



Enduring uncertainties. Medical accounts on caring for young people with variations of sex characteristics

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ABSTRACT

Objectives: The diagnosis of intersex or variations of sex characteristics (VSC) often has a big impact on families who fear social stigmatization. Research has shown that intersex populations often experience important health disparities and that poor mental health and daily function are common among youth with VSC. The present study aimed to explore what healthcare professionals of adolescents and young adults (AYA) with VSC find important in terms of care to this group of patients.

Methods: Semi-structured interviews were conducted with Swiss healthcare providers involved in the care of youth born with an intersex variation. The qualitative data were analyzed using reflexive thematic analysis.

Results: Analysis resulted in six major themes: (1) With regard to patients' and families lived experiences, interviewees reported that fertility was as a major issue for parents but not for intersex youth as they were said to live in the moment. (2) Respondents considered various forms of psycho-social care (professional support, peer support and informal support from family and friends) to be of fundamental importance for their patients, but many of them seemed critical about support from advocacy groups and activists. All healthcare providers reported significant gaps in (3) the transition process and (4) the establishment of multidisciplinary care teams due to structural, provider- and patient-related barriers. (5) Participants were in favor of a more holistic and patient-centred care approach and (6) were critical about the medicalized use of DSD (disorder of sex development) with patients and families.

Conclusion: These findings suggest that although clinicians work hard to implement a holistic approach to care, their intentions are often undercut by a desire to hold a position of medical control. Healthcare professionals need to come to see medical uncertainty not only as a threat but also as an opportunity.

1. Introduction

Individuals born with variations of sex characteristics (VSC) are persons in whom the development of chromosomal, gonadal or anatomical sex does not match the binary male-female model [1]. Since the Chicago Consensus Statement of 2006 [1] the diagnostic term for these conditions is DSD, which stands for disorders of sex development. The acronym, although widely adopted by health professionals [2,3] has been met with criticism by affected persons, parents and support groups who consider the first part of the abbreviation – disorders – as deeply problematic and stigmatizing and prefer to use terms such as intersex, VSC, differences of sex development, refer to diagnostic categories (e.g. CAH, CAIS etc.) or rely on more descriptive terms of how bodies work or look like [4–7].

According to Belgian gynecologist Petra De Sutter [8], word choice is not a trivial matter, but has a significant impact upon reality. That

terminology might influence medical decision-making and care is testified by the study of Streuli and colleagues [9] which shows that parental decisions regarding early genital cosmetic surgeries are greatly influenced by the type of counseling – medicalized or de-medicalized – families receive from medical providers. Likewise, the findings of the study by Johnson and colleagues [4] suggest that care providers' use of the DSD nomenclature might negatively affect intersex persons' healthcare utilization and participation in research. Similarly, the mixed methods study of Callens et al. [10] demonstrates how important it is for healthcare providers to use a shame-free vocabulary about sex, bodily variation and pleasure in order to improve the sexual wellbeing of intersex youth.

The 2006 DSD consensus statement (and in its update of 2016) and its discussions on language and terminology were closely connected to those on medical management and care [1,11]. In fact, apart from the introduction of the broad term DSD, the major recommendations of the consensus included

Abbreviations: AYA, adolescents and young adults; DSD, disorder (or difference) of sex development; HCP, healthcare professional(s); MDT, multidisciplinary team; VSC, variation of sex characteristics.

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(1) the deferral of cosmetic procedures until the age of informed consent, (2) open and ongoing communication with families, (3) shared decision-making and (4) long-term multidisciplinary care, including psycho-social support for both patients and parents. Despite this *ideal* of good medical care, the question remains to what extent this new medical narrative has been put into practice. Existing empirical evidence shows that in most countries the medical community has been rather hesitant to institute full deferral of elective surgeries because it is believed to challenge parents decision-making power [12–14]. For this reason, advocacy groups argue that the consensus statement has failed to defend intersex persons' right to physical integrity and self-determination. Despite important human rights advances, the main focus still lies on reaching the correct diagnosis to reduce uncertainty about optimal treatment rather than in protecting being intersex as a human variation of sexed embodiment [15]. There remains thus a huge gap between the rhetoric of change and actual clinical practice [16]. Furthermore, regardless of the focus on patient involvement and individualization of care, medical practices continue to be parent-rather than patient-centered [17] and the implementation of functional multidisciplinary teams remains difficult [18]. Finally, despite increasing calls for adequate counselling, there is still much room for improvement both in terms of the quantity (i.e. availability) and quality (i.e. experts) of sustained psycho-social support for both patients and their families throughout the life-course [19,20].

