Exploratory study:

on medical and social experiences of intersex people in Vietnam



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Researcher ***Tran Ngoc Linh***

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First of all, I would like to express my deepest gratitude to each individual and organization who has contributed to the journey of this groundbreaking research on the life and medical experiences of intersex people in Vietnam.

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Best regards,

Researcher ***Tran Ngoc Linh***

List of abbreviations and terminology

CARES Foundation	Congenital Adrenal Hyperplasia Foundation
DSD (Disorders of Sex Development) *hoặc* **DSD** (Differences of Sex Development)	Disorders of sex development (DSD) are conditions in which the reproductive organs and genitals do not develop normally Differences of sex development (DSD) is a phrase used for conditions in which a person is born with reproductive or sexual anatomy that doesn't fit the typical definitions of female or male
InterACT	interACT Advocates for Intersex Youth
iSEE	Institute for Studies of Society, Economy and Environment
Cộng đồng LGBTIQ+	LGBTIQ+ is an acronym for Lesbian, Gay, Bisexual, Trans, Intersex and Queer
MRKH	Mayer-Rokitansky-Küster-Hauser Syndrome
OHCHR	Office of the United Nations High Commissioner for Human Rights
TGI Justice Project	The Transgender Gender-Variant & Intersex Justice Project
TP. Hồ Chí Minh/TP.HCM	Ho Chi Minh City
UNFE	United Nations Free & Equal
UNDP	United Nations Development Programme

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Preamble

Intersex is still a topic with rare discussion and presence in discourses on gender and sexuality in contemporary Vietnamese society. Scientific research on intersex people in Vietnam is currently limited to medicine and medical intervention with inconsistencies in terms of concepts, classification and pathologization; and at the same time, current research also lacks a cultural, social, and political perspective on intersex people and their relationships with those around them.

While there is still much debate over the development and use of the terms, understanding of the concept of intersex has broadened and specialized in recent decades. With the development of terminology used to describe the condition and diversity of intersex spectrum, the international community's scientific understanding of intersex people has gradually improved. In Vietnam, although intersex is often classified with gender and sexual minority groups (LGBTIQ+), research on the LGBTIQ+ community in Vietnam often lacks the presence, contents, stories, and living experiences of intersex people.

Compared to other gender and sexual minority groups such as gay, bisexual, and transgender people, intersex people in Vietnam do not have representative organizations or interconnected communities in Vietnam. Therefore, understanding and awareness of the needs and legal rights of intersex people remain a blank field in advocacy efforts for the rights of LGBTIQ+ people. On the other hand, intersex is often not considered a primary identity, compared to other "labels' such as gay, straight, transgender, or gender-conforming. Therefore, many intersex people self-identify as transgender or heterosexual, and for them, intersex is more of a physical condition and pathology than an identity.

In recent decades, the world has witnessed an increasing presence and advocacy efforts for intersex people in many countries, aiming to end unnecessary medical intervention, forced surgery on intersex children, as well as the view that surgery is intended to "normalize" genitalia. In Vietnam, some doctors have also updated the latest medical opinions on intersex, as well as raised awareness on the problem of forcing unnecessary medical interventions on children. .

This research was conducted by the Institute for Studies of Society, Economy and Environment (iSEE) in Hanoi and Ho Chi Minh City, with the intention of collecting information and contributing to a common understanding of intersex people, communities and topic in Vietnam, aiming to design and implement projects and activities to better support intersex people in many aspects of life, such as personal health care, policy development, comprehensive social support systems and respect for the rights and needs of intersex people.

Definitions and Terminology

Terms such as “hermaphrodite,” “bisexual” or “intersex” have long been used to identify and describe individuals whose sex characteristics do not strictly fit typical binary concepts of male or female bodies. Since 2006, the term "disorders of sexual development" has been commonly used in the healthcare sector to classify medical conditions originating from abnormalities in the differentiation and development of genitalia (Lee et al., 2006). These “abnormalities” may include malfunctions in sex chromosomes, sex hormone synthesis, or insensitivity of genital androgen receptors. Each case presents at different levels, with a variety from mild to moderate and severe (Tran, 2021).

Discussions about the language used to describe people with atypical sex characteristics continue today with many complex nuances (Lundberg et al., 2018, Carpenter, 2018). In healthcare, experts want a term to accurately describe medical conditions, support the provision of appropriate medical services, and help patients understand their condition better (Pasterski et al, 2010). However, in social and anthropological forums, the use of medical terms can cause many negative impacts on the psychology and social relationships of those affected (Lundberg and al, 2018, Carpenter, 2018).

In this study, it is extremely important to clarify the terms used. Up to now, there are still many ongoing complex discussions, especially around the use and meaning of the terms "disorders of sex development" (DSD) and "intersex". Terminology has been a topic of discussion that has been explored in depth in many studies and publications, emphasizing the debate between the classification of diseases in healthcare, the rights and living experiences of relevant individuals. Our discussion of terminology in this study not only provides a definition of each concept used, but also helps to establish the foundation for an informed, empathetic, and progressive discussion to respect and acknowledge the diverse experiences of individuals with atypical sex characteristics.

Definitions and Terminology

1. Disorders of sex development and Differences in sex development

The term “Disorders of Sex Development” (DSD) (Vietnamese: Rối loạn phát triển giới tính) was first introduced during a professional conference in Chicago in 2006 (Lee et al, 2006, Lundberg et al, 2018). This term was originally created with the purpose of replacing existing terms such as "intersex" (Vietnamese: “liên giới tính”). Experts say that terms like intersex can mislead listeners into thinking that affected people have sex characteristics that fall between the lines of male or female (not male or female or both male and female). Although in reality, studies have shown that they mostly belong to the gender binary and have a clear sense of gender as men or women (Mhuirthile et al., 2022, van Lisdonk, 2014, Lundberg et al., 2018). Proposed with the intention of having a term for more accurate medical classification, “DSD” was quickly adopted by medical professionals (Pasterski et al., 2010, Lundberg et al., 2018). However, this clinical application soon faced resistance from those it sought to identify.

Many advocates and individuals in the intersex community found the term DSD to be poorly described and even pejorative (OHCHR, 2019, Carpenter, 2018). They believe the term is used to describe a medical condition, while many people do not see their intersex characteristics as a disease or unhealthy condition that requires medical intervention. The term "disorder" easily causes misunderstanding that the syndromes do not affect the body's health of intersex spectrum. A survey by the CARES Foundation in the United States found that “more than half of those surveyed said they would not choose services from centers or participate in scientific studies that use the term “DSD” (Lin-Su et al., 2015). Many individuals and groups working for intersex rights also refused to use DSD due to the negative effects it could bring. Johnson et al's study (2017) of attitudes toward the term DSD suggested that DSD could negatively impact access to health care and cause distress to those affected, causing some people to totally avoid medical care.

Recently, some scientists (Wiesemann et al., 2010, Tamar-Mattis et al., 2014, Cools et al., 2018) proposed to keep the abbreviation “DSD” but change the full name to “Differences of Sexual Development” to emphasize a de-pathologizing approach, and consider sexual development characteristics as a spectrum, in which those outside the typical range are “differences” rather than “disorders”. This way brings an advantage of still maintaining the connection with the old term, the habit of using and looking up its connotations, but clearly positively changes the attitude with which listeners and readers perceive the term.

Some terms in legal and scientific regulations in Vietnam

The first legal document regulating intersex in Vietnam is Decree 88/2008/ND-CP, issued on August 5, 2008, but few people know that it is a regulatory document about intersex people, because the terms it used are: " defects at birth", "sex not yet accurately determined", in which "birth defects" is divided into three cases: “bisexual male impersonating to be female,” “bisexual female impersonating to be male,” and “true bisexual”(male pseudohermaphroditism, female pseudohermaphroditism and pseudohermaphroditism).

Essentially, these are specific classifications of certain intersex characteristics, and do not cover the entire range of intersex conditions, but rather focus on conditions that are pathological or beyond from the usual binary classification system. This is understandable because the purpose of this document in particular, as well as the medical perspective at the time of issuance of this document, was to use medical interventions to "correct" and "normalize" intersex conditions into two typical “male” and “female”. This viewpoint can be clearly seen in the distinction between two concepts in Vietnamese law: "gender/

1.

sex reaffirmation" and "gender/sex transformation". In which, if the individual has a "birth defects" or " sex not yet accurately determined", "gender/sex reaffirmation" will be performed, but if the individual is not one of these cases, then identified as "gender-complete" (i.e., "transgender") and able to undergo "gender/sex transformation". The use of "gender reaffirmation" also contains an implicit stereotype that intersex people already have a gender that fits the typical men or women categories, and that intervention is about helping them return to the correct section. We will analyze this point of view in more detail in the following section.

In Vietnam, scientific documents and publications often use the terms "disorders of sexual development" or "genital differentiation disorders". In the community and society, phrases such as "true bisexual" or "bisexual" are often used in lay press articles to refer to people with intersex characteristics.

2.

Intersex

With at least 40 known variations of intersex conditions, experts and organizations say a term that provides common ground for the community of people with atypical sex characteristics is necessary. Advocacy groups and social organizations on human rights have also made many calls to use neutral language and discourage medically unnecessary interventions (OHCHR, 2019, Carpenter, 2018). A common term can facilitate the connection and collective actions among individuals with similar experiences.

