed" - Medical Silence and Secrecy in Families

So, and it's only over the last four years, as you probably know, that I've begun to talk about my own being intersex. Which is because of the secret issue. My parents were told nobody must know. That's doctors saying that nobody else must know. He must forever remain a secret. So, I wasn't able to tell anyone who I was. Like living with a stigma or with a fault line, you know, it's almost like a fault line.

(Chris, interview)

A prominent theme that surfaced throughout the interviews was the pronounced medical silence and secrecy surrounding intersex variations. In most instances, the medical community did not communicate transparently about their variations or

proposed treatments. As one interviewee, Mer, shared, “I was given the diagnosis in adolescence... a series of protocols were initiated, and silence was prescribed to me”. This secrecy imposed by medical professionals obscures the understanding of intersex realities and creates a societal taboo. As Mer indicates, “They tell me, well, this is something that people do not usually talk about. This is something that is not to leave here.” Mer’s narrative captures a sense of enforced isolation and loneliness as a result of medical silence and secrecy.

In Chris’s narrative, he recounts this silence and stigma in his journey of coming to terms with his intersex identity, saying, “So, and it's only over the last four years, as you probably know, that I've begun to talk about my own being intersex, which is because of the secret issue. My parents were told nobody must know. That's doctors saying that nobody else must know.” This narrative underscores the profound impact of imposed silence on his self-concept and social relationships. Chris likens this silence to living with a stigma or a fault line, saying, “There's something wrong with me, but I couldn't talk about it. Nobody, none of the doctors, explained what was being done to me.” Chris’s narrative captures a vivid image of an 'eggshell' existence, suggesting a self-contained world, opaque to external view and stigmatising in its very isolation.

Addy’s narrative provides a troubling insight into how family dynamics intertwine with this medical silence. She discloses, “The bodily variation was never spoken about. And they are still in denial about it, but abomination was the word my mom used. And the house with me under its roof was a den of iniquity. A curse on the family.” Here, familial denial and harsh moral judgments are amplified, which further contributes to the psychological trauma associated with secrecy and silence around intersex variations.

Camino's narrative introduces another dimension to this silence - framing intersex variations as a disease. She states, “Yes, fundamentally in a dialogue between doctors and relatives, that ends up coming to you, what you elaborate. It is that you are a person with a rare disease, and that makes the closet in which you find yourself padded inside”. This narrative illuminates how the language of disease can exacerbate the feeling of stigma and isolation, transforming the 'closet' of intersex identity into a 'padded closet' of illness.

Amazon, a UK-based intersex individual, further emphasises the implications of this medical secrecy. "And when it comes to an intersex child being born... there's like appointments booked, and it'll say something like hypospadias. Question mark. Circumcision. Because there's like these question marks around it, this grey area when it comes to our medical bureaucracy." Amazon's narrative brings to light how the medical system's rigidity perpetuates a binary conception of gender, with intersex individuals often coerced into fitting this mould, a reality that contributes to the "invisibility" of intersex lives.

Nevertheless, amid these narratives of silence and secrecy, Gala's² experience offers hope that things are changing and that the newer generations of intersex people can experience things differently. In contrast to other interviewees, Gala was informed about her variation by her parents in a clear and upfront manner, indicating the potential of openness in navigating intersex experiences:

Before I turned 15, my parents had already told me. Everything was planned as in a second round [to the hospital]; they had already explained everything to me as if I were an adult because they wanted me to go [to the doctor] with them the next day. Since I learned about my condition, androgen insensitivity, I always, always received information through my parents. It became a habit for me to rely on them for information, as I knew it would make me feel calm, and I had had a good experience doing it that way.

Finally, Chris's account of his mother's suicide attempt reveals a lesser-discussed aspect of this silence: its impact on families. It highlights the enormous psychological burden that the imposed silence can place on the families of intersex individuals. This psychological fallout is usually compounded by feelings of guilt, confusion, and distress as parents grapple with navigating a path for their children in a society unprepared to accept intersex variations:

Because my parents were told that had to remain a secret [...] Nobody, I don't think, is quite aware of the impact on the family. [...] But my parents must have gone through trauma and guilt. My mother actually tried to commit suicide when I was nine. [This happened] because nobody had talked it through with her...

²Gala is an intersex person in her early 20s

The profound silence and secrecy that surrounds intersex variations are propagated by medical institutions and perpetuated within family dynamics. This silence seems to transform into a societal taboo that fosters feelings of shame and isolation, affecting not only intersex individuals but also their families. At the same time, the narratives illuminate potential pathways toward healthier understanding and acceptance of intersex variations, paving the way for more open dialogues and improved mental health outcomes. The journey towards openness, as reflected in Gala's account, reveals the potential for transformation in the discourse surrounding intersex variations.

3.1.2. Impact of Misrepresentations & General Lack of Intersex Representation

*It's having a lot of puzzle pieces but not always knowing that they go together because there's no, there's no references, there's no frame of references, there's nothing. I mean. You don't know whether you're working on seven different jigsaw puzzles or one jigsaw puzzle. You just have all these pieces, and it turns out more and more that it's just one ***** puzzle that's a bit complex with a lot of parts, you know.*

(Addy, interview)

The narratives present a range of lived experiences, where two central themes emerge: (1) Lack of Representation and (2) Misrepresentation of Intersex in Media and Society. The themes intertwine and mutually influence each other, shaping the self-perceptions, self-narratives, and societal interactions of intersex people. Experiences of intersex people, as demonstrated in this analysis, foreground the emotional, psychological, and social impacts of such misrepresentations and the general lack of accurate intersex representation.

One of the most salient themes to emerge from the participants' narratives is their experience of growing up being intersex while dealing with misunderstanding, misrepresentation, and a notable absence of suitable role models or guidance. One of the participants says, "There wasn't a lot of information available about intersex... there was a lot of confusion about who I was and how I fitted into the world."

The lack of visibility hampers the self-understanding and self-acceptance of intersex people. When asked if there were any representations of intersex bodies during their growing years, the responses typically hovered around the rarity or the pejorative portrayal of intersex people, contributing to feelings of isolation and 'otherness.' An anonymous interviewee exemplifies this situation: "I didn't know that I knew intersex people until after I learned more about my own situation... [talks about a former classmate] I did stand up for her because other people bullied her over this because they suspected something really weird was going on. They said she was a mutant, whatever, you know, this kind of language."

The everyday use of the term "hermaphrodite" interchangeably with intersex was also highlighted as problematic by many interviewees in their coming-of-age narratives. "Hermaphrodite" is a term that was historically used to refer to intersex individuals. However, it is now considered outdated and offensive due to its association with non-human organisms and the implication that intersex people have both fully functioning male and female reproductive systems, which is not accurate. While it marked practically all of the participants' younger years as the first available reference in history or biology books, it persists in social discourses and media nowadays. Addy notes that the term was used pejoratively in a mainstream TV show, while Chris indicates that he was taught in school that it was a term for earthworms, and he did not have any other reference for intersex variations. This lack of correct terminology can lead to harmful stereotypes and misinformation about intersex people, contributing to their struggles with self-identity.

As Addy recalled, "I'd heard hermaphrodite a long time before I heard intersex. There were hermaphrodite pop-ups and stuff. There's so little cultural representation. But I don't know, we put on some TV show not that long ago and one of the characters there calling him Hermie the Hermaphrodite and then this other person goes, "he's not a hermaphrodite, he's a good person". And I'm like, **** it... it's just some really popular TV show and yeah, they would refer to him as Hermie, as hermaphrodite. But it's a term that more people are familiar with." Chris, in turn, shares: "That word, which I was, which my sister used, bless her, was hermaphrodite. So, hermaphrodite to me was earthworms."

The lack of visibility and respectful representation in the media also stands out as a shared experience, evident in Addy's statement: "You've got intersex people pushing stuff out, but it hasn't hit the mainstream." Amazon reflects on this sentiment, saying, "I don't think that people will still associate us with sinful acts or see us as a sign of the devil as what was recorded in mediaeval times, I don't think that's prevalent at all. I think that it's more a case of we've just reached this area now of complete invisibility, enhanced by the fact that we surgically alter intersex bodies to fit into this medical male or female box." Amazon further expands on the problem of representation within the media: "Totally the odd story. Pick up a national paper, and it'll be a woman who discovers that she has internal testicles or something like that. You know, yeah, the headline grabber. They don't wanna know any details, they just want a surface answer."

