Navigating Parental Decision-Making: Intersex Surgeries in Italy

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Navigating Parental Decision-Making: Intersex Surgeries in Italy

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**Declaration of Interest statement**

We have nothing to declare

## Abstract

Decision-making dynamics in Italian paediatric care for Intersex and Variations of Sex Characteristics (VSC) involve a complex interplay between medical practices, parental perspectives, and socio-cultural factors. This article explores how medical professionals and parents make decisions amid cultural debates on gender, the body, and autonomy. It addresses aspects of why surgical intervention, with limited child involvement, is often seen as the 'only option' in the 'conservative' culture of Italy. The article continues to highlight the rise of parent-led human rights-based activism in Italy, challenging prevailing narratives in intersex/VSC paediatric care. Using qualitative data from two studies, including interviews with 15 Italian stakeholders and 38 Italian parents, as well as participant action research, the article provides insights into Italian medical and parental perspectives. The findings emphasize the need for nuanced support, education, and resources to empower parents in order to uphold the rights and well-being of intersex individuals.

**Keywords**

Parents; VSC; Intersex; Italy;

## Abstract

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## Introduction

Innate Variations of Sex Characteristics (VSC) challenge the prevailing and often unexamined expectation that all bodies conform to standardized notions of physical binary sex categories. Since the 1950s, medical responses have focused on cosmetic 'normalizing' interventions in paediatric settings (Karkazis, 2008), drawing human rights critiques from the 1990s onward (Bauer et al., 2020). While VSC in themselves do not pose health risks (Dreger, 1998), there may be associated health issues that the aforementioned cosmetic modifications do not address or resolve. Medical literature and expertise in paediatric care concentrate disproportionately on gendered aspects, while health risks associated with VSC are under-researched (Davis, 2013), and adult care remains underserved (Berry & Monro, 2022). The medical tendency to promote “management” of variations to parents from infancy is influenced by cultural biases toward binary views of sex and gender, as well as homophobia, transphobia and anxiety surrounding bodily difference (Preves, 2002). Terminology, as well as inclusionary boundaries, in this field are mobile and contested (see Griffiths, 2018; Carpenter, 2020). Throughout this article we primarily use the terms used by the interview participants.

The decision-making dynamics in paediatric care for intersex/VSC are intricately shaped by the interplay of medical practices, parental perspectives and socio-cultural factors (Lampalzer et al., 2021). This article explores these nuanced dynamics within the Italian context, examining how medical professionals and parents frame decisions amid contemporary cultural debates on gender, the body and autonomy. It aims to understand why surgical intervention, coupled with limited child involvement, is often portrayed as the ‘only option’ in this ‘conservative’ setting, despite legal protections in other ‘conservative’ European contexts, such as Malta (GIGESCA, 2015) and Greece (Articles 17-20 in Law 4958/2022). We follow this examination with a snapshot of the emergence of parent-led human rights-based activism in Italy, with the intention of unravelling narratives regarding what is possible in intersex/VSC paediatric care in ‘conservative’ contexts.

The Italian perspective on intersex paediatric care, gender, and bodily autonomy interacts dynamically between global and local dialogues (Crocetti et al., 2021). Before the early 2000s, Italian parents had limited information on intersex/VSC in their native language. Although the internet and the first Italian patient groups have transformed this landscape (Crocetti et al., 2020), public awareness of intersex remains notably low (Prandelli & Testoni, 2021). This article provides a background on global developments in decision-making for intersex minors and an overview of Italian cultural discourses on two distinct yet related conversations: the body and gender; and autonomy and the body. We draw attention to a tendency to conflate intersex, sexual orientation and gender identity in Italian discussions, which impacts medical practice (Prandelli & Testoni, 2021; Crocetti et al., 2021) and the creation of effective protections (Carpenter, 2020).

Drawing on qualitative data from two studies and participant action research, we present insights into Italian medical and parental perspectives on medical choices for children with VSCs. The first section addresses the medical consensus favouring early genital surgery as the exclusive option parents will accept. We examine Italian medical perspectives on global developments, including issues such as bodily autonomy, communication and transition of care. We also explore the construction of an Italian conservative 'other' in relation to family, gender, the body and autonomy, as reflected in both Magisterium of the Catholic Church (Congregation for Catholic Education, 2019, 2024) and national-conservative right views. While Italy has been historically (Ben-Ghiat, 2007) and contemporarily (Capucha et al., 2014) negatively constructed as not adequately European regarding both civil and economic progress, political parties such as *Fratelli Di Italia* reconstruct social conservativism as a nationalist positive quality (Vassallo and Vignati 2024). Similar to Magisterium documents, medical responses to questions surrounding ‘autonomy’ often invoked ‘gender’ when discussing VSC, linking the conservative cultural context medical professionals ascribe to parents to treatment paths.