It's worth noting that every intersex individual is different. Because human sex characteristics are a combination of factors made up of interactions between chromosomes, hormones, and the development of internal and external genital organs. What we often call "biological male" or "biological female" are simply the two most common, typical combinations of sex characteristics. For example, both men and women have the presence of "male" and "female" hormones in their bodies such as estrogen, progesterone, and testosterone, but the place of production, blood concentration and interaction of these hormones with other organs and systems in the body are not the same. A typical "biological male" will maintain an average testosterone level of approximately 300–1000 ng/dL, a typical "biological female" will maintain an average testosterone level of approximately 9–55 ng/dL. Thus, when combining all other biological sex characteristics, we will understand why there is a rationale to consider intersex as a spectrum, and the way to call intersex condition "atypical" instead of "abnormal" is not only a way to reduce prejudice but also has a scientific basis.

A general term can also help individuals without a clear diagnosis find others who share similar living experiences. In situations where conditions of sexual development are rare or statistically uncommon, an umbrella term can provide an important connection to other individuals with similar experiences and circumstances, helping to create favorable conditions for community formation and advocacy to resolve issues related to inferiority complexity, stigma and discrimination.

The term "intersex" (Vietnamese: liên giới tính) is a general term that covers all individuals whose sex characteristics fall outside the binary spectrum of male and female. The term "Intersex" was chosen by the community and activists because of its neutrality and non-medical connotations. This term existed for a long time and there are also many conflicting opinions. Not all individuals with atypical sexual characteristics identify themselves

with intersex identity (Lundberg, 2018). Intersex is also considered "easily misleading" about the gender and gender identity of the affected person. However, some studies like those conducted by Jones et al. (2016) in Australia found that their participants tended to use the term "intersex" rather than "DSD" to describe themselves. “DSD” is only used when they want to access medical services. This reflects a desire for a term that more accurately describes their identities without negative connotations of disorder or abnormality.

The term "intersex" is increasingly used in communities, support groups, and advocacy groups around the world (Carpenter, 2018, Lundberg et al, 2018). These groups play an important role in providing community support services, aiming at reducing discrimination and human rights violations against individuals born with intersex characteristics. In studies on human rights, living experiences, or social situations, or in advocacy programs for intersex people, the term DSD is often not used because it places too much emphasis on medical aspects. Not everyone with intersex conditions feels like they have medical diseases. Currently, activists and related social researchers still use the phrase “intersex” or “people with intersex conditions” to talk about the community (Carpenter, 2018, OHCHR, 2019).

Due to the nature of the study, which focuses on the living experiences of individuals with congenital intersex characteristics, this report will use the term “intersex” to describe study participants. When discussing medical issues, the term “differences of sex development”, abbreviated as DSD, or the name for a specific condition of atypical sexual development may be used.

International studies on Intersex people

1. The minority of minorities

Over the past several decades, attention and concern for the intersex community and those with differences in sex development has undergone a significant shift, gradually going beyond the limits of the healthcare sector, and expanding into many other important aspects such as personal rights, freedom of decision, and bodily integrity. This expansion extends beyond simply a consideration of medical issues to include the impact of stereotypes and gender binary structures, which affect daily lives and mental health of people of intersex community.

The traditional view of intersex manifestations or DSD (differences in sex development) as medical issues that need to be "cured" as soon as possible is increasingly being challenged by new perspectives. These new perspectives emphasize individuals' right of choice and especially issues related to unnecessary surgical intervention on intersex children. In cases where intersex/DSD manifestations do not pose a threat or adverse impact on the child's health, advocates on intersex rights believe that there should be limitations on interventions to correct children's genitals for cosmetic purposes, a decision that can cause long-term effects on their health and future life.

The results of recent exploratory studies in Ireland, the Netherlands, Australia, and the United States show that intersex people are facing a series of difficulties in life: from being subjected to unnecessary medical interventions to delays in diagnosis, chronic health problems, infertility, and social stigma (Mhuirthile et al, 2022, van Lisdonk, 2014, Jones et al., 2016, Hart & Shakespeare-Finch, 2022, Rosenwohl-Mack et al., 2020). The lack of presence and information about the intersex community further increases feelings of isolation and lack of support (van Lisdonk, 2014). In spite of being frequently mentioned in activities and movements of the LGBTIQ+ community, intersex people still feel they are not recognized clearly and comprehensively. Even many people in this community feel they have been overlooked in research and a series of advocacy activities for the rights of the LGBTIQ+ community in general. According to World Bank data, intersex and transgender people are the most underrepresented groups in LGBTIQ+ rights projects, also described as "the minority of minorities" (World Bank and UNDP, 2016).

The biggest challenge in advocating for the rights and visibility of intersex people is the lack of reliable information, data, and research. Scientific articles on intersex or research focusing solely on this group of people are still very limited compared to the abundant research and literature for other minority groups in the LGBTIQ+ community. This needs further attention to ensure that intersex people are understood and properly supported. (Mhuirthile et al, 2022, van Lisdonk, 2014, Jones, 2017)

Although research on intersex people is becoming more and more popular, in many fields such as sociology, law, policy, human rights, or clinical health services, issues of the quality of long-term health care, or enhancing daily experiences for intersex people and their families, has not really improved.

2. Psychological challenge

The lack of proper information and awareness about intersex and DSD leads to many intersex people having a sense of inferiority and isolation due to being "different". Most cases of intersex people in the study by the Netherlands Institute for Social Research faced many difficulties in accepting their condition, sharing with family and relatives, as well as facing barriers to health check-ups (2014). In addition, issues such as self-image, gender dysphoria, limited ability to have sex, and infertility also cause many negative effects and put great pressure on their lives, preventing them from establishing intimate relationships or creating meaningful social relationships. Due to the secretive and sensitive nature of these cases, intersex people often cannot easily share their situation with those around them, leading to isolation and internalization of negative experiences, being discriminated, or feeling "different" or "not normal" (Hart & Shakespeare-Finch, 2022).

In social contexts, knowledge about differences based on social and demographic characteristics such as sex, ethnicity and age is still limited, which prevents the sharing and empathy with vulnerable groups. Jones's study of intersex individuals' relationships with their families (2017) indicates that these relationships often become more strained when family members consider intersex variants and syndromes "abnormal". Research results also highlight the need to accept the natural bodies of intersex people, instead of seeking interventions or "normalizing" their bodies.

Similar findings were found in research conducted in Australia and Ireland showing that intersex people face many difficulties in understanding and accepting themselves, as well as seeking comprehensive healthcare and full control over their own bodies (Hart & Shakespeare-Finch, 2022). Due to binary gender stereotypes, intersex people are often considered “neither male nor female” or “ambiguous”, causing feelings of incompleteness, inadequacy, and abnormality (Jones, 2017). Traditional gender norms and social expectations about having children also become a psychological burden for them. Despite this, participants in the Netherlands Institute for Social Research and other studies still clearly perceived themselves as either male or female and desired to be seen as a "full" and "normal" man or woman (van Lisdonk, 2014).

Besides physical health problems, intersex people are also more vulnerable in terms of mental health. Research on the health of intersex adults in the United States shows that the psychological health of intersex people surveyed is at a more alarming level than that of control groups (Rosenwohl-Mack et al., 2020). In this study, 31.8% of participants reported having had suicidal thoughts, much higher than the US national average (Rosenwohl-Mack et al., 2020, Substance Abuse and Mental Health Services Administration, 2021). Many studies suggest that the mental health of intersex people can be negatively affected due to experiences of social stigma and discrimination, as well as barriers in accessing appropriate healthcare services.

3. Social challenges

Intersex people continuously face numerous issues that violate rights, choices, physical integrity, and social and medical challenges that remain largely unaddressed in many places in the world (OHCHR, 2019).

At a systemic level, one of the most significant barriers the intersex community is facing relates to birth registration and legal recognition of their gender identity. Without gender affirmation surgery at a young age, which depends on parental consent, and in many cases is not necessary, the birth registration process for intersex people becomes very complicated. The practice of performing gender affirmation surgery on children has been condemned by many organizations such as UNFE and InterACT: Advocate for Intersex Youth, TGI Justice Project, as it violates the rights of intersex children, prioritizing social norms over personal happiness.

According to the OHCHR (2019) Background Note on Human Rights Violations against Intersex People (2019), there are currently insufficient legal protections and anti-discrimination measures for intersex individuals. Most anti-discrimination laws do not explicitly protect intersex people, leaving them vulnerable to discrimination in education, employment, and access to public services.

Discrimination is a common experience, especially if an individual's intersex status is known or if they are perceived as not conforming to traditional sex and gender norms. This discrimination is not only individual but also systemic, reflected in the lack of legal protection. Social stigma in terms of being intersex, often reinforced by negative cultural and religious attitudes, makes those affected keep silent, thereby preventing them from seeking compensation or support (OHCHR, 2019). This results in the intersex community being socially and economically marginalized, which often leads to higher rates of poverty due to early school leaving, limited employment opportunities and widespread discrimination (OHCHR, 2019).

As mentioned at the beginning of the study, in health care, intersex people often face unwanted medical interventions. These interventions, often with the aim of “normalizing” the bodies of intersex people, are often carried out without the explicit consent of these individuals. In many cases, fear of stigma and social pressure motivate these surgical interventions, which are not only unnecessary but also can cause long-term physical and psychological effects (Hart & Shakespeare-Finch, 2022).