The diagnosis of VSC often has a big impact on families who fear negative reactions and social stigmatization. Research has further shown that intersex populations often experience important health disparities and that poor mental health and daily function are common among youth with VSC [21]. Holistic support is of prime importance to foster self-acceptance and empowerment, especially during adolescence and young adulthood due to crucial physical, cognitive and emotional changes that characterize this developmental period. However, within the context of VSC, most support services are targeted towards parents of intersex children with the result that the needs of adolescents and adults are often overlooked [22].

The present article aims to contribute to the improvement of support services for adolescents and young adults (AYA), aged 15–29, with VSC in Switzerland. Under influence of The National Advisory Commission on Bio-medical Ethics (NCE 2012) and activist organizations (e.g. InterAction and Zwischengeschlecht, Swiss healthcare professionals seem to be more supportive of non-interventionist pathways but currently no specific clinical or legal guidelines exist to prohibit irreversible and unnecessary medical treatments [23].

An important step towards the sustainable development of holistic care for intersex youth consists in taking into account the viewpoint of both patients and providers in order to meet their needs, values and preferences and overcome potential differences in expectations. Here we focus on healthcare professionals, data on the perspective of AYA with VSC have been published elsewhere [24]. Particularly, we aimed to explore healthcare providers' (1) awareness of AYA's support needs, (2) their attitudes towards available (professional and informal) support models, (3) their beliefs regarding barriers to implement holistic care, as well as (4) their recommendations for improvement. To our knowledge, our paper reports the first findings from qualitative HCP interviews in the Swiss healthcare setting on this topic.

2. Theoretical framework

In line with standpoint epistemology [25], this study will take into account the researcher's positionality and its impact on the research topic, the research participants and the overall research process. Both authors are intersex allies, but do not identify as intersex themselves. The last author has a background in philosophy and bioethics but has a no medical expertise. The first author possesses a strong scientific and medical literacy, but does not yet hold a leading position in a medical institution. Hence, both authors are, to a certain extent, outsiders to the medical establishment. Still, the interview study was set up in the conviction that young intersex adults' quality of care and wellbeing can only be improved by fostering

an interdisciplinary dialogue between scholars in the humanities and professionals in the field of medicine.

3. Methods

The findings for this paper come from a larger qualitative study that aimed to gain data on what different stakeholders consider important regarding care of AYA with VSC. For this overall study HCPs, parents and intersex youth were interviewed. The three participant groups were not correlated per set because participating parents and healthcare providers were not necessarily the parents or treating physicians of the recruited AYA. Moreover, we were mainly interested in stakeholders' personal experiences and attitudes rather than in establishing what "really" happened in caregiving relationships.

3.1. Participant selection and recruitment

Participant selection was based on HCPs' involvement in the care for adolescents and young adults (aged 15 and 29) with variations of sex characteristics in Switzerland. No restriction was placed on the type of specialization (e.g. endocrinology, urology, surgery, gynaecology etc.) or on participants' nationality. Candidates were identified based on their affiliation with the Swiss working group on DSD, by browsing the professional pages of teams in DSD relevant departments of major Swiss university hospitals and through snowballing. Eligible candidates were contacted individually via email by the research team. As this is a qualitative study, no representative or randomly selected samples were pursued since that is neither necessary nor appropriate.

3.2. Ethics approval

A clarification of responsibility (jurisdictional inquiry) was submitted to the leading ethics committee which stated that the research project falls outside the scope of the Swiss Human Research Act given that no medical data were collected, but that the project fulfils the general ethical and scientific standards for research with humans.

3.3. Data collection

A semi-structured interview guide was developed based on a close review of the literature and on discussions with stakeholders from the 3 groups. To verify the adequacy of the interview guide, a pilot interview was conducted which resulted in some minor adjustments. Questions focused on the common concerns of families and young persons across the life cycle (as perceived by HCPs), on existing support services for youth, on the challenges that healthcare professionals face when caring for intersex youth and their families, on societal views of intersex and on conceptual issues with regard to terminology.

The interviews took place in Switzerland between November 2018 and May 2019. A few days before the interview took place, a study information sheet was sent to the participants. Before the start of the actual interview, the overall purpose of the study was explained once more and remaining questions were addressed. Participants were also asked about their preferred terminology (e.g. DSD, variations of sex characteristics, intersex etc.). All subsequent questions were customized based on this response.

The interviews were conducted by the last author, a senior researcher in bioethics with a solid experience in qualitative research. Before the start of the interviews, written informed consent was provided. The interviews lasted between 45 and 80 minutes. Except for one, all interviews were conducted in person.