Shifting our focus, we then explore the perspectives of parents in Italy who have made decisions regarding surgeries and communication for their children. Previous studies have explored various dimensions impacting parents’ decisions, including medical framing (Streuli, et al., 2013; Roen & Hegarty, 2018; Roen, 2019; Hegarty, Smith & Bogan-Carey, 2019; Timmermans, et al., 2018), psychological impacts (Roen & Pasterski, 2014; Wolfe-Christensen et al., 2016), and social implications related to medical practices, parental attitudes, and socio-cultural norms (Karkazis & Davis, 2015; Murray, 2009; Timmermans et al., 2019; Horowitz et al., 2024; Jones, 2017; Danon & Krämer, 2017). However, context-specific literature on parenting a child with VSC in different sociocultural settings is limited. By highlighting parental voices, this study seeks to address this gap in the literature in Italy, while illuminating motivations, societal pressures, and interactions with medical professionals. We seek to examine parents’ agency and their access to comprehensive information about alternative options, aspiring to cultivate a more nuanced understanding of the challenges they face. Based on our findings, we advocate for the necessity of nuanced support, education, and resources to empower parents in making truly informed rights-based decisions.

Finally, we examine alternative perspectives from Italian stakeholders, that challenge the assumption that ‘conservative’ Italian parents will invariably opt for early surgery and exclusionary communication practices regarding their children. These stakeholders underscore the growing significance of concepts such as bodily autonomy, shared decision-making, and the recognition of the child's emergent body (Garland & Travis 2020). This section delves into three recent examples: the activities of a new Italian parent association that supports bodily autonomy for their intersex children; increased institutional attention to intersex issues as evidenced by the ISS (Istituto Superiore di Sanità – National Institute of Health) InfoIntersex webpages; and the collaborative creation of a joint Italian position statement on intersex human rights.

Our primary objective is to contribute to intersex studies by examining the interplay between medical and parental perspectives, and highlight the importance of information and support in right-based models particularly in conservative cultural contexts. We also intend to contribute to Italian studies by addressing the portrayal of the Italian conservative 'other' as an impediment to discussions on fundamental rights in medical settings. By integrating the viewpoints of medical professionals and parents with cultural discourse surrounding gender, the body and autonomy, we aim to shed light on how presumed cultural conservatism influences parental decision-making options regarding early 'normalizing' interventions and communication with implicated minors. We advocate for a comprehensive and informed approach to VSC care that acknowledges the complexities of cultural influences and empowers families and individuals to make decisions that safeguard the rights and well-being of intersex individuals.

## Background

Paediatric treatment of intersex bodies has been a focal point of human rights debate since the 1990s (Chase, 1998) and has garnered increasing attention from international human rights bodies since the early 2000s (Bauer et al., 2020). Critique primarily centres on the surgical and hormonal 'normalisation' of sex characteristics (including infant genital form but also other aspects of sex characteristics) before the age of consent (Carpenter, 2016), implicitly questioning parental rights to make these proxy decisions. Since 2015, several western countries have shifted the legal right to modify sex characteristics to the individual (Malta, GIGESCA, 2015; Iceland, Act on Gender Autonomy, 2019; Germany, Gesetz zum Schutz von Kindern mit Varianten der Geschlechtsentwicklung, 2021; Greece, Law No. 4958/2022, 2022), significantly altering the care options available to parents. However, in most countries, parents retain the legal right to decide for these bodily modifications, as well as when and how to inform their children. Up through the 1990s, diagnostic information was often withheld from parents and individuals (Karkazis, 2008). Although informed consent laws led to changes in medical protocols in the 1990s, clear guidelines for informing individuals or involving minors in decision-making remain lacking.

In response to stakeholder and human rights critique, medical recommendations changed in 2006 during a Consensus Conference to include a 'patient centred model' and case "management" by multi-disciplinary teams. This model placed ultimate (legal) responsibility for medical decisions with parents, while the teams were intended to include psychosocial support for the family (Lee et al., 2006). In the 2016 update (Lee et al., 2016), shared decision-making (SDM) models were also proposed. Despite this, evidence indicates limited availability of psychosocial support for families (Ernst et al., 2018) and a lack of clear non-interventionist options in medical protocols (Liao, Wood & Creighton, 2015), resulting in the continued prevalence of surgical childhood intervention (Creighton et al., 2014; Monro et al., 2017). Jones' (2018) review highlights an ongoing divide: medical literature often supports early interventions, prioritizing parental or institutional choices, while broader social studies emphasize patient-centered, autonomy-respecting approaches, advocating against enforced procedures and favoring decisions postponed until adulthood.

Gardner and Sandberg (2018) argue for 'two future possibilities' regarding elective body modifications for intersex minors: a moratorium on proxy decision-making or enhanced SDM. However, SDM typically involves discussions between Medical Practitioners (MPs) and parents/guardians (legal surrogates for the child), not directly involving young patients (Timmermans et al., 2018). While general medical guidelines advocate for children's involvement in healthcare decisions that concern them, there are no medical mandates for this involvement in the absence of legal prohibitions of proxy sex-characteristic alterations.