The lack of public information about intersex bodies or related conditions increases the severity of these challenges. Advocate groups for the rights of intersex people have repeatedly called for awareness, education, and respect, not to consider intersex variations as diseases or abnormalities. However, with the current paucity of information in both mass media and scientific research, intersex people have not yet found a voice to share their experiences and call for their rights.

In short, the challenges that the intersex community is facing are multi-faceted, interdisciplinary, intertwined in the legal, social and medical fields. Despite some progress in recognizing their rights, these challenges remain largely unaddressed, which highlights the need for comprehensive and informed strategies to support the intersex community effectively.

Rationale of the study

Conducting social research on the experiences of intersex people in Vietnam, especially in urban areas such as Hanoi and Ho Chi Minh City, will contribute to addressing significant knowledge gaps and improving informed support for this vulnerable minority group. Intersex individuals globally and in Vietnam are facing many complex social, psychological and medical challenges. Traditional medical approaches to intersex variations or differences in sex development (DSD) often prioritize early interventions, including normalizing surgery, putting social standards higher than the rights and long-term happiness of the individual.

Although the presence of the LGBTIQ+ community is growing, intersex (“I - Intersex”) people are often overlooked, especially in the socio-cultural context of Vietnam. This study hopes to partly bridge this gap by learning about and listening to the living experiences of Vietnamese intersex people, focusing on their daily challenges, social interactions, and experiences in the healthcare system. This initial research is also a very important prerequisite to be able to identify and understand more deeply the psychological and social problems they face as well as their health care journey - from diagnosis to treatment. Hanoi and Ho Chi Minh City are the two biggest cities in Vietnam, with leading medical facilities, providing a unique context for this study.

In fact, there is currently a significant lack of comprehensive research focusing specifically on the intersex community in general. The study evaluates part of the health care landscape related to intersex individuals in Vietnam. This includes access to health care services, the process of diagnosis and “treatment”, and specific barriers within these systems. This understanding is key to identifying gaps in current health care models and the state of serving the intersex community and their families.

Intersex is a congenital condition, so it is associated with the physical and psychological development of children with intersex conditions. First and foremost, medical opinions and legal regulations related to intersex people directly impact intersex children and their families. Therefore, this is also an issue of children's rights, especially because intersex children do not clearly understand themselves, so medical opinions from medical staff or social opinions expressed through pressure, parents’ expectations will directly promote or limit the enjoyment of children's basic freedoms such as the right to physical integrity, the right to education, and the right to care.

Finally, the study aims to propose practical measures and strategies to improve the quality of life and support for the intersex community in Vietnam. The study seeks to influence policy development, improve health care services and social support systems that are inclusive and respectful of the rights and needs of the intersex community. The findings from this study are expected to contribute significantly to the broader debate on the rights and well-being of intersex people, influencing policy, healthcare practices and social attitudes towards intersex people in Vietnam.

Research question

1. What is the current legal, medical, and social context of intersex people in Vietnam?

2. How do intersex people living in large areas of Vietnam such as Hanoi and Ho Chi Minh City feel and experience about the life, social environment and medical diagnosis and intervention process?

a. What are the psychological and social problems that intersex people in Hanoi and Ho Chi Minh City face?

b. How is the process of medical access and intervention for intersex people in these areas? What difficulties and challenges are there?

3. What measures and strategies can be applied to improve the quality of life, create favorable conditions and best support for intersex people in Vietnam?

As one of the first social studies of the lives and experiences of intersex people, the first question was asked to provide an overview of the context of the intersex community in Vietnam. The second question focuses on personal experiences of intersex people in Vietnam to partly discover the common problems that intersex people are facing. The final question, which is also the main purpose of the research, is to support and create conditions to improve the quality of life of intersex people in Vietnam.

Research and sampling methodology

To answer the questions raised, the study consulted and analyzed data from three main sources: publications, research on intersex in Vietnam and internationally, in-depth interviews with individuals with intersex characteristics in Hanoi and Ho Chi Minh City and in-depth interviews with doctors and experts in medical services for intersex people in Vietnam.

Literature review and interviews with experts were applied to learn about the intersex context in Vietnam. The literature review method includes collecting and analyzing information from available data sources such as research reports, policy documents, scientific articles and related research works. This helps us get a general overview of the current situation that intersex people are facing in Vietnam.

In addition, we also conducted interviews with medical experts in the field of intersex, including doctors from specialized hospitals, to collect detailed and insightful information from people with professional knowledge and practical experience. Thereby, the study hopes to gain insights into the medical context, as well as medical services for the intersex community in Vietnam.

This study also uses qualitative data collection methods through in-depth interviews with intersex people to understand more about their life experiences as well as the physical and psychological problems they are facing. Through direct outreach and communication, we hope to deepen and better understand the issues, challenges and needs that individuals with intersex spectrum syndromes face in their lives in general and their access to medical services in particular.

However, the research has many limitations due to the new and sensitive nature of the research topic. Firstly, the number of intersex people participating in the study is only 6 people, all living in big cities like Hanoi and Ho Chi Minh City, research results will not fully reflect the views and experiences of the entire intersex community in Vietnam. Secondly, due to the subjective nature of in-depth interviews, the analyzed data are easily influenced by the subjective views of the interviewers and interviewees. Thirdly, because of time and resource limitations, the number of documents reviewed and referenced by the research team is not comprehensive, making it difficult to provide a detailed image of all aspects of intersex people nationally and internationally. Finally, the results obtained from the study are unlikely to be widely applicable to the entire community due to the lack of generalizability. Furthermore, information is obtained only from people who are conscious about their condition.

However, the research team also tried to come up with measures to minimize the limitations and weaknesses of the study. Furthermore, this is also the first preliminary study in Vietnam to explore the life experiences of intersex people. Without high generalizability, this study will still lay the foundation for further research on the intersex community in Vietnam.

Because the term of intersex in Vietnam is still quite new and not widely known, identifying an official intersex community to approach becomes difficult. Although efforts had been made to ensure that the study sample was diverse and reflected the goals of the study, such as posting and calling for voluntary participation of intersex people on social media platforms, the results were not very positive. Specifically, the research team posted a recruitment for research participants publicly for 1 month on iSEE's fanpage with about 130,000 followers but could not find any suitable sample, and the number of people leaving their contact was also extremely rare. The research team also contacted 73 different LGBTIQ+ and youth groups in all regions of Vietnam, but the number of intersex people contacted was very small.

Research and sampling methodology

In this situation, the research team decided to apply the Convenience Sampling method to approach individuals with intersex characteristics based on existing personal relationships. To expand the research sample, we continue to use the Snowball Sampling method. Specifically, individuals who participated in the initial study will introduce and connect the research team with other intersex people they know. Although the study used other sampling methods to ensure that the research sample was diverse and reflected the research objectives, such as posting recruitment and calling for voluntary participation of intersex people on social networks, none of the samples came from public job postings. Through the Convenience Sampling method, we obtained only 3 samples and then expanded further through the Snowball Sampling method. These difficulties demonstrate the closedness and lack of presence or awareness of intersex in the community in Vietnam.

In-depth face-to-face interviews were conducted by the research team with six (06) people with different intersex characteristics. Among them, one (01) person is currently living in Hanoi, the remaining five (05) people live and use medical services in Ho Chi Minh City. In-depth interviews focus on understanding personal experiences of research participants in the process of disease detection, self-identification, and in relationships with individuals, community, and society.

Research sample composition

Name	Place of residence	Gender at birth	Gender identity	Intersex manifestations/ syndromes	Physical manifestation	Medical experiences	Intersex identity
Phương	Ho Chi Minh City	Male	Female		Small penis, fat concentrated on the chest and buttocks, menstruation	Had surgery	Yes
Minh Anh	Ho Chi Minh City	Female	Female	Not yet diagnosed	Menstruation, small penis	Never check-up	Yes
Mai	Ho Chi Minh City	Female	Female	Androgen insensitivity syndrome, XY chromosome	No menstruation	Diagnosed	Yes
Hoa	Hanoi City	Female	Female	MRKH	No menstruation, no vagina	Vaginal reconstruction has been performed	Yes
Trang	Ho Chi Minh City	Female	Female	Androgen insensitivity syndrome, XY chromosomes	No menstruation	Diagnosed	No
Nguyên	Ho Chi Minh City	Female	Male	Hormonal disorders, very high androgen levels	Little, almost no menstruation	Went to the doctor, no specific diagnosis yet	No

Information about doctors:

- Doctor Ngo Hai Son, working at the Department of Maxillofacial, Plastic, Reconstructive & Aesthetic Surgery, Viet Duc Friendship Hospital.

- Doctor Nguyen Tan Thu, working at Nha Minh clinic, consulting and supporting people living with HIV and affected groups.

Due to the social sensitivity associated with diseases and intersex syndromes, interview participants were assured of anonymity. Names have been anonymized; the only interviewers mentioned by their real names are the experts or doctors.