Another UK participant expressed concern about the tendency of the media to sensationalise or focus on tragic narratives, which can lead to a distorted understanding and a perpetuation of harmful stereotypes about intersex individuals. As they explain, "The problem generally is in the tabloid press as we call it here... they tend to have a lot of the more sensational stories." This comment suggests a failure of the media to respect the complexity and diversity of intersex experiences, choosing instead to exploit these stories for their shock value. This sensationalism and misrepresentations end up being potentially very harmful and have real-life consequences for intersex people, as can be seen in Addy's, Camino's and Sarah's testimonies:

I think it was around the age of 10. There was ... a trans and intersex person. The tabloids found out that she was in a James Bond movie, and they were dragging her through the mud and they were destroying her life. She was in the James Bond movie for like a second, but they were destroying her life over when they found out that she was trans, intersex and I was like, wow, I found another person like me!
(Addy)

In 'Sex and the City', where Samantha is talking about a micropenis and saying, 'It was horrible'. She had a look on her face... she said a peanut, that 'It was a peanut. I had the worst sex in the world with the peanut. It was horrible.' And that does enormous harm to us because we carry that over to groups of friends and it's... It's horrible. (Camino)

And I've seen just a whole lot of hostility like that. It comes from anti-trans stuff for the most part, because there's this very strong attitude amongst some people that you're either male or female. If you're intersex, that's a medical problem and needs to be fixed medically. And like we have fought for years against this. Listen to us. And then there are people here who will then say, oh, if you're not fitting neatly into one of these boxes, then you're a mutant. They have had a lot of that kind of abuse. I would love to be able to take that and stay in the frontline all the time. But I have done my time and that kind of activism and it has done my mental health a lot of damage and I'm not going to put myself in that position again. (Sarah)

Interestingly, Camino's remarks show how stigma and lack of awareness can also lead to instances of deception and cover-ups. She admits to having to lie about her own body to avoid uncomfortable questions or scrutiny, highlighting the challenges faced by intersex people in their personal lives, particularly in intimate relationships:

Yes, I have felt the need to lie, and I have invented all sorts of things. When I had the vaginoplasty, I was with a guy I had been dating for seven years, and I made up a syndrome, a clockwork vagina syndrome, where the vagina starts wide, narrows, and then widens again, and it had a uterus, ovaries, etc. This was obviously a lie, and I told this guy that I needed surgery to increase that narrowness, make it larger. In sexual encounters, especially in casual encounters through dating apps, I tried to minimise the visibility of the scars. If someone asked about them, I would directly invent some excuse like burning my butt sitting on a barbecue. I actually said that once.

3.1.3. Self-Understanding and Affirmation. Learning about Intersex

Despite the medical silence and the lack of intersex representation, the narratives also reveal a process of transformative self-understanding and affirmation. The interviewees' narratives recount their journey from a medicalised understanding of their bodies toward a more positive affirmation of their identities. The first time the intersex participants of this study came across the term 'intersex' varied considerably, and the context in which they learned about it influenced their journey to self-understanding significantly.

Initial Exposure and Understanding

As evidenced in the narratives, the initial encounter with the concept of intersex variations is often shrouded in medical jargon that uses diagnosis labels and language focused on pathology. Mer, for instance, recounts this first exposure: "Exactly, this is what happens to me, I have a disease. I was diagnosed with this, so they had to remove my gonads... everything from the point of view of the disease, no?"

Gala first heard the term intersex at a medical conference. However, she recalls the term being used in an artistic presentation, suggesting that this artistic exposure might have provided an alternative perspective to the traditional medical understanding. Amazon's first encounter with intersex was through an online poll in a stand-up comedian group, which led to their realisation that she was not alone in her intersex variation. This encounter, though informal, was pivotal for Amazon as it was instrumental in connecting her to the broader intersex community and launching her activism journey.

Transition from Medical to Identity-Based Language

This transition in language marks a significant point in the journey of intersex people. Mer mentions a radical shift in her perception and vocabulary, moving away from medical terms to a more identity-focused language. This change reflects a journey from pathologisation to validation and acceptance of her body and positive reclaiming of the intersex identity:

My vocabulary and my way of seeing my body radically changed. The moment I understand my body as something valid, as something possible, as something desirable, as something that is pathologised by a series of social phobias or social mandates, I start to claim myself as intersex.

The importance of language is evident in Sarah's experience. The discovery of her intersex identity was an unexpected, late revelation in her life, occurring at the age of 27. This moment came after she had had exposure to the concept of intersex but did not realise its personal relevance. This brings to light the critical issue of how medical diagnoses are communicated and understood by patients, particularly regarding conditions such as intersex that intersect with personal identity.

Sarah states, "I think I was 27 when I found out that that was what my diagnosis meant and might have heard it maybe a couple of years before that. But no more than that." This statement implies that her intersex variation was not clear to her at the time of her diagnosis. This indicates a gap in her understanding, arguably due to insufficient or ineffective communication by healthcare professionals. Sarah's discovery of her intersex identity was self-driven, stemming from online research: "It was just finding things online originally." This implies that the internet can play a critical role in providing information and facilitating understanding of intersex, especially for people who might not receive comprehensive information from healthcare professionals.

Furthermore, Sarah's narrative highlights the dissociation she initially had from the term intersex. She states, "I knew that that's what my diagnosis meant. I just thought it was something separate from me. I didn't realise the connection." This disconnect between her personal identity and her medical diagnosis can be attributed to the traditionally pathologising language used in medical settings, which often fails to address the identity-based dimensions of her intersex variation.

It was only after making the connection between her diagnosis and the term intersex that Sarah began her journey of understanding and accepting her intersex identity:

It was interesting to have language for it. It was really important to me because it meant that I could start to look for community, even though at the time there was very little of that. In the UK, there were very few people and organised groups... It really made things much easier for me to understand and cope with. But I think it also made me, in some ways, more angry about the process that I've gone through before, and particularly about the fact that, you know, that my doctors hadn't talked to me in that way before they talked to my mother, but my mother didn't understand what she was being told. She's not very good at that kind of thing. So I hadn't had any useful feedback.

This narrative underscores the need for a more integrative approach to discussing intersex in medical settings, one that recognises intersex not as a medical condition but as a fundamental aspect of personal identity.

Impact of Cultural Representations

Cultural representations played a significant role in how the participants understood and embodied their intersex identities. The intersex individual's journey is not only about acceptance but also about battling cultural stereotypes and seeking visibility.

In her narrative, Camino reveals her struggle with feminine identity due to her being intersex. She recalls feeling like an imposter when she wore feminine clothes, fearing that she might be perceived as a "man in women's clothing." Camino's story underscores the tension many intersex people experience as they negotiate societal gender expectations. Camino also describes how media representation affected her, particularly an episode where intersex women were portrayed as shadowy figures, devalued and unable to live openly. She contrasts this with the empowered image of a male psychologist, Gabriel J Martín, who publicly embraces his intersex identity. This comparison shows how visibility and representation can be powerful tools for self-acceptance. However, it also highlights the imbalance in visibility between intersex men and women in Spain in the 2010s.

Evolution of Self-Understanding and Identity

Learning about intersex and incorporating it into their identity was a journey marked by personal growth for the participants. Gala recalls quickly understanding the concept of intersex and saw it as an explanation that made much sense. It brought clarity and affirmed her self-identity. For Camino, acceptance and contentment came after a process of struggle and self-doubt, as she describes moving from experiencing severe internalised transphobia and interphobia toward embracing non-normative gender expressions, hinting at an evolution toward non-binary identity, which reflects her comfort and acceptance of her being intersex.

In conclusion, the narratives highlight that the journey of learning about intersex and integrating it into personal identity is complex and multifaceted. This journey is shaped by a range of factors, including initial exposure to the term, the language used to describe the variation and the cultural representations they encounter. The evolution of language from medical to identity-based is a crucial aspect of their journey, fostering a

shift from pathologisation to acceptance. Moreover, cultural representations influence their self-understanding and affirmation. It is apparent that greater visibility and positive representations can play a substantial role in promoting self-acceptance among intersex people.

3.1.4. Future of Intersex Representation: Aspirations, Desires, and the Work Ahead

The interviews highlight various salient aspects that tie into the future of intersex representation. These narratives demonstrate the desire for authentic and ‘ordinary’ intersex stories, the need for intersex-generated cultural portrayals, and the aspiration for holistic representation, including the variety of identities and diverse cultural backgrounds.

Seeking Authentic and Ordinary Intersex Narratives

Many of the participants’ narratives focus on the need for authentic intersex stories that break away from sensationalism and shock value. For instance, Sarah identifies a prevailing pattern of tragic narratives in current intersex representations, which invariably lean towards painting intersex people as victims or sources of shocking amusement, being “horribly distorted”. As Sarah indicates, there is a scarcity of ‘ordinary’ stories featuring intersex people who discover their variation and continue to go on with their lives unabated, promoting the idea around the capacity of intersex people to live fruitful, fulfilling lives. She notes, "There are very few stories about someone who found out they are intersex and is perfectly OK with that and is catching on with life (...) And it's important to talk about the bad things that happen to intersex people, particularly within the medical establishment, and to say that we need this to change, but I think it's also important to say you don't have to despair and you know you can have relationships, you can have sex. You can, you know, have a normal life." This theme of seeking ordinary narratives challenges the prevailing discourse that intersex people are automatically victims of their intersex variation. Sarah's account speaks to a desire for intersex stories to be presented within an array of different narratives, not only ones that underlie conflict, tragedy, and pain. Importantly, Sarah also stresses the

need for diverse stories, including those that feature minority and disabled intersex people.

Intersex-Generated Cultural Portrayals

Another theme that is found across all narratives underscores the importance of intersex people being at the forefront of creating cultural artefacts to tell their stories in their own words or images. As Addy points out, "If we don't do it, nobody else will. And if other people do it, they'll do it wrong." Addy's observation reinforces the necessity for intersex voices to be heard directly rather than filtered through the perceptions of non-intersex creators, arguing that it helps avoid misconstructions or exploitations of their experiences. Addy's endeavour to create comic strips that tell the stories of intersex individuals presents an alternative and engaging medium of representation, aligning with Sarah's emphasis on using fiction and non-fiction narratives for 'incidental representation.'