Parents often lack informed support when making irreversible decisions, with clinicians lacking standardized tools to explain non-interventionist pathways (Liao et al., 2015). Nevertheless, parents are increasingly being held responsible for the ongoing practice of these surgeries (Liao, 2022). Some studies report experiences of parents being advised to delay the decision regarding surgery and explore alternative approaches (Lundberg et al., 2017), while other parents report being unaware of any alternatives to surgery (Sanders et al., 2008).

Research by Gough et al. (2008) and Sanders et al. (2011) report that parents are often overwhelmed by the uncertainty surrounding their child's variation, leading to socially mediated decisions driven by the desire for certainty and resolution. Social factors such as individual understanding, cultural beliefs, and social experiences can further influence parents' decisions to opt for surgeries (Parens, 2006). This includes desires to protect their children from discrimination and bullying (Duguid et al., 2007; Sanders et al., 2012) or to correct perceived imperfections in their child (Tamar-Mattis, 2006). Within this context, existing literature attests that a clear understanding of the risks and long-term outcomes associated with early intervention appears crucial but is frequently inadequate (Roen, 2004; Karkazis et al., 2010). There is a lack of tools to elucidate common variations in genital form, their potential sexual uses (Roen et al., 2018), or the possible negative effects of surgical repair and maintenance (Boyle et al., 2005). As indicated by Liao, Wood and Creighton (2015), parents do not receive adequate information about the negative consequences of surgeries, rights debates in this context, or credible non-surgical alternatives.

Research also confirms that medical framing significantly affects parents' decisions on surgical interventions. Prospective parents exposed to medicalized descriptions of VSC are more inclined to choose surgery compared to those who received more neutral descriptions (Streuli et al., 2013). There is also documented concern about parental regret (Lorenzo et al., 2014), distress and uncertainty following surgical decisions (Alderson et al., 2024). Ultimately, literature on parents' experience suggests that while responsibility for decision-making has shifted from medical professionals to parents, there has been insufficient information provided about the child's evolving body and non-interventionist options. This raises questions about the alignment of decisions with the child's long-term best interest and bodily rights. Within this global context, Italian parents also find themselves amid cultural debates regarding both gendered issues and bodily autonomy.

Italian VSC medical practice is often guided by an interventionist model, often referencing a ‘conservative’ cultural framework concerning gender to justify a lack of emphasis on bodily autonomy (Crocetti et al., 2020). The 2010 Italian Committee for Bioethics (Comitato Nazionale di Bioetica) opinion paper on intersex medical treatment exemplifies this ambivalence. The document rationalizes medical interventions that ‘harmonize’ physical, psychological, and social ‘disharmonies’, while asserting that bodily intervention must prioritize the best interests of the child, with ‘mutilation’ only permissible in emergencies, safeguarding fertility potential and conditions for satisfactory sexual activity.

Italy’s contemporary socially ‘conservative’ image is exemplified in the 2022 political confirmation of the populist radical right (Donà, 2022) and the Magisterium of the Catholic Church position statements (2019; 2024). Scholars have examined the rise of the global term “gender ideology” (often used in the original English, not in Italian) in Italian discourse (Loverno et al., 2016; Gusmeroli & Trappolin, 2021; Colella, 2021; Garbagnoli, 2016; Spallaccia, 2020), as well as intersection of gender-critical feminist and ‘conservative’ anti-gender positions in the Italian debate regarding gender and the body (Gusmeroli, 2023). Others have noted how Italian forms of perceived gendered variance have disappeared over time (Findlen et al 2009), and with the globalization of LGBT+ concepts (Vesce et al 2017). However, intersex is rarely addressed independently in these discussions[1], and when it is often conflated with Trans or other sexual orientation and gender identity (SOGI) experiences. The second author’s review of Italian media reveals that intersex topics are rarely addressed independently. Instead, they are typically discussed in the context of gender binarism, anti-discrimination laws, queer culture

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[1] Findlen (2009) does, however, highlight the Magisterium’s 18th century position that all tribads (lesbians) had VSC, that is larger genital form than the female standard.

and LGBT+ advocacy. This trend shifts the focus away from specific intersex issues, redirecting attention towards broader civic sexual and gender minorities concerns.

As emerges in the discussion of the interviews, fears and justification for early intervention often stem from a vague understanding of LGBT+ social issues. The Italian ‘conservative’ public discourse, including Magisterium statements, can be found to overlap LGBT+ social issues with intersex, further contributing to parental fears of social discrimination for gendered bodily difference. Although the populist far-right position may diverge from the Magisterium on numerous social issues (e.g. migrant human rights), there is significant overlap on issues regarding gender and bodily autonomy, such as opposition to legal recognition of same sex parents and puberty blockers for trans minors.