3.4. Data analysis

The interviews were recorded upon consent and transcribed verbatim for the qualitative analysis of the text. After accuracy check, the transcripts were transferred into the qualitative analysis software MAXQDA to support data analysis in a structured way. Reflexive thematic analysis [26] was chosen

to analyze the empirical data and to find patterns across the dataset. In a first step, transcripts were read several times to encourage data familiarization. Then, the two authors coded the data based on a close line-by-line analysis and examined the codes to identify potential themes. In order to reflect on the data and to make sure that nothing had been overlooked, in a next step, the two team members refined their respective categories and provisional themes by discussing and checking them against the dataset. When needed, sub-themes were added and similar ones were combined. In the last step of the analysis, clear definitions and names for each theme were generated.

4. Results

The semi-structured interviews were conducted with five healthcare professionals (HCPs), including three endocrinologists, one paediatric surgeon and one urologist (who is also a surgeon). All participants are involved in the care of AYA with a VSC. Most of them work in university hospitals. Only one provider worked in the adult healthcare sector.

Analysis of the interviews resulted in six major themes: (1) AYA's and parents' lived experience as perceived by HCPs; (2) the importance of psycho-social care; (3) lost in transition; (4) interdisciplinarity, still a long way to go; (5) towards a new care paradigm? (6) What's in a name: HCPs' view on conceptual issues (See Tables 1–6).

4.1. AYA's and parents' lived experience as perceived by healthcare professionals

Although parents were believed to be worried about how to disclose their child's diagnosis to people in their surroundings, according to HCPs, parents' main concerns regard their child's future psycho-social and physical well-being. All participants argued that the risk of infertility is an important source of distress for most parents, often already at an early age. [1.1] Unlike for parents, physicians don't perceive fertility to be a major point of concern for AYA. They seemed to attribute this to AYA's focus on "living in the moment". [1.2] When probed about AYA's questions and concerns about sexuality and relationships, opinions differed among HCPs. Some reported that regarding these topics, AYA with VSC are not that different from other AYA. Another physician stressed the importance of asking very specific questions to AYA and reported differences in sexual satisfaction among youth with VSC. [1.3]

Many participants argued that, like for other AYA, "not being different or special" is a central issue for many of their patients. Adolescence and young adulthood were said to be challenging transition moments for youth in general, but HCPs believed that these challenges are often amplified for AYA with VSC due to their perceived bodily difference. [1.4]

Table 1

Lived experience of AYA and their parents as perceived by HCPs.

1 Lived experience of parents
Physician 4: They don't want the child to be stigmatized by society (...) "How can I deal with the people that take care of my child and the naps and without saying anything?" The family, aunts, grandparents (...)
Physician 1: B: The main concerns are associated with psychosocial development: "will they be able to have a partner, a family, yeah, how will their life be changed by this diagnosis?"
Physician 5: The most concerning question is always fertility (...) Even if the child is 2 or 3 years old I have to talk about fertility (...) Next, growing is a quite important subject.
2 Lived experience of AYA
Physician 2: the question of fertility by the patients does not come up (...) we speak about fertility when they're about ten, twelve years old, but they really do not get it (...) It's not something that they're very much interested in when they're adolescent. Maybe because they have other problems.
Physician 4: children think in the moment and then if you tell them we can arrange this (...) then for the moment it's okay. As I said, it's not fertility which is a big thing, even for a 13-year-old girl fertility is far away.
3 AYA's Sexual health issues
Physician 3: I would say they're not worried at all (...) I don't think they have more problems than other adolescents. They have problems when they don't know what happens (...) So these patients that didn't know, they have more problems than those who know
Physician 2: These concerns are not expressed spontaneously; you need to ask a little more. (...) It is different, I think, compared to the rest of the population. Men with DSD express less concern about their sexual life and seem relatively satisfied. Women are much less satisfied, their sexual life is more problematic, because of anatomical reasons. But even if repair was successful, they feel a sort of shame.
4 Being different
Physician 5: They want to be and have a similar development like their peers. When their best friend is starting their breast development, they want to start breast development as well. If the others already had their menarche, they want the menarche as well (...) That is a problem when they are 14, 15 years old.
Physician 4: I think the most difficult period is really puberty. Which can be already difficult for other children and in these children it's extremely difficult (...) it is the latest point in which they really realize that they might be different. Usually during puberty, you want to be like all the others. You have the same clothes etc. You don't want to be different. This can sometimes be a real challenge.

4.2. The importance of psycho-social care

Overall, all respondents considered psycho-social care to be of fundamental importance to allow patients and parents to come to terms with the challenges related to their lived experiences. Throughout the interviews, HCPs mentioned three forms of support: professional support; peer support; and informal support from family and friends and from advocacy groups and activists. Overall, most participants were supportive of psycho-social care, but tended to be critical about the support provided by advocacy groups and activists. This might explain why HCPs tried to set up referral practices for both professional and peer support, but were much more reluctant to inform or refer their patients to intersex support groups. In what follows, we discuss all three forms of support with view to our interviews.