At the same time, many participants speak about the challenges in getting intersex-led representation out there:

To try and make anything and it's just it's an uphill battle. Everybody's left struggling [...so] it's all the more important that we produce these cultural artefacts. But it's harder because a lot of us don't have the resources or connections because we're intersex, because we don't have family support, or we've suffered employment discrimination, our medical discrimination that affects our ability to do anything or you know, so it's the cards are really stacked against us. So, it's such an uphill battle (Addy)

Wholesome Representation: Array of Identities and Diverse Cultural Backgrounds

Many interviewees articulate a desire for holistic representation that extends beyond the invasive gaze on intersex genitalia and the heteronormative lens. Camino argues for parity in the representation of intersex and endosex (non-intersex) bodies, emphasising that the focus on intersex people should not be limited to their physical differences but should equally cover other facets of their lives. Similarly, Gala expresses a wish to see more diverse bodies, in general, to be represented and argues against the stereotype of intersex people being traumatised or suicidal. She envisions such stories

in which intersex characters are depicted just like anyone else, without their appearance being the focal point:

I would like to see other types of body representations in a way. In the end, this has a lot to do with everything, including the discussion about the visibility of fat bodies, of bodies in general (...) People with different bodies, yes. Perhaps I wouldn't want to see stories that speak only of the drama that it has been, not just see those types of stories where an intersex character is a person traumatised and with suicidal thoughts. I would like to see real stories like Tilindula's, but I would also like to see, at the same level, representations of simply different characters (...). Just a girl who has a character, and that character is just like that, and is not an evil character. I mean, like seeing fat people, people with disabilities, women with body hair, intersex people... Accomplished people without it being a spectacle every time, no, and without the emphasis, the focus being on their appearance.

Mer emphasises the value of the option of anonymous participation and notes the need for creating more intersex local and culturally diverse content, highlighting the potential of regional narratives in fostering a more nuanced understanding of the intersex experience. Sarah's narrative echoes this as she also reflects on the white and other privileges in intersex portrayals:

(...) intersex activist narrative, so you have to be out and about everything, but then people can suffer really harsh consequences. It means that all the stories that we get sometimes are from those people who feel able to be out. And that, you know, that probably mitigates against minority communities and figures. But maybe one reason why they're so overwhelmingly white, for instance. Because if you've got a lot of other privileges, it's easier to take that chance. So, we need to create those spaces [for intersex people to speak up]. (...) And I think we also need more opportunities for people to speak anonymously and that's a little bit controversial within the community. I know intersex people. They say that they don't want that because it suggests shame. But at the same time, I think we need that volume of stories. And we won't get that until we make a little progress and just get more stories out there. (...) There is also fiction. And I think it's worthwhile having fictional intersex characters, ideally written by intersex people.

The Future: Multiplicity of Approaches and Voices

The analysis of the interviews suggests a future of intersex representation that is multi-dimensional. For the participants, it means generating narratives that reflect the mundane and the ordinary; it involves creating cultural artefacts, whether in the form of books, films, or comic strips, that are led and developed by intersex individuals. The aspiration is to push for holistic representations, covering a spectrum of identities, bodies, experiences, and backgrounds and consistently challenging sensationalism and binary stereotypes. It also involves navigating the balance between visibility and personal safety.

While there is a clear desire for more intersex representation, as Addy notes, this doesn't mean every intersex person should be expected to disclose their status or come out in public. The right to privacy and personal safety are fundamental, particularly given the potential stigma and discrimination that intersex people can face.

Anonymous participation, as suggested by Mer, is one potential strategy. This approach allows intersex individuals to contribute to the narrative and cultural portrayals of intersex without exposing themselves to potential harm. Alternatively, Sarah's suggestion of "incidental representation" could also offer a safe means of representation. By weaving intersex narratives into more significant, diverse stories, the representation of intersex people becomes less sensationalised and more normalised, potentially reducing the spotlight and the invasive gaze and, thus, the risk faced by intersex individuals who contribute to these stories. Addy reflects on the same idea of "incidental representation" by saying:

I would like to see movies come out where they're just showing love and community, or just sneak in a ***** intersex person, like one of the roommates is ***** intersex and they have a conversation at one point about it and it doesn't turn out a monster who murders everyone in the flat over it. I'd like to see books come out where it's not like, you're not intersex because your parents committed incest. It doesn't even have to be the main ***** character. But maybe, it's like Game of Thrones and one of the knights is intersex. They just happen to be, you know.

Moreover, there is a call for the establishment of secure platforms, as hinted at by Addy and Sarah, where intersex people can share their experiences without fear of backlash or discrimination. These platforms could range from social media groups and forums to workshops or events, effectively serving as safe spaces for intersex individuals to express themselves, share their stories, and generate intersex cultural artefacts.

Finally, these narratives underscore the need for allyship and support from endosex individuals and organisations in fostering safe environments and advocating for accurate and respectful representation. Allies can play a critical role in amplifying intersex voices without putting the intersex community at undue risk. It is a future where intersex stories are told, heard, respected, and normalised, contributing to a broader understanding and acceptance of intersex lives.

3.2. Engaging in Creating Intersex Representations

The presentation of these ethnographic results visualises the inductive analytical process from ethnographic data to general theoretical questions, presenting the analysis of the selected case studies in six sections:

1. The theatre play "Tilindula: Memorias de una Mujer Invisible" (*Tilindula: Memoirs of an Invisible Woman*)
2. The monologue/performance "Soy Lola y soy Intersex" (*I am Lola and I am Intersex*)
3. The opera "Alexina B."
4. The graphic novel "The Well of Silence."
5. The children's book "Un Secreto Pelirrojo" (*A Red-Haired Secret*).
6. Amazon Jackson's stand-up shows.

Each section begins with a description of an ethnographic vignette and is followed by a reflection on its relationship to broader theoretical issues. A more narrative style has been chosen to appreciate the ethnographic detail and the context from which the conclusions are drawn.

3.2.1. "Tilindula: Memorias de una Mujer Invisible" (Madrid, March of 2022)

The world and us, we all need more intersex representations like that. That do not focus on our genitalia. On our diagnosis. That show that we are whole people and that our stories don't turn around the medical category [...] I think that is what Tilindula manages to capture and transmit.

(Intersex person, interview)

In "Tilindula: Memorias de una Mujer Invisible," playwright, director, and lead actor César González sensitively portrays the life of Rufina, an intersex woman who lived in rural Spain during Franco's regime and spent 30 years of her life in home confinement. As a psychologist and LGBTQIAQ+ rights activist, César interviewed various intersex people and Rufina's family members to create an authentic and heartfelt portrayal of her life. "I wanted to explore the life of someone who didn't fit into the norms established by society, and through Rufina's story, we could dive into the complexities of sex characteristics and gender identity and how that affects a person's life," he explains.

César knew Rufina personally, as they both hailed from the same village in rural Extremadura. Intriguingly, César reflects that Rufina might have been the first "LGBTQI person" he met as a young boy, without even knowing it. The play came to life during the COVID-19 pandemic and lockdown, which inspired César to connect with Rufina's sister, Caridad, and her niece, Trinidad. They agreed to share Rufina's story, and César set out to "dignify the story" by changing the names and addressing not only Rufina's life but also the family dynamics, war, class struggle, trauma, and the identified patient concept:

Rufina had spent 30 years locked up at home. And just as we were starting a pandemic and a lockdown, we were going to spend months locked up at home, and it all came together in my head. One afternoon, I took the car to look for her sister Caridad and proposed to her, if she felt like talking about her story, and she said yes [...] Caridad, at first, was quite reserved: "What are you going to do with this story that is so private to me?" And I said, well, first of all, change all the names and then I want to dignify the story. I want to do something that not only talks about Rufina, but also about family dynamics, about what the war did to the family, which split it at the time, about class struggle, about trauma, about the "identified

patient”, about what cannot be said... And how the family organises itself around a problem [...] And so, well, I started to connect her experience with my own experience as an LGBT person and with this symbolic violence to which I believe we are exposed simply by being sexually dissident. And I talked to Camino, it was important that someone intersex told me what doubts crossed their mind, what concerns they had to deal with every day [...]

- So, the play is a combination of Caridad’s memories, her sister’s, and a bit of the memories “imagined” by you, right?

- Mhm, yes, also Camino and other people from the intersex community who had the script to study.