Uniquely, the 2019 Congregation for Catholic Education publication “‘Male and Female He Created Them’, Towards a Path of Dialogue on the Question of Gender Theory in Education”, offers a succinct contemporary Catholic stance on the management of intersex bodies. It identifies VSC as pathological, stating that “in cases where a person’s sex is not clearly defined, it is medical professionals who can make a therapeutic intervention” (p. 13), highlighting medical authority and surgical solutions over bodily autonomy. The text critiques ‘gender theory’, claiming it denies “the difference and reciprocity in nature of a man and a woman […] thereby eliminating the anthropological basis of the family […] Consequently, human identity becomes the choice of the individual”, in which individual autonomy acquires a negative attribute tied to the destruction of ‘conservative’ social conventions. Throughout the document distinct concepts of social role, sexuality, gendered identity and the gendered body are overlapped and thereby confused, while it is not clear if this is intentional or incidental. While acknowledging bodily variations such as VSC, albeit within a pathological and stigmatized context, they are discussed together with gender identity variance. The document claims that “Efforts to go beyond the constitutive male-female sexual difference, such as the ideas of “intersex” or “transgender” […] becomes, at the end of the day, only a ‘provocative’ display against so-called ‘traditional frameworks’ […] Similar theories aim to annihilate the concept of ‘nature’” (p._ 14). This statement implies that intersex human rights requests for the autonomy to maintain natural bodily variations are instead to be seen as provocatory attacks on the concept of ‘nature’ and ‘traditional’ social values.

While a socially conservative position linked to Catholic doctrine is mobilized in national debates, actual adherence to church teachings in Italy is ambiguous, with a substantial decline in church participation and adherence to fundamental beliefs (Marchisio & Pisati, 1999). Other rights regarding bodily autonomy, such as abortion and euthanasia, maintain tacit majority approval, despite the Magisterium’s clear positions. The country retains strong legislation protecting the right to interrupt a pregnancy (while it allows for an NHS service deficit through the practice of medical conscientious objectors; Reichlin & Lavazza, 2023). Despite no effective laws on euthanasia in Italy, the Constitutional Court's Decision No. 242 (2019) exempts those who assist a freely made and independent decision to commit suicide from criminal liability (Riva 2024). Recent actions by members of the ruling far-right party have instead blocked access to puberty blockers for Trans minors, despite their parents’ consent, while allowing their use on intersex minors without their direct consent. Bodily autonomy specifically tied to the gendered body remains a contemporary contested area.

## Materials and Methods

The discussion presented in this collaborative paper is based on secondary thematic analysis (Braun and Clarke 2014) of multi-method research gathered from two qualitative projects in Italy from 2016 to 2019 (XXX; first author) and from 2014 to 2017 (XXX; second author). The analysis also incorporates a secondary literature review on Italian perspectives on intersex/VSC. The reflections in this paper were inspired by ongoing discussions between the authors, who are endosex academic allies working in similar understudied situations. The authors independently reviewed their thematical analysed data, and shared anonymous quotations that represented the relevant sections discussed in the findings.

The XXX project involved qualitative and participant action research in Italy, Switzerland, and the UK, selected for their differing healthcare structures, activist types and national debates on gender. The research team conducted 40 semi-structured interviews in 2017 with intersex activists, patient association members, policy makers, and medical professionals (15 in Italy, 19 in the UK, and 6 in Switzerland). All participants were informed about the project's aim of investigating perspectives on intersex rights, and data was anonymised unless participants specifically requested otherwise. XXX adhered to strict ethical guidelines meeting both EU and national legal and ethics requirements, and was approved by the University of XXX Ethics Board.

The XXX (FV) project involved in-depth interviews with 38 parents of minors with VSC (22 mothers and 16 fathers) in Italy in 2016. A life-story interview method (Bertaux, 1999) combining a dialogic perspective (La Mendola, 2009) was used to enhance participants' storytelling. Participants started from the moment they discovered the pregnancy and follow a roughly chronological order to describe pivotal moments in their children's lives. Thematic analysis was used to synthesise the themes from the participants’ experiences and perspectives. During 2016 weekly or bi-weekly participant observation was conducted in paediatric wards in two Italian hospitals and during annual meetings of different VSC Italian support groups. The study was approved by the Ethical Committee for Psychological Research of the University of XXX.

Between October 2023 and February 2024, public documents, media stories and academic literature were reviewed to examine Italian culture wars regarding gender and Italian public perspectives on intersex. Material on Italian anti-gender culture wars were examined by the first author to identify references to intersex. Media accounts of intersex were examined by the second author with the intent of tracking the evolution of the national narrative and awareness of intersex. The secondary analysis of the qualitative material was contextualized in light of this additional literature review.

## Findings

In the following three sections we first present qualitative data on medical and parental narratives, followed by activist and institutional actions. We explore the conceptual links made by medical professionals between intersex bodies and social manifestations such as gender identity and sexual orientation, and how these concepts construct the image of Italian society as ‘conservative’. These themes arise in slightly different manners in the subsequent parental discourses, revealing an interplay of projections on the future of their child, as well as shadows of medical communication. The third section addresses actions and evidence of Italian parental and medical stakeholders interested in promoting bodily autonomy.

## Doctor explanations

Interviews and conversations with Italian medical specialists conducted between 2016 and 2018 consistently described a medical practice that involved early intervention for VSC, particularly regarding genital form. As one specialist indicates, “I perform many genitoplasty surgeries when the children are at most one-year-old” (Med 1_Center 1_XXX). The Italian DSD study group reports 5600 diagnoses annually with unidentified 456 operations across various categories[2]. Protocol has moved away from uniform consensus for interventions that address invisible biological variation, such as gonadal removal, as tumoral risk is considered to be less than once believed (Bertelloni et al., 2013).