Research results

1. Context of intersex people in Vietnam

1.1 Legal framework for intersex people in Vietnam

Currently, Vietnam only recognizes two sexes, male and female. Decree No. 88/2008/ND-CP is the first legal document providing regulations on gender reaffirmation surgery procedures, but only for cases of "congenital gender defects that are abnormalities" in a person's genitals from birth, manifesting in one of the following forms: female hermaphrodite impersonating male, male hermaphrodite impersonating female or true hermaphrodite" (Clause 1, Article 2, Decree No. 88 /2008/ND-CD dated August 5, 2008, of the Government). Articles 5 and 6 of the Decree stipulate "Medical standards for gender reaffirmation" as follows:

Article 5. Medical standards for defining congenital birth defects

1. Male hermaphrodite impersonating female:
a) Small penis, testicles can be felt or not, testicles can be seen via ultrasound or endoscopy, and the uterus and ovaries are absent;
b) Sex chromosomes are XY or testicular differentiation gene is positive or a combination of both above.

2. Female hermaphrodite impersonating male:
a) The genital with developed clitoris like a penis but no testicles can be felt, ultrasound or endoscopy shows a uterus, ovaries, and no testicles;
b) Sex chromosomes are XX.

3. True hermaphrodite:
a) Genitals cannot be determined as male or female. The gonads include testicles and ovaries;
b) Sex chromosomes can be one of the following types: XX/XY; XXX/XY; XX/XXXY or other chromosomal forms identified as true bisexual.

Article 6. Medical standards for determining gender that has not yet been precisely defined

Sex chromosomes can be similar to the case of female hermaphrodite impersonating male or male hermaphrodite impersonating female or true hermaphrodite, but the genitals are not fully differentiated and cannot be accurately determined as male or female.

Currently, Vietnam has allowed gender affirming care for transgender people (Article 37, Civil Code 2015), however, it has not specified in detail the conditions, procedures, and order to perform gender change intervention and replace ID papers for transgender people.

In 2015, Vietnam re-regulated the right to re-determine the gender of individuals in Article 36 of the 2015 Civil Code as follows: “Re-determining a person's gender is carried out in cases where that person's gender is congenital defects or not yet accurately formed that require medical intervention to clearly determine gender.” In addition to reaffirming that individuals have the right to re-determine their gender in cases where medical intervention and specialized agencies are needed to clearly determine gender, section 3 of Article 36 also allows “Individuals who performed gender change procedures have the right and obligation to register for change of civil status according to the provisions of law on civil status; have moral rights consistent with the gender that has been re-determined according to the provisions of this Code and other relevant laws.”

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In Vietnam, there are currently only three medical facilities authorized to perform the examination and issue the necessary medical certificate for gender reassignment, including Viet Duc Friendship Hospital, National Children's Hospital in Hanoi, and Children's Hospital 2 in Ho Chi Minh City. People provided with certificates from one of these three facilities can continue the legal process by contacting the civil status office to register a change of gender on identification papers, according to the provisions of Clause 2, Article 3 of the Law on Civil Status. Point E, Clause 1, Article 28 of the 2015 Civil Code also allows people who have gender reassignment to have the right to change their personal name. Once the legal process has been completed, the person who has gender reassignment will have the same rights to marry and adopt children as any other citizen, based on the laws in the 2015 Civil Code and the 2014 Law on Marriage and Family together with guiding documents. Inheritance rights and parent-child relationships are still guaranteed after gender change. In addition, changing gender also affects a number of other civil rights and obligations such as retirement age, maternity benefits, or gender-specific regimes.

1.2 Medical context of intersex people in Vietnam

Like many other countries, the medical context related to intersex people (differences in sex development) in Vietnam is still complex and full of challenges. Regarding the name, the terms "intersex" or "differences in sex development" are not widely known or used in society in general and the healthcare sector in particular. Health professionals involved in the study reported a tendency to use a specific disease or syndrome name, or the broader term “disorders of sex development” (DSD) for most cases where patients do not have typical internal and external genitalia. DSD is a new term used instead of names such as "female hermaphrodite impersonating male/male hermaphrodite impersonating female" or "true hermaphrodite" that are commonly used in the public. Doctor Ngo Hai Son of Viet Duc University Hospital said the name of the syndrome/disease needs to be accurate because it is also closely related to insurance benefits and treatment regimens. A term like “intersex” is just a common name in the community and is not used in healthcare.

DSD is not rare but is rarely reported or recorded in Vietnam. Through interviews, doctors said that normally, 1 case out of 4,000 - 4,500 people was born with an uncommon sex characteristic. However, due to the sensitive nature of this condition, many people do not go to medical facilities for examination and official diagnosis. This gap is partly due to patients' reluctance to seek medical help and disclose their condition, and partly due to difficulties in diagnosis and treatment, especially in small provinces and cities, where the understanding of specialized healthcare professionals about DSD cases is still limited (T.T.N.Anh, 2022). In particular, many medical facilities lack specialized doctors and necessary technical equipment for in-depth diagnosis such as chromosome analysis, urine steroid quantification, analysis of gene mutations causing DSD (T.T.N. Anh, 2022). Meanwhile, treatment of DSD requires a multidisciplinary approach involving pediatrics, endocrinology, surgery, gynecology, urology, and psychology (H.T.T.Yen, 2019).

Although it is a complex medical issue, there are still significant knowledge gaps in the health system regarding health care for intersex people, especially in the Vietnamese context. Medical experts interviewed said that during the training of general practitioners, knowledge about the diseases and syndromes of DSD is not widespread. Dr. Ngo Hai Son affirmed that general practitioners often know very little about these cases because this is not a disease that can be encountered frequently. In many cases, doctors meet the patient first, then look up in different literature, leading to a low probability of accurate diagnosis. What is more difficult is that the diseases and syndromes of DSD are very diverse, making it difficult to capture all. In addition, there are very few doctors specializing

in the diseases and syndromes of DSD in Vietnam, making it difficult for patients to know and access when necessary.

Study Findings

The scarcity of official information about intersex syndromes is also the reason why many intersex people feel embarrassed and afraid to access medical services. They even avoid and hide their health status out of fear of being discriminated against. The lack of medical professionals with in-depth knowledge and experience is also the reason why many intersex people have negative experiences during medical examinations and tests.

In 2021, Medical Publishing House released a book named "Androgen Insensitivity Syndrome - Hermaphrodite impersonating male", an in-depth publication about a prominent pathology in DSD variants (T.T.Son, 2021) . This is a research project of the collective of lecturers and students of the Department of Plastic Surgery, Hanoi Medical University for nearly ten years, with the purpose of providing the latest knowledge to support doctors and medical experts in the process of diagnosis and treatment to complex syndromes which require coordination among many different specialties. However, although there is a part about the patients' psychology, the book still focuses heavily on physical characteristics and specialized knowledge.

For cases diagnosed with the development of sex characteristics that do not differentiate between male or female/results in a blend of 'typical male' and 'typical female' characteristics., especially in young children and infants, parents are often advised to choose early surgical intervention to correct the children's physical characteristics to be consistent with male or female appearance. In the article on "Disorders of sexual development in children" (2019), Associate Professor Dr. Hoang Thi Thuy Yen concluded: "Children with sex development disorders need early surgery, preferably between the ages of 1 and 3 years old. Early surgery helps patients and families avoid psychological stress. Patients can live normally in the community and the morphology and function of the genitals are also better" (p.22)

Although this is a popular view of the healthcare sector nationally and internationally, there are also many opposing views, especially from the perspective of children's rights. Experts and doctors also believe that if surgery is performed, medical staff need to monitor the patient from childhood to adulthood (T.T.N.Anh, 2022). In most cases, such interventions are not medically necessary and can have serious negative consequences for intersex children as they grow up. Dr. Ngo Hai Son believes that performing gender affirmation surgery on children is not always necessary, especially when their health and function are not affected by intersex variations. Early surgery can also have many effects on physical development. So, if it is not particularly necessary, it is completely possible to wait until the child is well aware and empowered to decide whether to perform gender-affirming intervention.

In addition, intersex children are also completely capable of integrating into an environment with friends who have clear gender distinctions. However, this means that community awareness of intersex people needs to be raised. The doctor also said that it is necessary to educate and accompany children during this process to ensure that they have good physical and psychological development.

With regards to the psychological health of intersex people, medical experts share that current medical education related to intersex people mainly focuses on the preliminary and physical aspects of the body, and fails to mention emotional, sexual or reproductive

aspects. Doctor Son also shared that at his hospital there is currently no psychologist for intersex people. Normally, surgeons like him will be the ones directly involved in consulting with people who need to clarify or redefine their gender. Dr. Thu shared the opinion that issues such as medical intervention to help transgender and intersex people have happy and fulfilling sexual activities, or current needs and methods of childbirth are not yet recognized in official professional regulations. This shows a lack of resources to care for the mental health of intersex people in Vietnam.

1.3 Social context of intersex people in Vietnam

In Vietnam, the social context surrounding intersex individuals is complex and deeply rooted in cultural, traditional and social norms that have a significant influence on their lives. Intersex people in Vietnam often face the situation of limited knowledge, social stigma and lack of institutional support. Understanding and awareness of intersex conditions among Vietnamese people in general is still limited. The term “intersex” is not widely used. Intersex cases are still often referred to by the phrase “female hermaphrodite impersonating male/male hermaphrodite impersonating female” or “not male, not female”. Although these phrases often carry many prejudices and are pejorative towards people with uncommon sex characteristics, this is still the most common name of intersex people in Vietnam.