A crucial aspect of intersex representation in the play is the exploration of the effects of family dynamics and relationships on Rufina's life. The cast's performances create a comprehensive and empathetic representation of Rufina's story, allowing the audience to connect with the “mother's sense of responsibility, the sister who disconnects from Rufina's reality, the other sister who accompanies her without knowing how, and the father who immerses himself in work to distract from his fears”. These portrayals emphasise the intricate web of relationships and emotions that surround Rufina and contribute to her experiences as an intersex person. The feedback to the play published by Kaleidos members (2022) describes the experience of many intersex people as involving “el desabrazo familiar,” or family detachment, and the resulting “internalised anger, shame, and hyper-vigilance towards external judgement”:

This work clearly portrays the experience that many intersex people can live: the lack of family acceptance, the retroflected rage (when you feel that your right to be angry is delegitimised and you turn the anger towards yourself), toxic shame, hypervigilance towards external pointing out, the search for normativity by imitating endosexual (non-intersex) models of femininity/masculinity, the belief that 'nobody is going to love me', the feeling of being indebted to the people who love you, the guilt of feeling that you force your family to face difficult challenges, depression, loneliness... Also the phenomenon of 'the identified patient', as the author himself would reveal, through which family system dynamics are overlooked because all the attention is focused on the 'symptomatic' person. The

cross overprotection in different directions as a source of secrets and concealment; nobody talks about the elephant in the room for fear of causing harm. If we do not know how to address the issue, it is better to remain silent. A silence that renders us invisible. Hence the theme we approach from our activism: intersex families, we are silent, silenced, and made silent. Who wouldn't hide something they fear? (Kaleidos, 2022)

César emphasises the importance of understanding these emotions by saying, "I wanted to make sure that Rufina's story was not just about her physical variation, but also about her emotional journey, her relationships with her family, and how they all coped with their circumstances." One of the central themes in the play is the effect of war on Rufina's family. César highlights the importance of examining "what the war did to the family, how it tore them apart at the time", which adds another level of complexity by incorporating the historical context and social dynamics of small rural communities of that time.

Religion also plays a significant role in Rufina's life and her relationship with gender. The church becomes a space where she feels recognised and connected to something larger than herself. As Rufina states in the play, "I am a woman, and God knows it", she finds solace and acceptance in her faith. Her belief in God's love and acceptance of her as she is provides her with a sense of validation and self-worth that transcends the judgement of others. Rufina's relationship with her own body is complex and characterised by moments of crisis, anxiety, and doubts. In the scene when Rufina looks into the mirror, a cisgender man's (Sergio) reflection appears, which leads to an anxiety crisis for Rufina. She experiences self-doubt and questions her own identity as a woman. This doubt causes her to wonder if she is "the one who is blind, unable to see what others perceive, that others see a Rufino³". In César's understanding, "when Rufina feels disconnected from herself, she also becomes disconnected from her gender, her experience, her essence, and her womanhood". In these moments, religion offers Rufina space for self-affirmation and acceptance, helping her navigate the challenges she faces due to her being intersex.

³ the Spanish language's masculine version of the name Rufina.

This representation of religion in the play also serves to challenge the stereotypes and prejudices that often emerge in religious contexts. By depicting Rufina as a devout and spiritual individual, González invites the audience to question their assumptions about the compatibility of intersex identities and religious beliefs. This nuanced portrayal, as we think, presents an ability to encourage greater understanding and empathy among religious communities towards intersex people.

Rufina's struggle to conform to societal expectations of femininity and masculinity is another critical theme for intersex representation, as Rufina's character represents an example of an "intersex person who escaped medical intervention and lived without role models or guides" (Kaleidos, 2022). César's performance as Rufina highlights the internal conflict she faced in trying to meet these expectations while staying true to herself. He states, "It was essential to portray Rufina's struggle with her identity in a way that showed her humanity and vulnerability." In this regard, an important aspect of the play was the visual representation of Rufina, which was carefully considered by César. He discussed with Caridad how Rufina should be depicted on stage, considering her physical appearance and personal preferences. César recounts that Caridad asked him to be "clean-shaven and well-dressed", as Rufina herself would have been: "She would affectionately ask me, she would tell me, but you are going to come out clean-shaven, you are going to come out with your legs waxed, [...] please. I mean, remember that she took great care of herself [...] tell me that you are going to be well-shaven, with a nice little make-up". This attention to detail in Rufina's physical portrayal helped to create an authentic and respectful representation of her character.

The play also addresses the experience of isolation and loneliness that many intersex people face. Rufina's life is marked by her confinement within the walls of her home, hidden from the judgement and mockery of society. The feedback from Kaleidos (2022) emphasises the significance of this isolation, stating, "Her experience was lived in solitude, sacrificing her life". César acknowledges the importance of presenting Rufina's story to break the silence surrounding intersex experiences. "This is a story that needs to be told because there are so many people out there who are living their lives in silence, afraid to be who they are."

Regarding playing Rufina while being endosex, César acknowledges that for this play, he did not actively seek an intersex actor for that role due to a request from Caridad, Rufina's sister, who asked César to portray Rufina himself: "Son, please, you knew her, and if someone is going to go up on stage to represent her, it's you who should do it". However, César understands that portraying Rufina from a position of endosex and male privilege is a complex issue and recognises the need for the character to be played by someone who shares Rufina's intersex experience in the future, saying that he is willing to pass this role to an intersex actor.

The play's reception by Rufina's family and the wider community was a significant concern for César and Caridad. Caridad expressed her fears about potential negative reactions to the play, particularly from her small village in Extremadura: "She was afraid that people, well, that people would stand up and show rejection towards the story." However, the play was well-received, with Caridad and other family and community members experiencing emotional moments during the performance. For instance, after the play, when Caridad saw the actress portraying her mother, she exclaimed: "Ay, mi mamá!" indicating that she recognised her mother in the actress's portrayal. Another audience member commented that they felt like they were seeing Rufina again, alive and with them. This emotional reunion underscored the play's impact and the significance of its representation of Rufina's story. The reaction of the community from Rufina's village who knew her personally was also extremely positive and emotional, to the extent that they asked César to bring the play to the local theatre following the play's premiere in Madrid.

"Tilindula: Memorias de una Mujer Invisible" not only focuses on Rufina's life but also sheds light on the broader issues intersex people face. The play serves as a call to action for society to challenge its assumptions about gender, recognise the struggles faced by intersex people, and support their rights and visibility. As César emphasises, "It is essential to change our relationship with diversity, with the unknown, with what scares us, and open ourselves to the possibility of encountering the other and learning from their experiences".

3.2.2. "Soy Lola y Soy Intersex" and "Solo Apto Para Bichas Raras"

At the moment when I understand my body as something valid, as something possible, as something desirable, as something that has been pathologised due to a series of social phobias or social demands, I begin to assert myself as intersex and at first I do it through the creation of a character [...] And so the character is born, thus Lola is born and I, Mer, can tell my story to many different people. Something that I had kept silent for years, - suddenly, through theatre or through the creation of a character, - I am able to expel it.

(Mer, interview)

"Soy Lola y Soy Intersex" [I am Lola and I am Intersex] is a monologue written and performed by Mer Gómez, which explores her personal experiences of being intersex, using her alter ego, Lola, to tell her story. The monologue was first performed in Salamanca in 2016 as part of a project called "Con un par... de ovaries," which featured five different monologues. The project's title is a play on words, as "un par de ovarios" [a pair of ovaries] is a colloquial expression in Spanish that is used to convey courage and strength. Through this project, Mer and her colleagues sought to challenge traditional gender roles and stereotypes and to create a space where diverse voices and experiences could be heard. Despite the diversity of the stories, however, they all share a common thread of empowerment and self-discovery about one's navigating of womanhood. Thus, Lola's story is not presented in isolation but as part of a broader conversation about gender and identity.

Mer notes that the performances took place in small, intimate spaces that could only hold a maximum of 25 people and that the lighting was adapted to the particular setting. The performance did not use music, as the stories told were dramatic and humorous, focusing on the spoken words. The audience was arranged in a circle around the performers, and the actors moved from the audience to the centre of the circle to perform their monologues. This proximity created an intimate atmosphere that suited the content of the monologues. This intimacy was particularly significant in Lola's monologue, where she reveals that she is intersex: "Lola is sitting among the audience, surrounded by the audience next to other unknown people, and that's where it starts: I'm Lola, I'm intersex, and I'm going to tell you my story, and Lola gets up and goes to the centre".

Behind the monologue "Soy Lola y Soy Intersex" lies a deeply personal story. Mer speaks publicly for the first time about her own experiences as an intersex person and the impact that medical interventions have had on her life. "The play has a lot to do with my personal process of discovery and liberation from the burden I was carrying, of shame and guilt." She also shares her journey towards self-acceptance and her work as an intersex activist. She discusses the challenges she faced when trying to navigate the medical system and the societal pressures to conform to binary gender norms. The monologue highlights the lack of knowledge and understanding surrounding intersex issues, as Lola describes the confusion and shame she felt when she was told she was different and needed to be "fixed" and learning about the medical interventions that were done to her without her consent. Lola's story is an emotional one that speaks to the experiences of many intersex people who are subjected to non-consensual surgeries and medical interventions, together with the culture of silence and shame surrounding their bodies. Therefore, for Mer, this monologue is a way of raising awareness about intersex issues and advocating for the rights of intersex people.

Mer explains in the interview that playing Lola helped her navigate her intersex identity. By taking on the persona of Lola, Mer was able to distance herself from the emotional baggage associated with her personal experiences and take a more objective stance. As she states in the interview, "Lola is a powerful tool for depersonalisation. It's not about me, but about a person who has very specific circumstances." By taking on the role of Lola, Mer was able to "expose" herself and tell her story to different people, something that she had kept quiet about for years.