4.2.1. Professional support

Care providers stated that professional psycho-social support from experts is of crucial importance to enable their patients to process what has happened to them in the past (i.e. surgery) or to better understand what their diagnosis means and implies. Many of them also argued that this kind of support underlines the importance of interprofessional teamwork. [2.1]

Given the importance of psycho-social care, participants really tried to refer their patients to the psychologist for support. Still, they listed a series of important challenges - both structural and patient-related - that complicated this referral. One significant barrier identified by our participants was the lack of funding on the part of the hospital to employ a mental health specialist. Concretely this means that the psychologist is not an integral part of the medical team, but somebody external. As a result, patients and families need to set up additional appointments in order to receive this kind of support. Some HCPs argued that this constituted a major obstacle for two reasons. First, often patients feel somehow ashamed to go to the psychologist and secondly it is time-consuming. [2.1]

4.2.2. Peer support

Physicians strongly supported the concept of peer support as only AYA with VSC (and their families) can really capture the challenges and needs that their patients face. Support among AYA with VSC such as sharing their own experiences, ways of processing and coping strategies can be empowering. HCPs cannot provide this type of support, so it's important to set up peer contacts. They further acknowledged the importance of integrating the patient perspective into their care approach. [2.2]

Table 2
The importance of psycho-social care.

1. Professional support	
<i>Understanding diagnosis</i>	Physician 2: there are patients, they had a diagnosis, but they didn't understand the diagnosis (...) You have people of my age, who never had an explanation or an explanation they could understand (...) So they need support to understand what they have. So I think for adults and adolescents the psychologists and psychiatrists are the best, but psychologists mostly (...) if we go back to the older days, when physicians thought they could do everything by themselves and that's not possible. So you need to send people to experts.
<i>Challenges to psychological support</i>	Physician 5: It would be easier for patients to accept psychological help if we had a person in our team and she or he would come with me to the consultation and they [the patients] would know her and perhaps 2 or 3 consultations later there is a relationship (...) Our patients need to go on a separate date and they do not want that (...) Most of them they do not want any psychological help because first they do not want to admit that they are different and second, I have the impression they have so many dates with school with friends, with our department, that they do not want to have more appointments with doctors. Physician 4: This is still the image: "Well I don't have a psychiatric disease, so why do I need this?" That's the same in children with diabetes. We always say: "Well, but you have a chronic condition. And chronic usually means that there is no healing, there might be a very good treatment and <i>part</i> (emphasis) of this treatment is this psychological coaching, especially around puberty." (...)
2 Peer support	
<i>Sharing lived-experiences</i>	Physician 2: There are things and problems that do not seem so important to us; for example, the voice. Have you ever thought of a person who has a deep voice because they were exposed to androgens during development, but they are women? So they pick up the telephone and they're mistaken for a man. (...) These are things that we don't consider because we are concentrated on other things, but they're everyday things, you don't expose your genitals usually every day to everybody. But you expose yourself with your face and your voice. We should look at this and see what sort of discomfort these people face (...) we can learn so much from these people and then change (...) the patient knows much better
<i>Challenges to peer-matching</i>	Physician 5: Sometimes patients ask us and then we ask patients where we think they would fit together. (...) It's our job (...) It would be very helpful if we had for example 2 or 3 parents or 2 or 3 patients from about the age of 16, 17, 18 who say: "Okay, I'm a kind of peer-parent or peer-patient. You can always contact me if you have a patient with my disorder. I can I can help them; I can guide them." Physician 1: We are trying to connect families, but this is of course very difficult. There are a lot of ethical questions. (...) I think that something like that [network] is missing in Switzerland and we would like to support the formation of groups because I think this is very important that parents can talk to other parents and not only to professionals. Physician 5: It's always difficult for us because we do not have so many patients in our department. [Name of Swiss city] is a small city, it's not like Berlin or Paris or New York (...) and then it has to fit for example a Mosaic Turner with spontaneous puberty is something so different than a Turner patient without puberty. Sometimes it's already a problem for them if they are living for example in [Name of Swiss city] and the other patient in [Name of other Swiss city]. Then the distance is too far (...) That is the "Kantonsgeist". They always stay in their Kanton (...) and then you have the French speaking patient who does not want to or cannot talk to the German speaking one and so on.
3. Informal support	
<i>The role of parents</i>	Physician 3: [the role of parents?]. Understanding, helping, be patient, explain, I think we have an important role informing the parents, so they know what to do and what to say. Physician 2: the parents need to be helped by us from the beginning to accept the child (...) they need to work on themselves, but I think one of our roles is the bonding process (...) I think we need to help them and show them that the child is normal. So the role of the parents is support.
<i>The perceived role of advocacy groups and activists</i>	Physician 1: I still remember when I was a young resident that it was the surgeon who talked to the parents and made decisions with the parents (...) They didn't know at that time how to work with the parents and to support them so they could really make informed decisions. I think that these activist groups maybe twenty years ago or even more played a very important role to change that way of thinking in the medical community. Physician 4: I think they are not that important anymore (...) they had more importance in the older days but nowadays with the internet people who want information they get it. They don't need the groups. Physician 2: It is extremely important for certain people. It opens their eyes to know that they're not alone. There are very practical things that we don't think about, but the families go through. Change of sex assignment, bureaucratic, practical stuff, infections after operations (...) for some people I think it's very important, because they share experiences. So I think it's extremely important, if they don't get extreme. If they get extreme, then it's detrimental for everybody because we are not the enemy.
<i>HCPs attitude towards advocacy groups and activists</i>	Physician 1: I think this [LGBTQIA+ support groups] would be probably too confusing. That would be my impression for the parents. Imagine you have a new-born baby and then you go to these groups where there is such a wide spectrum of ideas. I do not know, I don't think that this is helpful in <i>this</i> special situation, of course later on, with teenagers, it is <i>their</i> choice to get involved with these groups, that is absolutely fine. Physician 5: For some groups there's only white and black and there's no grey. (...) So of course I understand that their suffering and they don't want anyone else to suffer like them. But sometimes they do not understand that their way is not necessarily the way of others and times have changed (...) but actually this is only my private opinion because I have had no personal contact with these groups (...) Perhaps we have to change our mind as well and ask these things to our patients as well; if they need such a group or if they want to have contact with such a group, if they already had contact with them (...) What I say to them in these 30 minutes of consultation is mostly lost the moment they leave me. Not everything, but a lot of it at least. But when they look this YouTube videos and films ... you can convey so much more information than in a consultation (...) They do not ask me where to go, they know much better than me. I can ask them perhaps.