In recent years, information about intersex people and other conditions of gender development differences has come into being more and more. In addition to the book "Androgen Insensitivity Syndrome - Hermaphrodite impersonating male" published by Medical Publishing House in 2021, there are more and more articles and websites about DSD or cases of gender affirming surgery in Vietnam. At the same time, advocate groups working for the rights of intersex people are gradually appearing in Vietnam and focusing their efforts on raising awareness and providing support services to the community. These groups aim to educate public servants, health care providers, and policymakers about the nature and characteristics of intersex people, as well as advocate for the rights and well-being of these individuals in the community. However, social activity groups dedicated to intersex people in Vietnam such as Intersex Vietnam or Intersex Asia do not have a high presence and recognition with limited operations, so they have not been able to make a great impact on society.

The social context in Vietnam poses unique challenges for intersex individuals, characterized by a lack of awareness, cultural and social stigma, and limited legal and health care support. While there are movements towards greater understanding and acceptance, there is still much work to be done to ensure that intersex people in Vietnam can live with dignity, respect and equal rights. This includes advocating for policy changes, improving health care practices, and promoting a more educated and inclusive society.

In addition, in most cases of conducting research or social activities for LGBTIQ+ groups, intersex people are often overshadowed, or placed behind other gender and sexual minority groups. The lack of accurate and comprehensive insights and education about intersex syndromes contributes to a society where intersex individuals may have difficulty finding their voice and identity.

To date, no social research delves into the experiences of intersex people. This study, conducted by the Institute for Studies of Society, Economy and Environment (iSEE), is considered the first preliminary research in Vietnam that focuses on the life and health experiences of intersex people living in Vietnam.

2. Experiences of intersex people in Vietnam

2.1 The process of self-discovery

2.1.1 Be aware of the "difference"

Analysis of interviews with intersex people reveals a complex and challenging journey of self-discovery. This process not only involves confusion about physical problems, facing many barriers in accessing medical services, receiving a diagnosis, and psychological struggles in understanding self-identity.

Of the six people interviewed, five were intersex people whose physical appearance and legal gender were female. Most of them mention the absence of menstruation as a clear sign of physiological differences. This often leads to anxiety and confusion not only for themselves but also for their families. A delay or complete absence of menstruation makes them and their families aware that there is a problem that requires medical help.

> *Well, that was around the tenth grade. Because other girls had periods, they had monthly menstruation, but I didn't. My family was also worried why I didn't, so we went to see the doctor. (Trang)*

> *I haven't had my period since high school. Still having puberty but no menstruation. I went to the Hanoi Obstetrics Hospital, but the doctor couldn't find the cause. (Hoa)*

> *At that time, I still had normal periods, but as I got older, my cycle became longer and longer. (Nguyên)*

In addition to not having menstruation, interview participants also described a deep feeling of being "different" from an early age. This awareness came not only from physiological issues but also from differences in genitalia compared to peers, causing many unnamed questions and fears about oneself. The lack of information and understanding about their condition led to confusion and not knowing who to turn to.

> *Growing up I didn't know anything, because at home I was raised as a boy. It wasn't until middle or high school that I realized why my genitals were different. That thing was very small. (Phương)*

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Actually, for me, from childhood to adulthood, I always knew that something was not right, [...] from childhood to adulthood, I never had a period. (Mai)

I wonder why men were like this, women were like this and why was I different, not like people talk about. (Minh Anh)

Actually, I still know that there was something very, very different about me. But I never really put my mind to finding out, but until I knew the results, I didn't think it was that terrible. (Hoa)

Phuong, a research participant, described the process of self-discovery, from identifying as a transgender (male to female), to her first menstruation in her life and the surprise when having a new understanding of herself.

For one I thought I was a transgender, but when I had sex for the first time, I was around 25 years old and I had been using hormones for about a year, then it was my first period. I was totally surprised; I didn't know anything. (Phương)

Phuong's experience highlights the complexity of intersex people's self-identity. Many intersex people feel uninformed and have no one to ask or provide guidance about their condition. All of the interview participants had never heard or had any awareness about "intersex" or why they had different bodies and development than the majority of their peers. This increases the feeling of isolation and difference. In addition, the lack of information also makes them feel lost and have nowhere to turn for help.

[...] While I was growing up, I felt that I had different genitals from men and women, that is, different from other children of my age, so I was confused and didn't know who to ask.[...] I didn't know what I was eventually, so I kept holding that fear until I grew up, not knowing who to tell, not knowing how to explain myself, I didn't dare to face it, so I was just so confused. (Minh Anh)

It was horrible, at that time I was in a state where I didn't know what was wrong with me, and the people who should have known what was wrong with me didn't know anything, I was very worried. (Mai)

[...] I also often had the feeling that I was different, no one told me anything, no one guided me. (Phương)

2.1.2 Medical diagnosis

The experience of diagnosis and use of medical services of intersex people in Vietnam, specifically of individuals participating in the study, is somewhat negative and still faces many difficulties. Firstly, interview participants described uncomfortable experiences of going to the doctor due to scrutiny or not having a medical facility they could trust. Nguyen and Minh Anh shared about feeling embarrassed about seeking medical help, reflecting the lack of comfort and shyness that many other intersex people feel when seeking medical care.

I went to the department to check up for women. When I went in, I was a bit shy. I still had to go in because it seemed unusual. I also considered that it could be related to many diseases. After the examination and ultrasound, the doctor asked me some questions. Then she said that it was normal, because the amount of androgen I produced was too much compared to the normal female body, so it caused a longer menstruation period. Now it just stopped. (Nguyên)

I didn't go, I didn't dare to go at all, I was afraid, I didn't know which establishment was reputable, safe, reputable, secure and had everything for me to go there, I was afraid, I knew I was different. (Minh Anh)

Some study participants shared negative medical experiences, including being treated like "foreign subjects" and difficulties stemming from inexperience and from doctors. This not only causes a lot of physical pain but also mental pain for intersex people.

[...] Looking at my test report at Tu Du hospital, I saw that I had XY chromosomes [...] at that time the doctor called it hermaphrodite, not intersex. (Trang)

Back then it was very traumatic because those people didn't know anything about this syndrome. They still think I had a hymen, it's just that my hymen was too thick to be punctured. Do you know what they did? They stabbed me and the problem was that it wasn't a hymen but human flesh. It was hurtful. I ended up getting inflammation because people kept stabbing at it. They took a cotton swab and then stabbed it into the urethra. (Hoa)

When I went for a checkup, the doctor didn't believe I was a man. The doctor kept adjusting my bones and wondering if I was a woman. [...] What's important was their attitude, their understanding of the subject, not just that every time I went for a checkup, I felt very shy. I didn't want to get examined either. Like I said earlier, when going to the doctor, I was touched and touched like that, I really hated being touched, so I even thought about leaving, because I felt like I was a strange creature, I wasn't normal, people were doing the same thing to me, so I felt very frustrated with those experiences. (Phương)

Not only that, the problem of misdiagnosis and lack of understanding of medical professionals about intersex bodies was also depicted through painful and inaccurate medical experiences of most participants. Due to the lack of specialized facilities, the process of diagnosing intersex individuals is often lengthy and causes a lot of confusion. Except for those who had not gone to the doctor, all interview participants had to go to many different medical facilities over a period of several years to get a suitable diagnosis.

I went to private hospitals, clinics and public hospitals. In general, I went to many places but had no results. (Mai)

This time I was examined at the endocrine hospital because my mother thought my disease was due to endocrine. After check-up at the endocrine hospital, I was transferred to the central obstetric hospital. After I went to the central obstetric hospital, they gave me birth control pills to stimulate menstruation, but after taking it, it still wouldn't come out. So, they sent me back to the endocrine hospital. [...] I also went to see 3 more doctors at different obstetric hospitals. Back then it was very traumatic because those people didn't know anything about this syndrome. (Hoa)

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I went to the doctor and couldn't find anything because I thought it was probably a different level of testing, but I noticed when I did the hormone test that the amount of male hormone was not very different from women. (Phương)

Cases that have received a diagnosis commented that going to the doctor many times caused fatigue due to having to go from place to place looking for an accurate diagnosis. The issue of expensive treatment and diagnostic tests also caused financial difficulties and affected the interview participants' decision to pursue treatment.

The doctor told me that if I wanted to recover, I had to take this medicine, which cost VND 1,500,000 for each pill. And I had to take it within a few months.[...] I didn't buy the medicine because it was too expensive. (Hoa)

[...] when people didn't know what was wrong with me, of course they kept forcing me to do all sorts of things, so we ended up spending a lot of money. (Mai)

In addition, Hoa and Mai also emphasized the need to contact doctors or experts who did research on intersex cases to get a quick and accurate diagnosis. However, that means they must also be aware of the fact that they are intersex, or have intersex syndromes, to proactively seek out information and contact doctors and specialists.

I think it's also fortunate that my family also had good relationships with quite good doctors, because I think without the relationship, the journey to find the correct answer would have been very long or the answer may not be found at all. (Mai)

When I arrived, he looked at me and I told him about the syndrome, and he knew it. It's like I spent a decade looking for the right person and found him. It's true that if you have a difficult illness, you have to go to the right person or place. As for the central obstetrics hospital, they are also exposed to normal cases. (Hoa)

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Despite these difficulties, study participants still expressed a strong desire to learn more about their health status even though the lack of information and professional support caused many obstacles for this process.

> *I also want to have a health check-up to know clearly what my situation is, what is the reason. I mean I want to clarify the situation to relieve the burden in my heart, which means I also want to go for a health check-up once. (Minh Anh)*

Interviews with intersex people show that, in the Vietnamese medical context, intersex people face many challenges in accessing health services. From shyness, misdiagnosis and lack of understanding by medical professionals, to negative and haunting experiences, all of them make it difficult and affect their healthcare. This highlights the importance of improving awareness, training and provision of appropriate medical care for the intersex community.