Mer acknowledges that, at first, she needed Lola as a character to be able to tell her story and navigate her intersex identity. She says, "It was a process. In the beginning, I needed the character of Lola. And then, little by little, the character of Lola was left behind, and Mer began to come to light [...] I wanted to make the decision myself. I needed to have this autonomy over what I wanted to say, where I wanted to say it, and how I wanted to say it. Well, I also went through different stages, and until I was really ready, I didn't start speaking as Mer [...] What Lola did was empower me so that Mer could come out of the closet with the people I chose and I wanted to share with".

Mer also explains that Lola served as a protective shield for her, allowing her to speak about her experiences without feeling too exposed or vulnerable. She says, "More than protecting yourself, the most important thing is to take care of yourself. On the other hand, apart from being an intersex activist, I work with intersex issues from different areas, so I am more than just an intersex person. Intersex is something that runs through me, and that is there. But I am also other things, so being able to internalise all of that, to realise that I am the one who is also making intersex visible from other places, was really important."

Mer highlights that Lola's physical appearance was one of her distinctive traits. She wore a black t-shirt and sported a long, flowing mane of hair tied back with a bandana. Mer had also studied "Theatre of the Oppressed," a style of theatre that involves using objects or symbols to identify a character, "to get into character," and felt that it made sense for Lola to wear the bandana as an identifying object, something that would distinguish Mer from Lola, her character.

Mer's next performance as Lola came in Salamanca in 2019 in "Solo Apto Para Bichas Raras." Lola undergoes a significant evolution compared to her previous performance in "Soy Lola y Soy Intersex." In "Solo Apto Para Bichas Raras," Mer takes a more comedic approach, using humour to challenge the audience's assumptions about intersex people. The title, which translates to "Only Suitable for Weird Bitches," is a play on the derogatory term "bicho raro," or "weirdo," which is often used to stigmatise intersex and queer people. Mer uses humour to subvert this stigma and to encourage the audience to see intersex people as individuals with their own unique experiences and perspectives.

The character of Lola in "Solo Apto Para Bichas Raras" is different from the Lola in "Soy Lola y Soy Intersex" in many ways. While the first Lola is timid and almost invisible, the second Lola is more visible and commanding. As Mer explains, the performance "changed hugely. The mood of the character was different. In the first play, Lola was just starting to come out of the closet and you could see that evolution during those 20 minutes, as Lola slowly gained confidence and told her story. In "Solo Apto Para Bichas Raras", Lola is a revolutionary. She opens the door of the room where the play is taking place and declares to the world that she is 'sick of the fucking patriarchy'". As Lola

speaks, she becomes more and more assertive, and by the end of the performance, she is shouting her truth to anyone who will listen. She and her companion climb onto a chair and shout out a series of adjectives that describe them and others like them, including "misfits," "marginalised," "deviants," "hysterical," "free" and "hyenas".

Mer's evolution as an intersex activist is clearly reflected in Lola's transformation. As Mer explains, "In the Academy, in feminist activism... I started to establish connections with intersex support groups like GrapSIA, and I began to know more intersex people and make a journey throughout Spain, meeting people with whom I am still in contact." Through this process, Mer develops "her identity as an intersex woman and an activist", which she proudly displays in her new performance.

Therefore, "Solo Apto Para Bichas Raras" represents a significant evolution in Mer's performance as Lola. Through these monologues, Mer is able to express her intersex identity and her activism in a way that is empowering and liberating. Lola's character reflects Mer's own journey, and her transformation is a testament to the power of self-discovery and self-expression. The play is an assertive statement of resistance against the oppressive forces of the patriarchy and a celebration of the many diverse and beautiful identities that exist in the world:

So, that monologue puts all the empowerment and definitive dissonance of Lola on the table. Lola goes there to say: "I am the same as the others; I am just another person." These intersections cross me, but I am proud to be a woman, to be intersex, to be bisexual. And to have come to identify the oppressive apparatus that the cis heteronormative patriarchal system that has created [...] that taboo that for many years I lived with my own body, so it is very beautiful the evolution that Lola has.

3.2.3. "Alexina B." -Opera, Liceu, Barcelona, March 2023

*And it is to me that you direct your insulting contempt, as to a disinherited one,
as to a being without a name! But do you have the right?*

Mes Souvenirs, Adélaïde Herculine Barbin (Paris, 1874), as cited in
(García-Tomás, 2023)

"Alexina B." (García-Tomás, 2023), a ground-breaking opera created by composer Raquel García-Tomás and librettist Irène Gayraud, marks a pivotal moment in opera and the representation of intersex people within the arts. Set in 19th-century France, the opera tells the life of Herculine Barbin, an intersex person discovering the themes of identity, love, and societal oppression. The idea for "Alexina B." appeared during a conversation between García-Tomás and Gayraud. Wishing to compose a French opera set in the 19th century, García-Tomás approached Gayraud for suggestions. Gayraud proposed basing the opera on Herculine Barbin's life, as her memoirs are the earliest known autobiographical record of an intersex person. The creators recognised the potential to share a powerful and historically important story while raising awareness about intersex experiences (García-Tomás, personal communication, March 20, 2023).

Therefore, the opera's narrative is inspired by the life of Herculine Barbin, or Alexina B., as described in her memoirs, "Mes souvenirs, Herculine Barbin." Assigned as female at birth, Alexina grew up in a convent and later pursued a career in teaching. She fell in love with Sara, a fellow teacher, during a time when 19th-century France enforced strict heteronormative rules. Consequently, Alexina decided to redefine her identity as male, legally changing her name to Abel Barbin together with her legal sex. Sadly, she could not adapt to her new circumstances and, experiencing extreme isolation, poverty, and despair, ultimately took her own life.

At its heart, "Alexina B." is a story of love, identity, and struggle against societal norms. It is love for Sara that catalyses Alexina's self-discovery and forces her to confront societal rules, leading her to re-evaluate her gender identity and place in the world. This central theme of love and self-discovery drives the opera's narrative. It reflects on the challenges faced by intersex (and queer) individuals in heteronormative societies in both the past and present days. The opera also questions conventional gender and femininity constructs, prompting audiences to examine their own understanding of these notions. García Tomás emphasises the importance of depicting love as a universal human experience transcending gender and sexual identity. By concentrating on love's emotional depth and complexity, the opera aims to cultivate empathy and understanding among audiences, encouraging them to look beyond labels and categories.

The composer stresses the responsibility and importance of preserving the core of Alexina's narrative, requiring a delicate balance between artistic freedom and being faithful to the source material. This balance ensures that the opera is not only captivating and entertaining but also accurately reflects the struggles and victories experienced by Alexina and other intersex individuals. García-Tomás conducted thorough research and consulted various sources to achieve this balance. She collaborated with intersex individuals, researchers, and activists to gain a comprehensive understanding of intersex issues and experiences. The composer also studied primary sources, such as Adélaïde Herculine Barbin's memoirs and other relevant documents, providing invaluable insights into the historical context and societal norms that influenced Alexina's life. In doing so, the composer guaranteed that the opera stayed true to intersex experiences while allowing artistic expression and interpretation. In addition to honouring Alexina's story, García-Tomás aimed to create a work that would resonate with modern audiences. She accomplished this by adopting an interdisciplinary approach, integrating music, visual art, and technology (including projections and multimedia) to produce a rich, immersive theatrical experience.

Furthermore, the libretto, according to its author Irène Gayraud, followed an ambitious goal to incorporate two things:

“It had to respect the tone, vocabulary, and content of Alexina B.'s testimony, which is firmly rooted in the 19th century, while also creating a contemporary work that is conscious of the issues and demands of intersex people today. Composed of three acts that cover the major moments in Alexina/Abel's life, the opera portrays not only Barbin's suffering but also the happy moments in her life. Alexina/Abel experiences intense love with Sara, who reciprocates with passion and totality” (Gayraud, as cited in Sandoval, 2023), and, notably, the love scene between the two is the longest scene of the opera, giving it weight and emotional significance.

In staging "Alexina B." at the prestigious Liceu, the creators have brought the story of Herculine Barbin and intersex people to the forefront of contemporary cultural discourse. Through its emotionally charged music, powerful narrative, and sensitive portrayal of Herculine Barbin's experiences, the opera provides a platform for intersex

voices and contributes to the broader cultural understanding of sex characteristics and gender. By employing good practices in intersex representation, "Alexina B." serves as a model for future works seeking to portray the experiences of intersex people authentically. This example should encourage opera composers, librettists, and directors to engage with contemporary social issues and amplify the voices of those who have been silenced historically.

Finally, García-Tomás, reflecting on the impact of staging an opera about a historical intersex character at a prominent venue like the Liceu, expresses deep gratitude for the opportunity to present this story in the main hall, highlighting the usual belonging of such narratives to smaller, more marginalised spaces. The placement in Liceu, according to her, significantly broadens the reach of the story, making an impact through media attention and bringing the term "intersex" into mainstream discussions. She shares:

With all humility, we are trying to create a work of art, and we believe that these topics can also be addressed in this high art genre and, at the same time, portray this story with beauty [...] I would like for people to leave with a curiosity to better know the story of Herculine, with a greater sensitivity towards the demands of intersex individuals, and also with a greater curiosity for new creations in general (García-Tomás, 2023).