Although many participants recognized the fundamental role of peer-support for the wellbeing of their patients, they found it very challenging to set up this type of support. They argued that the organization of peer-support heavily depends on the willingness of the physician and on the availability of other AYA and their families who offer themselves as volunteers. They further referred to some important ethical barriers, such as privacy and confidentiality. [2.2]

Some physicians also believed that the rather small number of patients with VSC and the rarity of these variations made it difficult to match AYA with the same condition. Although Switzerland is a relatively small country, they argued that the geographical dispersion of AYA with VSC, together with the different language communities constituted considerable practical obstacles for their patients, something they attributed to the typical Swiss

cantonal¹ mindset. Only one physician considered the possibility of peer support online, but was unaware of any sites or online communities herself [2.4].

4.2.3. Informal support

Family, and in particular parents were seen as the main source of informal support by most physicians. The HCPs saw it as their role to support parents by enabling them to bond with their children, and by providing information

¹ Switzerland is a federal state composed of 26 states, or cantons, which together form "the Confederation". The cantons, as states within the State, have considerable legal and political sovereignty.

Table 3
Lost in transition.

1. Lack in continuity of care	Physician 2: There is absolutely, as far as I know, no transition and no adult endocrinologist who wants to take these patients. That's very difficult, so they get lost.
	Physician 3: I think that we have to find the right people who are ready to help these young adults. (...) Psychologists and nurses are very important. And I think these two persons should be the red line between childhood and adulthood.
2. Physician related barriers	
<i>Lack of expertise</i>	Physician 1: I think it could be improved so that also the adult endocrinologist is a <i>specialist</i> in DSD and not just somebody who treats 99% diabetes patients or whatever and has only one patient with DSD.
	Physician 4: sometimes it's not that easy to find the right partner. Especially for Turner women, for example. For a long period, it was always the gynecologist which we thought to be the most important one, but this was shown not to be true (...) nowadays we know that Turner women need a cardiologist because you have to check the blood pressure, so the cardiologist is much more important than the gynecologist.
<i>Discomfort</i>	Physician 2: They [physicians] are at unease with regard to the rareness of these diseases, if you want to call it this way, I think there might be a problem because nobody is specialized in that. (...) it's the complexity and the social impact of these diseases that sort of scares some of the colleagues. These are conditions that need multidisciplinary (...) They also raise ethical concerns (...) then you have certain cultural aspects, let's face it, I mean, sex is a complex issue.
	Physician 4: The gynecologists are not that much interested in this replacement therapy (...), it's more interesting in puberty where you have to adapt always to age, to the weight of the children. In adult medicine it's not like that.
3. Patient related barriers	
<i>Timing of transition</i>	Physician 4: you have to plan the transition. It's what we do in our hospital this is somewhere between 16 and 20. So we have 4 years the time and I mean there are patients where we can feel that with 16 they don't want to sit with other children anymore in the waiting room and then you do it earlier. And other ones who are very happy and then you do it until they're 20.
<i>Past medical experiences</i>	Physician 2: adolescents, you know, they are complicated (...) But for DSD, I see, there are [other] difficulties. Maybe the patients also are not, you know, very much, they don't want to see doctors (...) the people of my age they were, you know, examined every six months (...) It's very, very pained (...) nobody wanted it, at that time we thought this was the right thing to do. There was no bad intention, so we were convinced that that was the right thing to do, and now we are convinced we should do it better.
4. Structural barriers	
<i>System differences and financial barriers</i>	Physician 2: They don't bring any money. I mean after the operation is done, the rest is just on us. (...) a cantonal problem? It always is (laughs), I mean, it's an additional element that makes it difficult (...) I don't think every university hospital should have adult endocrinologists taking care of DSD patients. But we should have one or two (...) the focus is only on the pediatric patients, we sort of forget the rest.