Some medical practitioners desired protocols respecting bodily autonomy but cited obstacles such as inconsistent national protocols, lack of mandates to inform children about diagnoses and medical choices, and a conservative culture. What is indicated when referring to Italy as a ‘conservative’ culture requires particular attention and unpacking. While framing their working situation, MPs critique the Italian medical system for its lack of consistency and protocol. In further discussion of parental interactions and decisions, they described perceived ‘conservative’ attitudes towards (and/or ignorance of) both autonomy and SOGI themes.

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[2] https://www.dsd-it.it/#

Globally, both patient groups and medical specialists worry about protocol inconsistencies resulting in frequent early interventions also by non-specialists. As one specialist noted: “all you need is a medical and surgical degree, a specialty in paediatric surgery, and you can do it [surgery], nobody can say anything” (Med 3_Center 2_XXX). Another indicated that patients arrived at their regionally recognized center for genetic diagnosis confirmation after undergoing irreversible interventions elsewhere (Med 5_Center 3_XXX). While some participants described Italy as ‘behind’ other countries with regards to aspects of medical practice and civil rights regarding SOGI issues, research indicates this is not an issue isolated to Italy. Claims that non-interventionist protocols are lacking also come from countries that are seen as otherwise ‘advanced’ or ‘progressive’ regarding SOGI rights.

Italian specialists critiqued the lack of mandate to involve minors in treatment decisions. Gaps regarding direct communication to minors were lamented, a geneticist indicating “The teenage doctor is missing... communication of the diagnosis continues to be incomplete” (Med 5_Center 3_XXX). A DSD-team sexologist indicated seeing numerous late adolescent patients who would ask them “Can you explain to me what I have, how I was when I was born? Because no one has ever explained it to me” (Med 3_Center 2_XXX), while another psychologist on a DSD team (Med 2_Center 1_XXX) stated there were numerous families that they didn’t even see.

This psychologist went on to describe parental resistance to diagnosis communication, touching on social fears:

“A key issue is that families should be prepared by doctors and practitioners to be aware, to be able to properly communicate…The fear of parents is that they may develop…a sexual orientation that is difficult then to carry on in life... Always the "prejudice" argument, "secret" ... after 18, according to them” (Med 2_Center 1_XXX).

Another specialist indicates a medical push towards earlier diagnosis communication (but not decision involvement) that is met with parental resistance:

“It still happens because there are some families who don't want to communicate this, however, the relationship that is built with the family now is that of instead saying that sooner or later you have to reveal what used to be kept secret” (Med 4_Center 3_XXX).

The issue of bodily autonomy for children was addressed with trepidation, with only one MP clearly advocating in this direction. While many supported age-appropriate of diagnostic communication, they questioned the ability of minors to make serious, irreversible decisions, indicating: “if we raise people who can't even go home alone in junior high school, how can they decide on surgery--in Italy. In other countries the kids will be more mature, more ready. Not here.” (Med 1_Center 1_XXX).

The majority of the interviewed MPs conveyed the idea that Italy “wasn’t ready” for the social acceptance of concepts such as a third gender, gender plurality and sexual plurality. Research has indicated a general ignorance about intersex among non-specialist MPs in Italy (see Prandelli & Testoni, 2020), where an implicit link between ‘deviant’ sexuality, genderqueer and intersex was reiterated. Significant to our investigation of the perception of a ‘conservative’ culture, is that these themes emerged specifically when discussing bodily autonomy. For example, when asked what they thought about the 2015 Maltese law prohibiting indirect consent for the modification of sex characteristics, a specialist responded by discussing third or no-gender civic indicators: “since especially here in Italy we have a binary definition of sex, not assigning it for now is not even contemplated" (Med 4_Center 3_XXX). While this comment overlaps non-surgical options with civic gender marker options, it also affirms what cannot yet be *considered* in Italy.

A Urologist further described a 'conservative' culture unprepared to accept VSC bodies:

"In Italy there is a society where one is either male or female. It is not yet accepted in a simple way that there can be a spectrum, a diversity, and still be complete and happy people, serene even… so they have the fear that the child will become a transsexual, a transvestite, that he will be on the sidewalk at night being a viados. There are these preconceptions. It is very much a Catholic nation." (Med 1_Center 1_XXX).

While referring to the Vatican and anti-gender culture wars, the subtext describes 'conservative' fears as functional to linking distinct categories such as the gendered body, identity, presentation, and sexuality. The same specialist went on to link this 'conservative' fear to parent decisions: "The other thing that parents reject is to postpone surgery. This is a concept that just isn't accepted, postponing surgery until the kid is older and is involved in the decision doesn't exist." (Med 1_Center 1_XXX).