3.2.4. "The Well of Silence"

*Sometimes I wish I could pick up the phone and have a conversation with my
11-year-old me.*

*- Dear Chris. I don't know what journey we'll be going on. At the moment I feel
lost, afraid, confused. I hope when I catch up with you, our life journey can be
used to change the world.*

Your 11 y.o. Chris xxx

*- Dear Chris. You are an amazing boy to have gone through so much. Maybe in
years to come your life journey will not be for nothing.*

Your (much older) Chris xxx

(North, 2021)

As Chris writes about himself on the last pages of his graphic novel, “Chris North is an author, independent scholar, and creative arts facilitator, and believes in the power of comedy. He is an intersex advocate and activist [...]. “The Well of Silence” tells his story from a traumatic childhood and adolescence to “finding himself” in later years”, becoming a journey from “the well of silence” to “well-being” (North, 2021). In “The Well of Silence,” Chris North, now 76, shares his remarkable and challenging life as an intersex person. His graphic novel is a powerful exploration of identity, resilience, and the importance of understanding and accepting one's true self. Using a “tapestry” of very graphical and symbolic metaphors and quotes, North offers a profoundly personal account of his life while addressing the broader issues intersex people face.

The novel begins with a sense of urgency, as North writes, “I need to tell you my story and who I REALLY am! Listen so you can understand. Hear me, hear me. Please listen! Listen while I am still here to tell it. Still **not too late**...”.

The book takes us through Chris’s childhood and adolescence, which were defined by medical violence and silence. For much of his life, Chris struggled with the secret of his being intersex, which had been hidden from him by doctors and his parents. His feelings of living with a stigma and a “fault line” led him to a lifelong search for understanding, connection, and a way to share his story. Throughout his life, Chris struggled with the feeling of being overlooked as a person while his body was constantly scrutinised. This sentiment is encapsulated in his quote, “As a child, my body was looked over, but I, as myself, was overlooked.” In his book, Chris shares, “I didn’t know the story of my medical history until I accessed my... records on April 10th, 2018. Seventy-two years old. I gave an inward scream when I read the truth and who [I] could have been ... I’ll never know.”

Born in 1946, he underwent extensive genital surgery as a child without explanation. He endured inhumane medical abuse that made him feel “like a bird pinned to a fence”, a scene that he captures in his novel and talks about in the interview:

The impressions you get as a child, you never forget, even at the age of three. And I remember because I had extensive surgery, you know, genital surgery. And they didn't want me touching the stitches between my legs, and I was bandaged by my wrists and ankles to the bed. Like a bird being pinned to a fence. [...] It's a very

vivid memory to me, you know. But nobody explains to me [...], you know, if they'd explained things. But they didn't. They just did it, you know? [...] No, it's never ever talked about. It was being done to me, but nobody told me why [...] So that's why I want my graphic novel. The idea would be to have it published and used hopefully as a text, you know, where people could unpick those things a bit, unravel them.

One of the key themes of the novel is the idea of "sanitised voyeurism," which North uses to describe the invasive and objectifying ways medical professionals often treat intersex people. "Look what we've found!! Remove it, remove it, rem... What's left?" illustrates the dehumanising experiences Chris endured as a child, providing insight into the psychological impact of such treatment.

So, you've got a group of doctors standing around [...] and just looking at you [...] But the fact that it is because it's so personal, it's about why we wear clothes. Well, it's called private parts for a reason, right? And again, it goes back to that reality that it's because it's so personal and, and... significant. That's why it makes it even more embarrassing and even more... I mean, I remember having been photographed again. I would have been about three-and-a-half. I'm being photographed between my legs with a camera. And in the graphic novel, I've pulled it, the voyeuristic eye of the camera. The fact I've remembered it, from that age, it's quite important, to remember that [...] That it's my body that was scrutinised.

As Chris notes, it was not only his body that was looked over but also his emotions, feelings, and needs. By sharing his story through "The Well of Silence", Chris aims to raise awareness about the emotional and psychological aspects of the intersex experience, which are often overshadowed by discussions focusing solely on the physical aspects:

In my adult life, [I tried] to find organisations that would help me or enable me to get into a relationship or to be able to be open about myself. But all of them that I found were focused on the body. It was with the body rather than me as a human being. Yes, my feelings and needs and emotions, and yeah, where are those? The support group that I attended, it was all very, very much about the physical. There's nothing about the emotional. Or psychological or... What is the difference

between sex and love? I mean, a very basic thing, but none of that was ever discussed. It was always fun, the size of body parts and what fits into another. I mean, putting it very basically, but that's as it was. [...] We are all unique in different ways, but I was as I was. I was fine as I was. I had things to offer. I could have had a relationship with someone given a different pathway, yeah. Does that make sense?

In his novel, Chris often uses animal motifs to talk about the different aspects of his life story. He says, "I mean, the animal motifs are very significant, and I didn't realise that. But they are. You know, the mouse and the seagull and the elephant". The mouse, for Chris, is a soul animal, which represents taking a close look at the things that had been previously overlooked. It accompanies Chris's character throughout the novel at different stages of his life; the seagull may signify his desire for freedom, and the elephant illustrates the feeling of being a "freak", as a doctor once called him, as well as the resilience it takes to live as an intersex person:

I was 45 but being faced by a consultant made me feel like five again:

"Have you seen the film The Elephant Man? You do know you're a freak?"

Is it an elephant in the room? You need a very thick skin to be intersex.

The secrecy and stigma Chris faced became the catalyst for his graphic novel. He describes the feeling of being "enclosed in an eggshell", which he needed to break free from to find his true self. It was only in the past four years that Chris began to talk about his intersex experience openly. As he opened up, he found a "rich tapestry of people" who became part of his network and supported his self-discovery. Despite his many accomplishments in life, as Chris says, it was the ability to openly say "I'm intersex" and be met with understanding and acceptance that became remarkably important to him.

Chris began writing down his life story in 1991, but it wasn't until 2018, during a transformative counselling experience, that he was encouraged to complete his autobiography. This process eventually led to the creation of his graphic novel, through

which Chris was able to “convey feelings, thoughts, [...] stories, whatever happens to be”. He reflects on the writing process as “enormously therapeutic” and an experience that reconciles his past with his present.

Chris’s journey comes full circle as he transitions from being a child in a hospital bed to becoming a social worker and advocate for others in similar situations: “From ME being the child in the hospital bed, I was now a social worker and advocate for the children and young people in THEIR hospital beds.” Despite the challenges he faced, North's story is ultimately one of resilience and hope. He writes, "This continuation of my story focuses on aspects of my life since 2017 [and] what changes are needed for the holistic care of intersex people of all ages. By telling our stories, we can inform others, and in different ways, find our own paths home." In the end, "The Well of Silence" is not just a story of pain and struggle but also one of triumph and transformation, in which Chris takes readers on a "road less travelled", using his own experiences to inspire hope for others. As Chris states in the closing lines, “My hope is that with all the complexities and struggles for those of us walking these and similar ‘pathdays’ and pathways, we can transform our lives into journeys of success, joy, courage, and determination. This is NOT the end.” His story serves as a powerful reminder of the ongoing journey towards acceptance and understanding for intersex people and their right to bodily autonomy and dignity.

3.2.5. "Un Secreto Pelirrojo"

"Un Secreto Pelirrojo" [A Red-headed Secret], written by a Spanish intersex activist and psychologist Camino Baró and illustrated by Núria Fortuny is a profound children's book that interweaves themes of diversity, acceptance, self-discovery, and societal norms, using the metaphor of hair colour to discuss intersex experiences. The story unfolds through the character of Andrea, an eight-year-old red-haired girl living in a world where people are classified as either blonde or brunette. The author deliberately chooses this age as it is often a time of “transformation, change, and self-discovery”. The story emphasises the importance of understanding the societal and psychological implications of being different and the internal and external struggles associated with it.

From the start, the author uses hair colour as a metaphor to demonstrate society's rigid gender binary. The differentiation according to hair colour and its implications—different bathrooms and playing different games—reflect the limitations imposed by rigidly binary societal norms. This contrast reflects the societal norm of dividing people into two sexes, male and female, based on physical characteristics and assigning them roles and expectations.

The medicalisation of difference is a critical theme in the book, as Andrea's journey of self-discovery parallels the experiences of many intersex people. When her hair starts turning red, the doctor advises her family to dye it blonde to conform to societal expectations, paralleling non-consensual cosmetic surgeries often performed on intersex babies to make them fit into the binary gender norm. This can be seen in the doctor's statement:

"The girl is as healthy as an apple. However, she is a redhead, too different from the others! Because we don't want her to be singled out at school for this reason, we recommend that she come in every week to dye her hair blonde. This way, no one will ever discover this secret. And remember: don't tell anyone, not even Andrea herself! She should never know the truth."