	Physician 5: for all chronic patients to leave the pediatric department [is challenging] because we handle our patients totally different than the adult doctors. For us it's we have to organize everything, if they don't come to us, we call them and if they need anything we write letters or we send them prescriptions and so on. In the adult department it's so different. They have to call and if they miss an appointment they have to look for the next appointment. (...) in our department at the beginning at least parents are quite important (...) And in the adult department parents they don't play any role anymore.

to them. [2.3]. Participants were much more divided about support from advocacy groups and activists. Some HCPs believed that the role of these groups is relegated to the past: although they brought about an important shift in the medical management of VSC, they are no longer beneficial today. Other physicians thought they could still be important in terms of support and awareness raising as long as they do not become "extreme". Some HCPs seemed to regret the hostility of some activists towards HCPs. [2.4]

A few respondents also expressed concern about the fact that some of these groups do not focus only on intersex but cover LGBTQIA+ issues in general. They argued that this risks to be confusing, especially for parents.

Table 4
Interdisciplinarity, still a long way to go.

1 The need for improvement	
Physician 4: I think, especially in a small country like Switzerland, we should collaborate more because everybody has some of these patients but nobody has a lot of them and of course experience always remains limited (...).	
Physician 2: I don't look at patients <i>alone</i> . It's really a teamwork and that is the best you can do for us and for the patients (...) the multidisciplinary team is actually a pediatric creation (...) these patients are a little complex, they are anatomically complex and they're psychologically complex; it's ethically complex (...) most colleagues do not like these sorrow things, they're not experts. Nobody really, so it's a pediatric thing, the multidisciplinary.	
Physician 1: One thing that is missing in Switzerland is a Swiss network that helps professionals in the widest sense (...). The quality of care that is provided also depends on the experience of the healthcare professionals involved, so if there is a psychologist who sees one DSD patient per year, I do not think he or she is qualified to really give <i>good</i> support to these families. So, we try, we are working on this to create a Swiss network so we can at least exchange ideas, maybe discuss cases etc.	
2 Different mind-sets	
Physician 3: It is difficult to understand really how it [MDT] works and how it should work Well here we try (...) the ethicist. I think we <i>should</i> ask her more often (...) she is a member of the group but nobody calls her (...) it's <i>our</i> fault (...) It's a problem of organization or a problem of willingness, you know? Do we want that or not? Do we think it's important or not? I think it's highly important. Why didn't I do that more often? I don't know.	
Physician 2: you have to defend the phenotype and the psychologists say that this procedure could have traumatic effects. You know that's a different point of view. Some of us were a little bit irritated by this sort of questions because we just wanted to work (...) in the beginning of our history as a multidisciplinary team (...) it was 2012 or 2011 (...) he [ethicist] was coming up with these ethical questions and then we were like: what is this? (...) I mean, it's absolutely essential that he dared to speak out, but in the beginning it was a sort of, pfff (laughing) now he <i>needs</i> to be there.	
3 Structural barriers	
Physician 5: I talk more about future problems for example: "What are your fears?" and "What are the different possibilities for example for fertility preservation or counselling." I'm more open for that but not enough (...) I know where I need help and it's sometimes difficult to get help (...) I always say: "I'm not a psychologist." (...) I do not get the support I want (...) for me and for my patients (...) It's just a question of money.	
Physician 1: in Switzerland, in many hospitals people are afraid that they lose patients, and that they are not as important anymore when they send more complex cases to a bigger center. So, there are a lot of political issues behind it and maybe the ego of people, (...) but that is going to take another few years until that will be implemented from the political side to not allow smaller hospitals anymore to do the management of complex DSD cases.	