Describing Italy as possessing a conservative culture that fears specific SOGI social categories that are in turn overlapped with VSCs, suggests that options to create non-interventionist pathways are eclipsed by the assumption that *parents* are not ready to accept the VSC their children are born with. Medical assumptions of societal pressure and fears impacts parental decisions, often resulting in early surgical procedures on VSC children to align their bodies with binary expectations. Consequently, the potential for promoting bodily autonomy in this medical setting remains underexplored and underdeveloped.

## Parent explanations

This section explores experiences of Italian parents navigating their child's intersex diagnosis, focusing on how they manage decision-making solitude and perceive social expectations. Key themes include reframing of the diagnoses in the absence of a comprehensive support system, conservativism in relation to children’s gender and autonomy, and societal and cultural pressures regarding the performative body. Parents’ narratives reveal the delicate balance between cultural norms, parental decision-making, and their roles as proxies for both their children and social expectations.

Without detailed information and effective support systems, parents consistently express decisions as personal or family matters, often accompanied by a sense of solitude. This sentiment persists regardless of the type of variation, moment of diagnosis and child’s age at the time of the medical intervention. As one parent aptly articulated, while the diagnosis technically provides information, the implications of that information remain elusive: *“*They tell you technically what it is, but you don't know what the psychological or behavioural impact is that is implied by that information” (F4_FV).

Parents proactively employ different strategies to make sense of their child’s diagnosis and its medical, social, and cultural consequences. Research emphasises that parents' balance their child's well-being with socio-medical expectations. This balancing act can lead them to perceive non-lifesaving surgeries as mechanisms to safeguard their child’s future, both during adolescence and adulthood (Danon & Krämer, 2017; Sanders et al., 2012). This is particularly relevant when VSC are invisible in daily life.

Communication between parents and healthcare professionals, though formally present, often lacks comprehensiveness due deficits in protocol, psychosocial support, and non-interventionist approaches. Consequently, parents feel compelled to respond and act as proxies for their children, who are seen as unable to articulate a choice because too young or unaware of their variation: “you take the responsibility away [from children], because you are the one facing [surgery], not them [...] If they had undergone [surgery] at ten years old, the conscience would have been theirs, they would have had to bear the emotional consequences. Instead [with early surgeries] they are the ones undergoing the surgery but I bear the emotional part” (M14_FV).

Parents also respond to sociocultural expectations and norms within solitary decision-making. The sole mother who refused medical intervention for her child, described non-lifesaving interventions as psychological life-saving mechanisms for parents lacking psychosocial support: “a parent cannot make the decision, unless it is a life-saving operation, which is not the case here. [Surgery] is a psychological life-saver.” (M13_FV).

Parents combine their desire to protect their children with the expectation of mistreatment due to bodily variation, leading to decisions driven by potential social stigma: “I listened to the doctors and their recommendations. […] I know I am a very anxious person and would have gone into crisis if my child came home crying, saying, 'Mom, they teased me because I am neither male nor female, or because my body is different from others.' So, I would have suffered the most. […] Maybe it would be right for the person concerned to choose, but I believe that [in Italy] we are still too behind to do that" (M9_FV).

Parental anxiety about potential bullying and societal rejection drives them to make decisions that they believe will protect their child, often restricting the child's bodily autonomy. However, the quotes suggest decisions to choose early surgeries are based more on the *parental* emotional struggles and potential social stigma, rather than their children’s potential preferences. Despite awareness that it might be better for the child to make the choice themselves, the ‘conservative’ cultural environment is depicted as unsupportive of this autonomy.

In the context of societal and cultural pressures surrounding a performative gendered body, parents often face an uncertain future with limited information and a lack of non-interventionist medical protocols. As a result, parents anchor their decisions to familiar social-cultural norms, reflecting societal expectations in their children’s behaviour and performative aspects of the gendered bodies: “now I'm reassured that she's got all her pieces of a little girl in her mannerisms. When she plays she's a bit of a tomboy, however, every now and then she plays with dolls, gets her nails painted...” (F5_FV). This underscores the psychological and social solitude in which parents experience, acting as proxies for the societal pressures that compromise their children’s autonomy to make decisions about their own body even at a later age. The following quote illustrates this dynamic: "The surgery is a priority for the girl to feel like others. [...] Knowing that you cannot have a sexual [penetrative] relationship while a boy is interested in you can be distressing." (M13_FV). This parent prioritises surgery to ensure the child conforms to heteronormative sexual societal norms. The perceived need for surgery to facilitate future sexual relationships underscores the lack of respect for the child's autonomy.

Religious and cultural expectations create additional pressure, with parents often feeling their child’s value is tied to their ability to procreate: "For us now as we are structured [in Italy] both on a Catholic and a mental level, a woman who cannot procreate is nothing… [My daughter] pays attention to the fact that in our religion the womb is very important, in the sense that a woman is not just a woman, a woman is [created] to procreate. So, we no longer go to mass." (M13_FV). This perspective affects decision-making and interactions with the community, including family members. The decision to stop attending mass signifies a rejection of these restrictive definitions, yet it underscores the profound impact of religious and cultural contexts on their perceptions of gender and autonomy. Italian parents often operate within a conservative cultural framework that emphasizes traditional gender roles and values. This conservatism heavily influences the support to surgically create a performative gendered body: “If [my daughter] had refused, we would have insisted. [...] ‘look it's for your own good’ because later you will feel the need, if only to make happy, to please, to satisfy let's say, your partner” (F13_FV). Such deeply ingrained values can override the autonomy of the child. The parent's insistence on surgery, even against the child's potential refusal, underscores the prioritization of future societal acceptance and conformity to traditional gender roles over the child's immediate autonomy. The emphasis on making the partner happy reflects a conservative view that a woman's value is tied to her ability to fulfil traditional roles within a relationship.