2.1.3 Looking for information

Along with the confusion of feeling "different", receiving a diagnosis from a doctor does not help intersex people understand more about their bodies. Individuals participating in the study cited many difficulties ranging from access to information, lack of official sources, to inconsistencies in different sources and lack of support and explanation from medical specialists.

Participants also mentioned feeling surprised and confused when going to the doctor. Uncertainty from medical professionals or the necessity of waiting for results motivates them to search for more specific answers and explanations via the Internet.

> *When the results came out, I was so shocked that I just didn't understand, so I did some research on my own [...] I saw that the doctor said there were no details [about the orchiectomy surgery] so I didn't have enough evidence, I wanted to learn more about that. (Trang)*

> *I also came back and automatically searched for the symptoms I had, before the doctor had the final answer, I already knew what I was, just not for sure. (Mai)*

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Trang and Mai mentioned a lack of information from doctors, which forced them to search on the Internet themselves. The lack of information from professionals increases the difficulty in self-learning and learning about their health conditions. Trang also reflects the contradiction between online information and doctors' advice, causing confusion and not knowing which source of information to believe. This partly reflects the lack of official/legit information sources and competent experts in medical activities related to intersex people.

[...] I looked it up online first, then I went to see the doctor again to talk about that problem, and the doctor said that based on his evaluation, I should remove my genitals as soon as possible, it's like holding a timed bomb which can blow at any time. But on the internet, some say that it still releases hormones. So, if I removed it, it might cause my health to not be as good as before. (Trang)

In addition, all study participants mentioned having to read, access information sources, or join groups in English. They expressed difficulty in finding information in Vietnamese, and in some cases had to rely on a translator.

Another limitation is that when I actually did research online, there was no information in Vietnamese at all. (Mai)

Online social networking and forums that most interview participants mentioned included Quora, Reddit, and Facebook. Minh Anh attended an offline event of LGBTIQ+ groups and directly asked about intersex people.

I looked for (a group of people with similar physical conditions) but couldn't find it. I also asked on the forums, then even created a group myself but there was no information, and no one participated. In the end, I found a MRKH group, but globally, not in Vietnam. (Hoa)

From Wikipedia, I knew the name of that syndrome, so I looked for a group chat on Facebook, a private community chat group, then I realized it was the one I was in. I read a few things that everyone shared in that group, and I saw that everyone was in the same situation as me. (Trang)

In 2020, I saw an article on Quora with the translation, I didn't know, but they said that intersex people have characteristics like this and that. (Minh Anh)

All interviewees commented that finding people with similar experiences helped them feel less alone and less confused. The process of self-discovery and hearing the sharing of people in similar situations also helps them expand their thoughts and awareness about intersex issues in general, and self-identity in particular.

I also went there [to an LGBTIQ+ intersex group event] and then I realized that these people really existed, and then I got to talk to people who had information about intersex, at that time I felt somewhat comforted, there were people who knew about it rather than me being completely in the dark, something like that. (Minh Anh)

When I had more contact with the community, my thoughts became more open, and I felt that my health and awareness were also much better than before. (Phương)

However, information coming from the community is not enough. Nguyen, a study participant, described difficulty finding information for self-identity.

Actually, I think it's limited or I haven't learned much yet. I've done some research, but there are so many types of intersex, it probably makes it difficult for people to determine which type they are. As I mentioned, when I say intersex, people think there are two genitals. It's very annoying to hear that because in reality I'm not like that [...] But it is very rare to find an expert to help. You can only ask within the community, but not everyone in the community is an expert. (Nguyên)

Information about intersex in Vietnam is limited and there are many prejudices, causing many barriers in self-identity for affected people. While the community can provide a valuable source of information and empathy, a lack of expertise can limit the ability to provide comprehensive and accurate support to those affected.

2.1.4 Psychological burden and self-acceptance

After overcoming the obstacles of diagnosis and self-identity, interview participants also described a complex process of accepting that they are people with intersex characteristics, or confusion and psychological difficulty in self-recognition.

Many people express shock and disbelief when they first learn about their physical condition. Facing new information and lack of knowledge, it is understandable that intersex people react with surprise and denial.

> *I don't remember but at first, I didn't believe it. I also went to see 3 more doctors at different obstetric hospitals. (Hoa)*

> *At that time, I didn't realize who I was at all, I was just myself, I was just running away from myself. I didn't know who I was, and then I looked for it and couldn't find it, so I just ran away, isolated myself to feel safe, so I let it go, denied everything, denied all reality. (Minh Anh)*

After the initial shock comes confusion and worry about health, the future, and the ability to build relationships. Because they had no one to share with, almost all interviewees were confused about what kind of life they would have or what their future would be like. Additionally, infertility is always a concern, regardless of whether they wanted children at the time or not. They believed that their inability to have children and being intersex would somehow be a huge obstacle in their life experience.

> *I was confused, my mentality at that time was very unstable like I didn't know what the future would be like if I were like that. (Trang)*

> *I couldn’t have children and I couldn’t have sex. I don't have a vagina, nothing. I cried, tears streaming down my face. The information came to me so fast, I felt like the whole sky was falling on my head. (Hoa)*

At that time, I understood the reason, but I felt that I was having emotional difficulties not from the issue itself, not from the infertility factor of being intersex. It's just more like me, didn't know how to live my life from now on. I didn't know and I haven't decided whether I should perform a surgery or not, or I was worried that in a decade or two, at the end there will be any health malfunction. It would be difficult for me to find a partner in the future. Many things, but not anything specific. (Mai)

However, interviewees also emphasized the importance of time and maturity. The moment of discovering a "difference" is a sensitive and difficult moment for any individual. By finding support and connecting with people in similar situations, intersex people can open up and gradually accept themselves. Overcoming traditional views on gender or the need to get married and have children, many interviewees expressed finding joy and happiness in other aspects of life.

It's a bit like when I was young I was growing up, I was scared, very scared, at that time I didn't even know myself, so I was very scared, but when I grew up it was over, I accepted myself. (Minh Anh)

I'm not male or female, I just think I'm me. (Phương)

Well, at first I felt sad, but later I felt a little lucky because I knew early, so even though the first few years of finding out in high school, it was a bit of a crisis, but at least I knew the issue, now I'm better, the way I see it is that I have many choices, I can choose to get married or not. Then if I meet someone who understands me, I can still move forward. I don't have to bind myself that I have to live alone like this for the rest of my life or something. I have other joys that are not just that. (Trang)

The process of self-acceptance is a complex and personal journey, sometimes fraught with difficulties and challenges. Every intersex person has unique experiences and a unique approach to accepting and understanding themselves. This long and strenuous process is also a huge challenge and can be part of a negative impact on the lives and experiences of intersex people.

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2.2 Relationship with family

Relationships with family members are also an important part of the lives and experiences of intersex people. Coming out to family or family reactions to intersex individuals reflects the complexity of navigating the research participant's intersex experience.

In addition to facing internal psychological problems, intersex people also face pressure to disclose their medical conditions to relatives and family. Phuong and Minh Anh mentioned not coming out to their families due to society's and their own parents' prejudices against things that do not match traditional social standards in Vietnam.

> *[...] I didn't dare to tell my mother because she lived in the countryside, so I was afraid that people would judge my mother, like I was born abnormal. That is, my genitals were different from men's and women's since I was born, so I didn't want to mention this again. I was afraid that people would look at my mother as a woman who gave birth to an abnormal child. It's like having an abortion, something like that. I didn't want that to happen again [...] I was also afraid that my mother would feel guilty about that. (Minh Anh)*

> *Well, because she didn't actually know, she would consider it a disease, because in the past there were diseases that were gender disorders that needed to be treated, so she wouldn't understand, she only knew it is male, female or gay? (Phương)*

Partly Minh Anh is also worried that the mother may feel guilty or responsible for her condition. In Hoa and Mai's case, after coming out, they noticed that their mother showed signs of self-blame. Hoa commented that her mother refused to believe and accept that she did not have a vagina, even after coming to take care of her post-surgery, partly reflected her mother's denial of giving birth to an "imperfect" child.

> *My mother thought it was my paternal family, my aunts also had puberty late, but still gave birth to five or six children. Well. So, my mother kept thinking like that and never let anyone touch me because she thought that if someone touched me, it would be like something else. [...] My mother didn't believe it, so she didn't do much and I had to do it all myself [...] By the time I had the surgery, my mother still didn't believe it. (Hoa)*

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She was sad, then she blamed herself, then said that when she was pregnant, she was sad and that, so now I am like that. (Mai)

In addition, the fact that family members consider intersex as a genetic disease also makes intersex people feel more inferiority complex and sad.

What about my sister? She didn't know, she didn't comfort me. But she understood. She didn't want to have a baby because of those genetic reasons. My mother wanted her to, and so did me. But one time I overheard my sister told my mother that if the baby was like me, it would be miserable for her. I thought, "Am I really miserable? so I try to live. (Trang)

Of those interviewed, half had no intention of disclosing to their families that they were intersex. They came out as transgender because the concept was somewhat more familiar to their families.