One participant acknowledged that she does not really know these groups on a more personal basis and admitted that she does not ask her patients whether they would like to establish contact with them or maybe have already done so. None of the interviewees seemed to refer their patients to these groups. [2.4]

4.3. Lost in transition

Adolescence and young adulthood are a time of significant developmental transition and have an important impact on psycho-social wellbeing.

Table 5
Towards a new care paradigm?

1. Past vs. present practice	
Attitudes towards early surgical intervention	<p>Physician 3: What are the real indications?" [to operate] Really, there aren't any. So they say: "There can be complications if we don't operate." Wrong. "It's easier, when the child is small." Wrong. (...) when there's no indication, you have to get the consent of the child, before operating, I wouldn't do any operation otherwise. (...) It's very strange to see that DSD is the only field and subject where parents or patients are angry with the doctors.</p> <p>Physician 1: being a surgeon of course I am not against surgery (laughs) but it <i>should</i> happen within this whole setting of support from many sides and if then the <i>whole</i> group and the parents decide that in <i>this</i> particular child and in <i>this</i> particular situation it is good to do a surgery early in life, then I am happy to do that. But, I do not want to be the person telling the parents you <i>have</i> to do that otherwise your child will be unhappy for the rest of his or her life.</p>
Regret about practice in the past	<p>Physician 3: From 91 to now, my care practice has changed, drastically (...) I started to read about ethics, about patient outcomes, about behavior and, well I mean for me it was more and more clear, that we should be very careful about this (...) are we really doing the right thing? It was 99 (...) for two girls I have made vaginas when they were 9 or 10, it was a big mistake, I wouldn't do that again.</p>
2. Perceived challenges and recommendations	
Supporting parents	<p>Physician 2: So for <i>me</i>, when I talk about variations of sex development, I try to mitigate the idea of differences or of diseases because it's a very difficult and complex situation. (...) if the parents do not accept the child, everything is much more difficult. So acceptance and bonding are absolutely necessary. That's why I try to be as moderate as possible.</p> <p>Physician 1: The "typical" parents come to me, the surgeon, and say: if you can do something to make my child look normal, then please do it. You understand what I mean? Our job is to make them really understand what they decide and why and this is sometimes very challenging (...) everybody wants to be <i>perfect</i> (...) and then of course these parents want the perfect child.</p> <p>Physician 3: We try to explain that this difference doesn't mean much (...) I think it's important to that they know that we will do the surgery if the child is really bothered with the "problem", - you shouldn't call it a problem when talking to intersex people. If the child has really problems with that we will do it earlier. If there is any complication, we will do it earlier. When they hear that (...) probably they they're more at ease and they accept that.</p>
Correct diagnosis	<p>Physician 1: the most challenging is still to make a correct diagnosis in the beginning. I think that once you have that, then in, I do not know, 75-80% of the cases, you somehow know what to expect, and how to talk to the parents, how to explain them (...) the clearer the diagnosis is the more we can <i>know</i> about the future and can therefore inform the patient and the parent, what to expect and how to deal with it (...).</p>
Role of the surgeon	<p>Physician 3: Why do we have a surgeon in the team if the surgeon does not operate? If you have a surgeon in the team it means that the child will get an operation, sooner or later. Maybe it's a mistake to have a surgeon in a team. If anyone would say: "We will not operate on your child." Why are you here? I don't know. Maybe it's a mistake (...) I think for the moment it is important the surgeon says, you do not need an operation.</p>
Societal views	<p>Physician 1: The other challenge of course is society. I mean, in theory it sounds wonderful, everybody can grow up as he or she or whatever she/he (...) whatever that sounds in theory wonderful and of course I would support that, but that is not reality (...) generally speaking, people have problems accepting that, <i>really</i>, as I said in theory it is nice, but how would the other children accept a child who does not know which toilet to use, in schools, etc. (...) then of course for families that choose to go this way, to leave it open, then they need a <i>lot</i> of support to allow the children to grow up without stigmatization. We see so many different parents from different parts of society, if you have an "intellectual" family who is capable of thinking about all the consequences and about how to provide support, but it is completely different in the case of a family where we really have to struggle to inform the parents and to make them understand.</p> <p>Physician 4: you have the whole spectrum, the broadness ... well there are intellectual people who (...) try to understand why and what happens and things like that. And well, on the hand people who think: we don't have to touch anything. This is god's will and..."</p> <p>Physician 2: you know how multicultural we are and maybe there are situations in which the parents might push for a certain gender or sex, because it's socially better than being a woman, and there we need to be a little careful with that.</p>
Awareness raising	<p>Physician 3: School, of course, if the peers know what it is about and what this difference means, it would be much easier. (...) but this is a problem, schools, X (Name of a Swiss philosopher) tried to give lectures in the schools at the age of 16, 18, which is good, about intersex and what is intersex and not only about sexual education (...) here at least they have a lot of problems with sexual education and a lot of parents don't want that at all. (...) She organized these courses for 1 or 2 years and after a certain time, she had to stop.</p>
Societal openness towards difference	<p>Physician 2: I think the situation is much better nowadays. I mean there's much more acceptance. It's not yet, complete, but there is more acceptance, if a boy sits to pee it's actually better (...) so it's something that is much more accepted. So I don't see special concerns.</p>
Critical self-reflection	<p>Physician 3: [some of the most challenging aspects is] trying to be sure for myself that it's not a medical problem. It's difficult. I still believe it is and these adolescents don't want to hear that. They don't want to hear that they're patients, they don't want to hear that they're sick, they don't want even to hear that they have a difference and sometimes it's not very easy.</p> <p>Physician 4: I just don't know whether parents have the right to tell us: "Well we would prefer that the child is just neutral (...) I have a little bit a problem with this neutral stage for over 15 years. I mean, there is a certain time where you have to know whether you use this or that toilet and whether you take the shower at school with these or that children (...) I'm not sure whether I'm tolerant enough for the third sex. I think this third sex is just not accepted (...) (...) But I'm fully aware that there are other opinions which are also, which are valid (...).</p>