The author invites readers to reflect on the concept of 'normalcy', the societal pressures to conform to standard physical appearances, and how medical professionals may pathologise differences, even when they do not inherently cause physical harm or discomfort. The doctor's words highlight the anxiety that many societies feel about anything that challenges binary norms. The secrecy and avoidance of truth mirror the silence and stigma often surrounding intersex variations. When Andrea discovers her actual hair colour, she feels "very sad and lonely", echoing the isolation many people feel upon discovering that they are intersex – usually through a medical diagnosis.

As the story continues, Andrea starts questioning societal norms: "Why can't I participate in sports played by brunette people? Why do I have to wait in line for the blonde's bathroom if the brunette's one is empty? Why can't I choose my future job based on what I like?"

The character of Noa introduces a new perspective in the narrative. As a fellow outsider, they serve as a catalyst, helping Andrea question societal norms and explore her identity. Their friendship strengthens as they navigate through their shared experiences, providing a strong support system for each other. The turning point comes when Andrea meets others with different hair colours in Villalba Morena, where she finds acceptance and community. The narrative emphasises the importance of diversity and acceptance, encouraging readers to appreciate differences. It also shows the importance of positive role models for self-acceptance and a positive identity.

The book ends on a note of self-acceptance and celebration of diversity. Andrea no longer hides her red hair, embodying her authentic self. The closing lines, "Rainy days may come, but we will shine brighter than ever because, if we unite, we are the rainbow", beautifully encapsulate the message of unity in diversity. The rainbow symbolises the wide range of identities beyond the binary, a nod to the LGBTQIA+ community, celebrating the beauty of all colours, or in the context of the metaphor, all types of bodies, identities, and expressions.

Behind "Un Secreto Pelirrojo" is an intimate exploration of Camino's own intersex identity and her role as an activist within her community. Camino's book was initially inspired by her street performance as part of the theatre "Encuentros", where she shared her experiences through a monologue at the Reina Sofía Museum in Madrid. Camino recounts how this performance provided an opportunity to directly engage with the public, where she would approach people and offer to perform a short representation. Her chosen theme was intersex, and she would narrate the story of Andrea, the protagonist of "Un Secreto Pelirrojo". This allowed her to share her story on a personal level, inviting dialogue and understanding:

I loved that experience; it was beautiful because people would look at me and ask, "What do you want?" And I'd say, "Do you have 5 minutes? It's just to tell you a story, a little tale. We are here doing a performance", and they'd agree. "Okay, go ahead." And I would be listened to by people of all ages. It was very beautiful. And I told them everything, and after telling them the tale, I'd say, "Well, this is related to intersex, do you know what intersex is?" Then I'd give them a brochure and say, "I am an intersex person, now you can say you know an intersex person. By the way,

we are more numerous than redheads. Have a great day, goodbye!" Then I'd move on to another person, "Hello, how are you? Can I tell you the story of Andrea?"

The way in which Camino wove her narrative during the performance was reflective of her own journey. She chose to tell her story in the third person as Andrea and then revealed her own intersex identity. This approach served to draw parallels between her own experiences and those of her protagonist, creating an empathetic link with her audience as she asks her listeners:

"Have you ever felt like Andrea, like having an obligation to fit into a gender and having to modify your body?" And they began to tell me, "Yes, we have to wax, yes, we have to do such and such". "Well, then imagine an intersex person who, on top of that, has to literally modify their body, removing organs, removing gonads, hiding their karyotype, taking medication, etcetera."

Camino's narrative in *Un Secreto Pelirrojo* is deeply personal, acting as a form of reconciliation with her past. When asked whether she identified with the character of Andrea, she responded, "Yes, and think that when I was Andrea's age, I had no idea at all, so it is like a kind of reworking from adulthood of what my story would have been if I had known about me being intersex from a certain age". This suggests that the process of writing the book provided Camino with a sense of reconciliation, allowing her to reinterpret her own experiences through the lens of her character, Andrea. The book became a "balm", a way to rewrite her past with the understanding she now possesses about her experience as an intersex person. This process of fictional sublimation allowed her to appreciate herself and celebrate her identity, saying, "There I am, enjoying the red colour of my hair, my freckles, my red hair, and there was nothing wrong".

The book has had both very positive and critical reactions from its readers. Some people from the intersex community, as Camino shares, felt the book did not accurately represent their experiences or that it conflated intersex and transgender identities. Camino acknowledges these concerns but maintains her belief in the importance of her book. She states, "I think it's important to tell our own stories, even if they're not perfect or don't represent all intersex people". She argues that "*Un Secreto Pelirrojo*" is her

journey, meant to stimulate discussion and raise awareness about intersex issues, even if it does not encompass every intersex individual's experience.

The publication of “Un Secreto Pelirrojo” marks a “significant milestone” in Camino's journey, providing her with a platform to share her story and raise awareness about intersex. Moreover, the book's impact extends beyond her personal experience, as it also serves as a valuable resource for others seeking to understand the experiences of intersex people. It provides insight into the complexity and diversity of intersex experiences, breaking down the stigma and misconceptions associated with being intersex. “I hope this book serves to open society's eyes and helps other intersex people to feel understood and accepted.” While discussing the future of intersex rights, Camino notes the importance of representation in the fight for equality. She believes “Un Secreto Pelirrojo” contributes to this mission by providing an authentic intersex narrative. “The intersex [rights] battle will continue and be strengthened with real and authentic stories like the ones I told in my book”.

3.2.6. Intersex in Comedy and Stand-up shows

It's just the thing that sort of is about me and I am here to break down some stigmas tonight and raise some awareness with you all because like I said, I've got a little bit of a calm. Stated, there is no word for it really. It's a conflict of personality, ok? Because in 2018, what I want to let you all know is that I am a confident female comedian who is really into sex. And what that means is I'm a confident female comedian who's really intersex.

(Amazon's 2018 stand-up show. From Amazon's personal video collection)

Amazon Jackson is an English comedian, intersex activist and, in her own words, an “intersex nonbinary woman”. Her decision to 'come out' on stage as an intersex person, to demonstrate the power and challenges of using comedy to navigate her experiences and raise intersex visibility, illustrates her journey against the backdrop of societal misunderstanding and prejudice, and her persistent efforts to challenge them through comedy:

To my surprise (and relief), the pun, when repeated correctly, initiated a great response, and I continued through my act, thoroughly enjoying the feeling of scoring my first ever applause breaks in my hometown of Hull.

Amazon's decision to reveal her intersex identity during a stand-up performance prompted a response from a colleague who questioned if such a subject might be 'too dark and edgy' for comedy. Amazon recalls, "“Why do you feel you have to be so dark and edgy?” were the words Comedy Buddy said, with an embarrassed frown." This exchange captures the initial resistance and discomfort some people might feel when confronted with unfamiliar or uncomfortable topics. However, Amazon was not deterred. She countered, "What is so dark and edgy about being intersex? That is who I am!" Her defiant stand emphasises her commitment to embracing her identity and challenging societal norms. Amazon believes comedy provides an ideal platform for presenting the realities of being intersex in a relatable way, stating her aim is to "remove the stigmas associated with intersex people".

Her comedic approach is effective as it not only eases the audience into the topic but also helps in dismantling stigmas and stereotypes associated with intersex individuals. For instance, she humorously addresses the confusion that often surrounds the term intersex, noting the "panic in the room" and quipping, "What does intersex mean? Has the comedian just dropped an extinct pronoun that we know as hermaphrodite? Has the comedian got a willy as well as a little mini moo moo?"

Amazon uses this humorous context to clarify what being intersex means to her, saying:

"What intersex means to me is that I have the external body of a female and the internal gonads...surgically removed and the genetic makeup and somewhat brain of a man." Amazon employs humour and comedy to navigate her experiences as an intersex person. Comedy gave her a creative medium to express herself and to articulate the experiences, emotions, and struggles associated with her intersex identity. The purpose she derives from comedy is well captured in her words, "I'm working out who I am, but I'm also using it [comedy] to educate people, so it's sort of two-fold."

Furthermore, Amazon uses her comedy to highlight important social issues and injustices intersex individuals face. She discusses medical interventions performed on intersex infants, commenting:

“So, like I say, I’m here to raise awareness and why am I doing that? Why is it important? That I raise awareness about who intersex people are. For me, it didn't really affect my life as a cisgender female growing up, which is what I was characterised at birth. And just let me say that was a mischaracterisation by the doctors because I am very much an intersex person. And the thing is, we haven't got a place in society nowadays. Doctors are still persuading parents that they should allow them to mutilate intersex babies. And take away decisions that are important to intersex people. As we grow up, we are then traumatised by these things that are done to us. So, it leads to things like me, you know, you can take away my gonads, but I'm going to go out to have the balls to fight against social injustice. Yes. So, there is no place in the world for us at the moment, but that is something that we are fighting for.” Using humour as a vehicle for her message, Amazon manages to raise awareness about these issues while making them more accessible and less intimidating for the audience, “you know, just tying it all into comedy and making sure that the audience understands that I’m not just giving jokes to make fun of it, I’m explaining what the serious consequences are of living this life, but perceived in a way that is entertaining and funny.”

In terms of societal understanding of intersex and its representation, Amazon offers a nuanced perspective. She recognises the progress made but underscores the need for further growth. "Intersex is starting to become known now," she observes. "But what isn't known is the different variations of intersex... and that's where the education comes in."