Up until now my parents still don't know, they just thought I was a transgender when I finished surgery and when I came back there, it was like my mom really loved me and took care of me, cooked for me, at that time I didn't have to work anymore, and even now my mother still seems to have started to see me as myself, which is also lucky, only my relatives didn't accept me. (Phương)

Actually, my family is very traditional and does not like the LGBT community. At that time, I also came out to my family in panic and anger. My family was meeting together and arguing passionately. At that time, I was so upset that I said it out loud. I said I am a transgender man. My family didn't say anything. (Nguyên)

In addition to the lack of information about intersex making it difficult to share, some research participants also had the opinion that this is a sensitive and secret matter that is difficult to share.

Because my mother and I don't talk, I don't talk to her much. I don't know if my mother knew about my irregular menstruation, but I can't talk about that sensitive issue with my parents. Only my sisters knew. My sisters knew a little because I'm also a traditional person. I don't talk about those things. (Nguyên)

2.2

However, the remaining half of the participants felt it was important to let their mothers know about their condition, to receive help and support from their families during the lengthy check-up and share about life problems.

> *In 2019, I decided to go on my own without telling my family. I felt like this was getting a bit out of my control, so I went home and told my mom. (Mai)*

> *I couldn't work something like this alone, and my mother gave birth to me, I couldn't keep her out of this, she deserved to know, then I started by asking her to come in. Generally speaking, in fact, when talking about the discovery of the intersex condition, it's not just a journey of that person, but also the journeys of so-called family members around. (Mai)*

> *My mother is always strong, so she just comforted me and stayed by my side. Sometimes it's like when we confided night, then when I cried, she said it's okay, it'll be okay later. I could stay with her forever. She didn't seem sad or anything, but like now when I look back at that time, in my tenth grade, there was a picture of my mom at that time, and she didn't look as happy as she does now. (Trang)*

Faced with many challenges, intersex people make diverse choices of openness with their families. This is also a complex part of the self-discovery process of intersex people, reflecting the diversity and multidimensionality of personal experiences and the special culture and social context of Vietnam.

2.3 Social relationships

Based on the above quotes, intersex people's relationships with those around them in Vietnam reflect a complex and diverse journey. In a social environment where gender issues and differences still have many barriers and misunderstandings, intersex people often face feelings of isolation, not being understood or accepted.

Some study participants shared that they felt unable to enter into a romantic relationship due to fear of not being able to have children and the related social consequences. This not only affects their ability to create meaningful relationships but also creates heavy psychological pressure, making them feel not confident and strong enough in pursuing personal happiness.

> *[...] my teacher also said that the most unfortunate thing is infertility, I felt that it might be sad, but I didn't think that in the future it could be a barrier when I wanted to have a romantic relationship. But when I liked someone, I didn't dare to move forward. I gradually got used to it. (Trang)*

> *[...] there are also a few people who seem to care about me and also want to enter into a relationship, so I always tell them before starting a relationship that I am an intersex. (Phương)*

Meanwhile, despite being open about their intersex status to others and being open and frank about their status with others, in many cases, research participants still felt not understood and sympathized. In some cases, the reactions of those around them, even though they are not discriminated against, make them feel that their personal pain and challenges are being overlooked.

> *[...] I had a bad experience with a few trans men in the community where we often hang out together and talk, I told them that I was intersex, so I thought that would make sense, and they would understand. But then they said oh that was so cool, that I could have the right to change my gender and change my name. What's that, my despair is everyone's wish. (Minh Anh)*

One time I also shared these things with two other subjects, and they were also open. They say it's all right, then I can adopt a child. But they talked like a child and were too hasty, so I don't feel secure.[...] I wanted them to be aware of the seriousness of the problem and not be so dismissive. They need to think first. But when they said it's ok, it made me feel like it's not a problem. (Hoa)

Therefore, the need to have an intersex community to share and support each other is important to all interviewees. They expressed their desire to have a community where they could find sympathy and understanding. Such a community not only provides comfort but also helps them not feel alone in their journey.

I want to have that community, to know I'm not the only one. When I know that my case is not so rare, I feel much more comforted. In my case, most of them are normal, but there is only one problem. I'm very confused, especially about having children. Like you can try, but probably succeed. It's not exactly 100% infertility. If there were a group of people sharing their experiences of trying to give birth or adopting children, we would have more confidence when making those choices. (Hoa)

[...] Because in Vietnam there is not much of a movement, not much of a community, I also have a dream and did talk to a few intersex people, so there are also connections. But it doesn't exist in Vietnam yet. If there was one, then surely in general we would always want to have a community. (Mai)

[...] There are things that are difficult to talk about and can only be shared in the community, only insiders will understand. As normally people will say what's wrong with this person, so I had to explain from the beginning, which makes me very embarrassed. So, I don't want to share, want to keep it safe, it's good to have a private community to share. (Phương)

Research participants' shares clearly demonstrate the need for openness and mutual understanding in the community. Acceptance and support from those around them can help intersex people feel safe and respected. Building a strong and supportive community is essential to help them overcome challenges and live a fuller and happier life.

2.

2.4 Connect with the LGBTIQ+ community

Most research participants knew about the activities of the LGBTIQ+ movement in Vietnam but did not receive much support from these groups. Furthermore, many people do not see the presence of intersex people in community activities. Nguyen, who identifies as transgender, despite having characteristics on the intersex spectrum, feels he received more care as a transgender person. Phuong had similar experiences. The clinic Phuong used is also friendly and designed for gay and transgender groups.

> *Actually, I haven't seen anything that specializes in intersex. (Minh Anh)*

> *When I was enlightened about the LGBT community, it was a bit too much because I didn't think I was a type, a very special type like that, there was no one in the community. (Phương)*

> *Honestly, I support the LGBT movement, but I doesn't really relate to that group.(Mai)*

> *Most people ask me what my identity is, I will answer transgender male first. If I see that people seem to know about my community, I will talk more about intersex people. Because knowledge about intersex is not yet widespread, no one knows about it. I don't understand it deeply enough to be able to explain it to other people[...] because I rarely know intersex people. No one asked me out, so I forgot about it. I forgot I was intersex (Nguyen)*

In the experience of these research participants, activities for intersex people were very few, limited to posting a few informational articles on websites. Some groups specifically for intersex people such as Intersex Asia or Intersex Vietnam are only sporadically active or almost no longer active. Furthermore, participants also reflected that there are almost no widespread awareness-raising activities about intersex people. Even in the LGBTIQ+ community in Vietnam, the intersex group is still a minority, and there are still many prejudices and a certain lack of understanding within the community itself.

[...] my despair is everyone's wish, oh my gosh, it's all kind of confusing. They are not in my situation, so they don't understand what I have been going through. They only see its benefits and want that benefit. (Minh Anh)

That seems like a prejudice. (Phương)

However, having a community in general also provided many positive experiences for some of the intersex people participating in the study, especially those with a transgender identity. Phuong and Minh Anh are the two people who participate in the most activities of the LGBTIQ+ movement among the participants, and also receive a lot of help from the community.

[...] when I have more contact with the community, my thoughts are more open and I feel that my health and awareness are also much better than before, especially in the past, I wouldn't have a partner [...]. Besides, I can feel like I can monitor my health, so it's better, and I have a lot of advice. The doctor's advice made it better. (Phương)

In fact, intersex people will have a part that is very similar to transgender people, the first is gender confusion, they don't know who they are and what to do, the second is that there will be some transgender, transgirl intersex or transman intersex, because we felt different about our body, so we would like to have our body matched with our feeling about gender, I had to go to trans. They are a place to consult about mental health or connect with other organizations (Minh Anh).

Based on the shared experiences of study participants, it is clear that the intersex community in Vietnam faces unique challenges in finding more extensive presence and support from the LGBTIQ+ movement. Most participants knew about the activities of the LGBTIQ+ movement but felt that existing groups in Vietnam did not have many activities to support or advocate for the rights of intersex people. This highlights a serious gap in the activities of the LGBTIQ+ community in Vietnam. The scarcity of intersex-specific activities or mass mobilization campaigns leads to a widespread lack of awareness, further highlighting this gap. On the other hand, some participants, especially those who identified as transgender, found positive experiences and support within the broader LGBTIQ+ community, which helped them broaden their perspectives and improve their happiness.

Discussions

Study participants shared many similar views, especially regarding the lack of appropriateness and quality of medical care services for intersex people. According to medical experts, there are still major gaps in knowledge about diseases and syndromes of gender development differences. In addition, experts participating in the study also believe that lack of exposure and insufficient training results in the fact that many medical staff do not know how to provide care or cannot provide effective diagnoses and advice to patients with gender sex development differences. Intersex people in the study also expressed hesitation when accessing health care services, or had many negative medical examination experiences due to lack of understanding and sensitivity of medical staff.

Currently, the common approach to cases of children with sex characteristics outside the male-female binary spectrum is still early surgery. There are many reasons given, such as "avoiding psychological stress" or "living normally". However, experts participating in the study also consider that performing unnecessary surgery may have a greater impact on health after adulthood, and requires close monitoring to minimize risk. Furthermore, diagnosing cases of differences in sex development and performing sex-determination surgery in Vietnam is only provided in big hospitals in central cities due to the level of knowledge of specialists. Health care services in small provinces and cities regarding related diseases are still very limited. Interviews with experts and a review of documents, sanctions, and regulations on providing medical and health services for intersex people in Vietnam show that there is a need for an official and updated definition on intersex people and diseases and syndromes of sex development differences, along with reforms in policies. This highlights the urgent need for increased medical awareness and training in Vietnam to ensure that intersex individuals can access and receive consistent and appropriate health care services.