The fear of social stigma and being labelled outside the confines of traditional bodies and gender roles, drives parents to ensure their child's variation remains hidden: "If they find out that my daughter does not have a vagina, they'll say she is a tranny, that she had the surgery because transsexuals have surgery. That's why [my daughter] has to leave this context […] because it's difficult to explain and it's very easy to misunderstand, it's almost mathematical that they'll misunderstand" (M13_FV). The derogatory term "tranny" reflects deeply rooted transphobia, highlighting the pressure on parents to ensure their child fits within socially acceptable gender categories. This pressure undermines the child's autonomy and reinforces harmful gender stereotypes.

In conclusion, this section illuminates the pivotal role of surgery as a proxy psychological life-saving mechanism for Italian parents of intersex children, underscoring the profound impact of the lack of psychosocial support. Amid the pervasive solitude, parents often resort to non-lifesaving interventions as a means of navigating the complexities imposed by societal expectations and the fear of a conservative culture. The narrative suggests that fostering greater support protocols and networks could promote alternative options, alleviating parental fears and allowing for decisions that prioritise the well-being of their children without succumbing to the constraints of perceived societal norms.

## Alternatives

Medical and parental narratives confirm the general perception of Italy as a country with a conservative culture. Intersex human rights claims insist on the primacy of bodily autonomy and integrity over cultural positions regarding the gendered body. However, dialogue surrounding VSC medical protocol continues to incorporate the links made in popular culture between distinct gendered concepts, ironically negating the right to bodily autonomy due to a lack of civic protection in other social realities. In this context, we highlight resistance not only to the idea that Italy *is* a conservative culture, but also that it is made up of parents who cannot handle having a child with bodily differences.

This section challenges assumptions that early intervention is the only option in a 'conservative' culture by delving into recent initiatives that seek to broaden the discourse beyond the dichotomy of autonomy versus fear of discrimination. First, we explore the endeavours of an innovative Italian association founded by parents (peer advocacy), which aims to support others in choosing bodily autonomy for their intersex children. We then highlight new institutional attention to intersex issues, as evidenced by the ISS website (institutional advocacy). Lastly, we present the collective creation of a joint Italian position statement (grassroot advocacy).

By juxtaposing three distinct public actions undertaken by parents, public institutions and activists we bring in alternative Italian stakeholder perspectives that challenge the assumption that Italian parents in a 'conservative' social context will inherently opt for early surgery as well as excluding the child from communication. These alternatives do not directly confront the image of the Italian system as 'conservative' with regard to 'gender' discourses. Instead, these initiatives reshape the current discourse by emphasizing bodily autonomy, shared decision making, and the recognition of the child's emergent body.

In 2021, the Italian NGO ‘Genitori e bimb intersex mai più soli’ (MPS; *Parents and intersex children never alone again*) was founded by a group of parents who sought support from patient groups and intersex activism after learning their child was born with a VSC, and were pressured to make quick decisions about their child’s body. MPS provides parents with various forms of peer support. As an officially registered charity, MPS also aims to collaborate with maternity wards to offer immediate support to new parents, ensuring they do not feel alone and helping them make informed choices. Unlike other parent support groups, MPS adopts VSC/intersex terminology - as opposed to DSD of variation specific terms - and a human rights framework, while welcoming families across the VCS spectrum. They provide a safe space to discuss medical procedures and protocols prioritizing the autonomy and integrity of the child. As reflected in their name, MPS addresses the sense of solitude and lack of support parents experience, offering information and support to promote rights-based decision-making and prevent rushed irreversible decisions, such as genital surgeries.

In June 2023, the Italian National Institute of Health (ISS) launched the InfoIntersex web project, in collaboration with the National Office Against Racial Discrimination (UNAR) and in consultation with Italian VSC representatives. InfoIntersex aims to reduce health disparities by providing health and legal information for intersex individuals, families, health professionals and the general public filling a crucial institutional gap. Recognizing the impediment posed by the lack of comprehensive information, the platform is an institutional advocacy effort, balancing the historical dominance of a medical approach to intersex issues with recent human rights discourse. InfoIntersex navigates complexities such as the controversy around early surgery carried out outside a medical emergency, while offering contact details for Italian medical centres conducting surgeries.

In October 2023, Italian patient support groups, intersex activists and allies published a joint statement on intersex rights claims in Italy. Following other collaborative examples, the Italian joint statement provides a clear position statement on the priorities and rights claims of people born with VCS, through 6 sections that include a Preamble, Rights, Health and Well-being, Policies, Inclusion and Support and Guidelines. Medical allies have further referenced the joint statement to promote a rights-based perspective in medical settings in Italy (D'Alberton & Di Grazia, 2024).