Throughout her act, Amazon also uses humour to challenge societal norms and expectations. She pokes fun at gender stereotypes, quipping, "What that equates to in everyday terms for me is that I'm pretty crap at housework, and I like to spend a lot of time playing with my titties." This not only gets laughs but also pushes back against binary gender roles.

The reactions to her initial 'coming out' performance were encouraging, both from the audience and her peers. Amazon recounts, "This was me revealing myself as an intersex person (verbally) not just to a room full of strangers, but to my comedy

colleagues too. It all felt so right!" The positive response marked a significant victory in her journey, signalling the acceptance and appreciation of her authentic voice.

Despite the initial apprehensions of her colleagues, their reactions post-performance were notably different. Amazon recalls, "After my act, I approached my comedy friends from earlier: 'Not so dark or edgy, huh?' I asked. They laughed, we laughed." This shift in perception underscores the transformative power of humour in breaking down barriers and challenging misconceptions.

Amazon's journey illustrates how comedy can be a powerful medium for navigating personal experiences, raising visibility, and challenging societal norms. Her narratives underscore the importance of increased representation of intersex individuals in popular culture and the need for society to engage with and understand diverse identities. As Amazon eloquently puts it, "Too dark for some people or not, we each have a cause to be heard."

3.3. Reflection on Intersex Representations

The transformative journey of intersex cultural representation, as illustrated through various case studies, highlights the profound influence of self-created narratives in challenging societal norms and fostering a sense of belonging among intersex people. Below, we summarise the major themes identified in the present report.

Media Sensationalism and Fetishisation

The portrayal of intersex characters in mainstream media often leans towards sensationalism and fetishisation. These narratives, driven by ratings and viewership, often misrepresent the intersex community, perpetuating stereotypes and misconceptions (Roen, 2019). The challenge lies in countering these narratives with authentic, self-created representations that offer a more nuanced and accurate portrayal of intersex lives.

Medical Gaze and Trauma Narratives

Historically, intersex narratives have been dominated by the medical gaze, focusing on medical interventions, surgeries, and the pathologisation of intersex bodies

(Cabral, 2016; Carpenter, 2018). Contemporary intersex representations emphasise empowerment, agency, and self-acceptance when moving away from these trauma narratives, challenging the medicalised perspective and advocating for bodily autonomy.

Positive Visibility and Authenticity

Central to the discourse on intersex representation is the emphasis on positive visibility and authenticity. Self-created intersex narratives provide a platform for intersex people to share their experiences with dignity, authenticity, and an "appreciation for embodied diversity" (Koyama, 2013; Davis, 2015). The narratives underscore the active challenge to the sex-gender binary and the heteronormative order. Intersex characters emerge as protagonists, with their stories and personalities depicted wholesomely, devoid of the medical gaze and the sensationalism or fetishisation often seen in media (Cabral, 2016; Carpenter, 2018). This shift from a medicalised perspective to one that celebrates embodied diversity is pivotal in reshaping societal perceptions and fostering acceptance.

Empowerment Through Storytelling

Narratives serve as more than just stories; they are tools for empowerment. For authors and intersex readers or viewers, these representations serve multifaceted functions. They provide a platform for intersex people to voice their stories, marking the beginning of a journey of activism and advocacy for many. This act of storytelling empowers intersex authors with agency, enabling them to challenge societal norms and reclaim their narratives (Pagonis, 2018).

Identity and Validation

Positive representation is crucial for the formation of positive self-identities. For many intersex people, these narratives offer an opportunity to feel "seen" and comprehended. This sense of representation fosters a profound pride in their intersex identity, emboldening them to disclose their identity to others and engage in enriching dialogues about intersex (Jones, 2016; Baratz & Feder, 2019).

Community Building and Mentorship

Beyond individual validation, these narratives serve a pivotal role within the broader intersex community. They emerge as reference points, especially for the younger cohorts, offering guidance, hope, and a profound sense of belonging. By sharing their stories, authors and creators lay down a path for future generations, ensuring they do not grapple with feelings of isolation or misunderstanding (Fausto-Sterling, 2012; Diamond & Garland, 2014).

Legal and Ethical Implications

The legal and ethical dimensions of intersex representation cannot be overlooked. Many countries still grapple with recognising intersex rights, leading to a lack of legal protection and recognition for the community. Ethical considerations, especially in medical interventions without the informed consent of intersex individuals, remain a contentious issue (Jones, 2016).

The Role of Education

Education plays a pivotal role in shaping perceptions about intersex. Incorporating comprehensive sex education in school curriculums, which includes discussions on variations in sex characteristics, can pave the way for a more inclusive and understanding society (Baratz & Feder, 2019; Fausto-Sterling, 2012).

4. Conclusions and Good Practices

The results, derived from an in-depth narrative analysis of the interviews and a thorough examination of self-created intersex portrayals, show the adverse effects of silence and secrecy on the lives of intersex people. This stigma not only isolates intersex individuals but also hinders their integration into social and community settings. Added to the familial and medical secrecy, the misrepresentation in the media exacerbates the situation. The inability to address intersex topics privately, combined with inaccurate and harmful media portrayals, frames intersex people in terms of 'otherness', instead of "diversity", often leading to emotional and psychological distress. Intersex people are frequently depicted as 'different', a difference framed as traumatic and socially isolating. This 'otherness' has been shown to impact the self-esteem and psychological well-being of intersex people significantly.

Personal narratives counter the stigma of hegemonic intersex representation by moving from a medicalised perspective to one affirming identity. This self-affirmation process involves a continuous struggle against hegemonic representations in search of positive cultural references. The narratives identify different trends in media production that move away from stigmatising and pathologising depictions of intersex people as subjects of adversity or physical difference and instead advocate for an affirmative and multifaceted representation. Hence, being an intersex person should constitute one of the many possible traits of the fictional media characters or a media plot, not necessarily the central one. Promoting diverse bodily and psychosocial characteristics associated with intersex people and involving intersex actors in their portrayal would aid in visualising and normalising intersex experiences.

These findings are synthesised into a set of recommended good practices for creating respectful and accurate intersex representations. By focusing on the vital role of these self-created representations, this report concludes by underscoring the importance of centring intersex voices in their own narratives and the role they play in advocacy, societal change, and the personal well-being of intersex people.

Good Practices in Intersex Representation

Research first: Artists, journalists, writers, theatre and film directors need to do their initial research on intersex and consult with advocacy groups and intersex activists to ensure that their representations are respectful and accurate. This research can include reading books and articles written by intersex people and attending intersex-led events, conferences, mixed groups, and seminars.

Include intersex people and listen to what the community demands: Intersex characters should be played by intersex actors whenever possible to promote authenticity and avoid harmful stereotypes and misrepresentations. Casting intersex actors and hiring intersex consultants can also provide job opportunities and increase visibility for intersex people while seeking feedback from intersex experts on scripts and character choice is crucial for the accuracy of depictions. Ask and take into consideration the actual political and social demands of the intersex community.

Centre intersex voices: Content creators across disciplines should aim to centre the voices and perspectives of intersex people themselves, written or told in their own words, rather than having endosex (non-intersex) authors or experts speak on their behalf. By doing centring intersex voices, one can ensure that the stories are authentic for intersex people and the intersex community as coming from within.

Agency: Intersex people, who have been historically subjected to non-consensual medical treatments, should be portrayed as capable of making their own decisions about their bodies and their gender, and their choices should be respected.

Language: The correct use of language is crucial in the creation of positive intersex representations. Consult with your local intersex advocacy groups to ensure that the language that is being used is respectful, accurate, and non-pathologising.

Avoid sensationalism and pathologisation: Intersex should not be used as clickbait or depicted as a medical problem that needs fixing. Instead, intersex should be portrayed as a natural variation of human biology and experience. Depicting intersex as a shocking or exotic medical condition perpetuates stigma and harms the intersex community.

Avoid negative representations: Intersex characters' storylines should stop perpetuating harmful stereotypes by portraying intersex people as supernatural creatures, monsters, villains, and serial killers. While the diversity of representation is important, in the present day, when intersex realities are still widely unknown, positive representations are as crucial as ever.

Diversity of roles: Intersex people should be portrayed in various contexts, including as friends, colleagues, family members, romantic partners, and parents, to help increase visibility and promote a better understanding of intersex realities. Depicting intersex people in a variety of roles, scenarios, and relationships can help counteract the notion of intersex people being defined by a medical condition and seen only in the role of patients, which erases their individuality as human beings. Creating diverse representations also ensures that different intersex people have a character to whose story they can relate.

Show intersex joy: Intersex representation should not solely focus on the trauma and struggles experienced by intersex people but also talk about intersex joy, desire, and pleasure. This positivity can involve portraying intersex people as successful individuals with fulfilling lives and loving relationships who take pride and appreciation in their bodies.

Engage with global and intersectional perspectives: Intersex representation should engage with diverse social realities and cultural contexts. Consider portraying intersex people of different ages, ethnicities, socio-economic backgrounds, gender identities, and sexuality. Furthermore, intersex representation should not be limited to the Western contexts but should recognise the global diversity of intersex experiences. This diversification can mean collaborating with intersex advocates from different regions of the world and incorporating a range of intersex narratives into the storyline.

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