All of the intersex participants in the study mentioned feelings of confusion, anxiety, and stress when discovering they had uncommon sex development characteristics or syndromes. In addition, with regards to family and social relationships, they also shared a lot of hesitation and loneliness when they couldn’t come out. Similar to the findings in international studies on intersex people, the lack of information and understanding about intersex people is one of the main reasons why study participants have many problems accepting their identity and sharing with those around them. The inability to have children is also a reason why many research participants hesitate to enter into or pursue a relationship or think about starting a family.

With family relationships, half of the study participants had the choice to share with their family and somewhat received support. They talked about how family support, especially from the mother, was an important part of their examination, pursuit of a formal diagnosis, or recovery from surgery. In Jones's study (2017) of the relationships between intersex individuals and their families, the fact that family members viewed intersex variants and syndromes as "abnormal" often led to more stressful relationships or caused more trouble for the intersex person. This is also reflected in the findings of this study. Some research participants expressed concerns that their parents blamed themselves for their conditions or that family members did not want to have children because they were afraid of genetic differences in gender development. The fact that intersex bodies are often associated with diseases also causes many psychological problems and sadness for them and their loved ones.

Another important finding in this study is the need for intersex people participating in the study to have a community to share with. They said their feelings of loneliness and confusion were significantly reduced after learning they were not alone and that there

were others going through similar experiences. In particular, they need to learn and refer to the experiences of people who have had gender affirmation surgery, or surgeries related to their syndrome, to be able to make appropriate medical decisions. Partly because medical staff have little experience, or the medical consultation process is not complete, intersex people feel the need to learn about the experiences of similar people.

The experiences shared by participants in the Vietnamese context resonate strongly with findings from recent exploratory studies in Ireland, the Netherlands, Australia and the United States on the challenges that intersex individuals often face. These studies highlight a range of difficulties, including unnecessary medical interventions, delays in diagnosis, chronic health problems, infertility and social stigma. This international perspective, as van Lisdonk (2014) notes, emphasizes a common theme: isolation and lack of support of intersex people is due to the lack of presence and adequate information about their community.

The experiences of research participants show that the context of intersex people in Vietnam also has many similarities with intersex people in the world. The lack of intersex representation in LGBTIQ+ activities and research is a common experience in many places. It may be due to insufficient information, or reasons of sensitivity, shame, hesitation to open up, and also partly due to the diversity and subgrouping within the community of intersex people that intersex people do not often appear in the LGBTIQ+ community movement. However, the lack of activities to support intersex people or activities to raise awareness about intersex people is also the reason why intersex people do not feel the connection between them and the LGBTIQ+ community. As mentioned in the studies of Jones et al (2016), Carpenter (2018), and Monro et al (2021), intersex people often feel ignored or marginalized, not fully recognized or understood by society. This is further complicated by the paucity of scientific literature and research focusing specifically on intersex individuals compared to more extensive research for other minority groups within the LGBTIQ+ community.

This emphasizes the need for increased research, awareness and more inclusive advocacy for the intersex community. This not only aims to address their unique medical and psychological needs but also ensures their representation and inclusion in broader social movements and communities. By doing so, we can work towards a more inclusive approach that fully recognizes and supports the diverse experiences and needs of the intersex community.

Recommendations

Based on the experiences of intersex people participating in the study, and the medical experts interviewed, with the aim of improving life and medical quality for intersex people in Vietnam, the research team proposed some recommendations as follows:

1.

Amending the legal framework and improving support policies for intersex people:

It is necessary to promulgate and enforce laws and policies to protect the rights of intersex people. This includes anti-discrimination laws, policies that ensure the right of body integrity, and the ability to legally identify gender without requiring medical intervention. Decree 88/2008/NDCP needs to be amended to prohibit medically unnecessary surgeries when the child's intersex condition does not affect the child's life or health, and to encourage intersex children to decide their desired gender and body when they turn 18 years old, and at the same time, other policies must be issued to reduce discrimination against intersex children, and address cultural and social prejudices that their parents experience so that intersex children and their families are not pressured to have surgery "as soon as possible". Doctors and psychological consultants need to be provided with updated knowledge and insights. Consider acknowledging “Other” alongside “Male” and “Female” on population database systems.

2.

Enhance medical resources:

Improved training and resources for medical professionals in Vietnam are needed to diagnose and treat intersex cases accurately and empathetically. This includes updating medical education curriculum to fully include intersex variations, ensuring doctors understand the non-binary nature of these conditions, and are well equipped with the tools essential for appropriate diagnosis and care. Although not delved into in this study, medical and surgical intervention on children has been shown to have many serious consequences on both physical and mental health. Many advocate groups on human rights and intersex rights have been recommending avoiding unnecessary surgical procedures aimed at 'normalizing' intersex children unless medically necessary. Patients and their families need comprehensive information and counseling to make informed decisions.

3.

Raising awareness and educating the community:

Raising public awareness about intersex conditions can reduce stigma and misinformation, and to some extent reduce the isolation and anxiety of intersex people. Educational campaigns to inform the public, including school-based programs, should be implemented to promote an inclusive and accepting environment for intersex individuals from an early age.

Recommendations

4. **Build and maintain intersex-specific communities:**

For too long, intersex people have been overlooked in campaigns and activities of the sexual and gender minority community. Establishing and maintaining networks, forums, and community centers dedicated to intersex people and their families is extremely necessary. These will be places where intersex people and their families can come to share experiences, learn information, and access support resources.

5. **Strengthen research on intersex people in Vietnam:**

Encouraging and funding research on specific intersex conditions in the Vietnamese context will provide better insights and data, supporting more effective policy making and health practice.

6. **Cooperate and coordinate resources to ensure rights for intersex people:**

Collaboration between government agencies, health care providers, the intersex community, and human rights organizations can ensure a comprehensive approach to addressing the challenges that intersex individuals face. These partnerships can help develop policy, awareness campaigns and provide needed services.

Implementation of these recommendations requires multi-stakeholder engagement, coordinated efforts, creation of a welcoming and understanding environment, appropriate service delivery, improving quality of physical and mental health for intersex people in Vietnam.

Limitations of the study

This exploratory study was designed and conducted with the desire to learn about medical examination experiences, as well as the family and social relationships of intersex people and the difficulties and challenges they encounter in everyday life. However, due to the nature of this preliminary and exploratory study, we faced a number of difficulties and limitations during implementation, mostly coming from accessing intersex samples. With over 40 incredibly diverse intersex variants currently identified, it is beyond the scope of a qualitative study to seek out and interview intersex people of all variants. Therefore, with 06 intersex people participating in the interview, the information collected and research results are not representative and have generalizable value for all intersex people in Vietnam.

It's noteworthy here that the people with intersex identity that the study accessed also included subjects who self-identified as intersex without an official diagnosis from a doctor. We still integrate this sample into the study because when learning about the response to the health examination and care needs of intersex people at medical facilities, doctors themselves consider that intersex cases are rare and the medical team in Vietnam has not received specialized training to diagnose, treat and intervene for such subjects (if necessary). Therefore, medical diagnosis is not the only standard to determine the intersex status of participants in research, to avoid missing those who have not or do not have the desire to seek medical support and intervention.

Conclusion

With medical understanding of the concept of intersex gradually expanding and developing, this creates space for activities to raise awareness in society about the presence, rights and life in general of intersex people. Although there are still gaps in knowledge and professional understanding in the medical community and in society's general awareness of intersex concepts and people, there are non-profit community associations and groups operating towards the rights of intersex people in the country and the region. However, these organizations are small and do not have high recognition, still in the early stages of internal development and community building.

One of the difficulties in establishing a community group working for the rights of intersex people lies in connecting and building a community, because the characteristic of intersex is perceived by the subject itself as a physical condition, and/or pathology instead of a communally connected identity. Therefore, it will be very difficult to use the pride-based approach model that social organizations have applied for many years to the advocate movement for the rights of LGBTIQ+ people to the intersex groups.

Intersex people still have to face stigma and discrimination in their families and society, with the guilt of having a body that people around them perceive as "abnormal", "deficient" or "incomplete", which creates heavy pressure on the psychology of intersex people, especially when having to share or "come out" about their intersex status with family, relatives, friends, or even doctors and medical staff. They face this problem on their own for a long time or until it affects their health so much that they are forced to seek support, diagnosis and treatment from a medical facility.

Intersex people in need still encounter many difficulties in accessing doctors and specialized examination, diagnosis and health care services. On the other hand, doctors have little specialized training in intersex issues because these are rare cases, and will often treat them reactively, on a case-by-case basis. The shortage of personnel with expertise in the field of intersex leads to the fact that service providers (doctors) and people in need of examination and treatment (intersex people) have not yet met each other.

Gender affirmation intervention for children is still a common practice in Vietnam, but there are waves of opposing views expressed from the perspective of children's rights or within the medical community, as well as there is a shift towards avoiding intervention if the intersex condition does not affect the child's development and life. In addition, the lack of mental health care for intersex people is also a concern, as this topic is still viewed almost exclusively from a medical and surgical perspective. In general, more qualitative and quantitative research is needed, with a multidisciplinary approach, not limited to the medical field, to better understand the life experiences and difficulties and challenges that intersex people face.

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