The actions of MPS, InfoIntersex and the joint statement help bridge the information gap and provide crucial support channels. They address the lack of comprehensive information that often leads to hasty surgical decisions, raising social awareness through reputable entities, and ultimately *socially* normalizing VSC. These initiatives offer a view into the multifaceted landscape of growing intersex advocacy in Italy, contributing valuable insights to social science and medicine. They highlight the complexities and progress in advancing intersex rights and well-being in Italy, moving beyond cultural conservatism and identifying current gaps and future challenges.

## Conclusion

This paper examines the complex dynamics of decision-making in intersex/VSC paediatric care within the Italian context, focusing on the relationship between medical practices, parental perspectives, and socio-cultural factors. Our findings indicate that medical professionals and parents frequently portray surgical intervention as the primary, and sometimes only, option available. This perspective is significantly influenced by cultural debates on gender, the body, and autonomy. In the Italian context, where traditional views on gender roles and bodily norms dominate, this portrayal reflects a culturally conservative framework. However, there is a growing movement challenging this status quo, advocating for bodily autonomy and intersex human rights.

Medical professionals in Italy continue to prioritise early interventions for visible discrepancies in gendered bodily presentation, reflecting a deeply ingrained belief in the necessity of surgical normalisation. This approach is reinforced by a culturally conservative framework that links intersex bodies with broader social issues such as gender identity and sexual orientation, often critiquing bodily autonomy. Parental perspectives echo these themes, influenced by medical communication, sociocultural expectations and projections for their child future. While these results are consistent with previous studies, they also highlight what are the underlying sociocultural motivations maintaining the status quo in Italy. This insight is crucial as it demonstrates how moral and cultural norms shaping medical professional, parents and the general public narratives vary from country to country and identifies factors that hinder the implementation of holistic and protective policies in Italy compared to other countries.

Despite a global push towards respecting bodily autonomy, several factors hinder its implementation in Italy, including the lack of uniform national protocols, informed support for parents, the absence of mandates to inform children about their medical choices, and a perceived prevailing conservative culture. Medical specialists expressed a desire for non-interventionist protocols but cited these obstacles as significant barriers. The notion of Italy as a 'conservative' society complicates efforts to shift away from early surgical interventions, as societal and cultural fears around gender and sexuality heavily influence both medical and parental decision-making.

The interplay of societal expectations, psychological solitude, and parental decision-making provides valuable insights into the unique experiences of Italian parents raising intersex children within the realms of supposed conservatism. A prevailing sense of solitude permeates parents' narratives, grappling to translate the medical information into their lives. Parents employ various coping strategies within the solitude of decision-making, prioritising sociocultural norms over their children's autonomy. Amid cultural expectations, parents make decisions anchored in trauma avoidance and familiar social references, acting as proxies for societal expectations.

Recent initiatives, including the innovative work of 'Genitori e bimb intersex mai più soli' and the InfoIntersex web project by the Italian National Institute of Health, showcase a growing movement towards bodily autonomy and human rights-based activism. The 2023 joint statement published by Italian patient support groups, intersex activists, and allies represents a pivotal moment in the ongoing discourse, aiming to align institutional priorities with the needs of the Italian intersex community. These efforts underscore a paradigm shift towards prioritising bodily autonomy, shared decision-making, and the recognition of the child's emergent body.

The findings of this study highlight the urgent need for continued advocacy, research, and policy development to support more equitable and informed decision-making processes.

Current medical practices often lack comprehensive information and support for parents making rights-based decisions, leading to decisions that marginalise the child's involvement and prioritize surgical solutions. Our results align with Jones’ (2018) findings, indicating that medical systems - in Italy and globally - often prioritize parental social fears over patient-centered, rights-based approaches. This highlights the urgent need for alternative options such as autonomy-respecting reforms in intersex/VSC care as well as the importance of fostering stronger support networks. By examining the development of rights-based approaches in Italy, we aim to inspire a re-evaluation of what is possible in intersex paediatric care and policymaking circuits, particularly in ‘conservative’ contexts. Future research should focus on developing and testing interventions that enhance informed, rights-based decision-making in these settings.

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Highlights

- Medical and Parental perspectives on surgeries for intersex minors, and those with Variations of Sex Characteristics (VSC), in the ‘conservative’ context of Italy.
- Italian culture is portrayed by some stakeholders as too ‘conservative’ to support bodily autonomy for children with VSC.
- Surgery is employed as a psychological lifesaver for parents when faced with a lack of information and support, and as a buffer against social discrimination instead of patients' medical autonomy or need.
- New actions from activists, advocates, and institutions attempt to bridge parental solitude with right-based alternatives that support bodily autonomy for minors with VSC.

Ethics approval for the EU Intersex Citizenship (EUICIT) project was obtained from the University of Huddersfield, UK.
Ethics approval for the Facing the Variation (FV) was obtained from the University of Padova.