However, in the case of AYA with VSC this period is also characterized by a transitioning from paediatric to adult healthcare services. All HCPs reported significant gaps in the transition process. Nurses and psychologists were sometimes indicated as the ideal bridge figures to facilitate the transition process. Next to structural barriers, perceived challenges were both provider- and patient-related. [3.0]

Participants often emphasized that DSD is an umbrella term for a wide spectrum of variations and that this diversity is fraught with multiple challenges. For example, due to small patient numbers, healthcare professionals in adult healthcare often lack medical specialization. Moreover, it is not always easy to identify who should take over the care of these patients during transition because over the course of time and depending on the condition, one type of provider might become more important than others. [3.1] Some respondents believed that the complexity of these conditions scares many of their colleagues off. Next to this discomfort, some HCPs also argued that physicians are often not interested in adult patients with VSC as they,

compared to children, aren't challenging from a medical point of view. [3.1]

Next to physician-related obstacles, participants also pointed to patient-related factors that complicated the transition process. First of all, chronological age was not considered to be a good indicator to start the transition. HCPs said it was important to adapt the process to the individual patient's needs. [3.2] Some physicians also argued that adult patients are often reluctant to continue seeing medical providers due to traumatic experiences in the past. [3.2]

Finally, HCPs also listed several structural barriers. For example, adult patients with VSC were said not to be very profitable. On the other hand, transition was rendered difficult due to geographical dispersion and the need to organize the transition across Swiss cantons. Finally, one participant argued that the system differences between the pediatric and the adult healthcare setting are huge and render the transition process more challenging for their patients. [3.3]

Table 6

What's in a name – HCPs' view on conceptual issues.

1. DSD as an umbrella term

Physician 4: for me it's not so bad because it's so broad; maybe it's too broad. When we formed these DSD study groups with Swiss paediatric endocrinologists, well in the beginning we were not sure whether we should include Turner patients, Klinefelter patients (...) It's broad, so it's okay but it doesn't tell you a lot. I mean if you say: "I'm doing a study with DSD patients." It is such a difference whether you speak about Klinefelter, Turner, even within CAH it's such a big spectrum.

Physician 5: I have a problem with this classification (...) hypospadias for example (...) it's so different from for example Turner syndrome or Klinefelter syndrome (...) I'm not very happy that this is all DSD (...) and you emphasize with DSD always this sexual part [genitals] (...) but there is the brain as well and the attitude and the feelings of a patient.

2 Word-choice with AYA and families

Physician 3: With the families (...) I never use disorder and I have never used it (...) Disorder is out of my vocabulary. So what I use with the parents is *variation* of sex development and we use this in the department (...) I think it's important not take on this term of disorder because it is stigmatizing and it means that you have to treat them.

Physician 1: for me it made absolutely sense to stop this terminology intersex because it has been connected to disease and to not very nice words. So we started using DSD in the sense of disorder some time ago, but we changed, or me personally, I have changed to difference (...) because not all differences are pathological, that means that it is a disease that has to be treated. In many situations it is *just* a difference.

Physician 2: The word intersex might be used on purpose by certain patients who like to identify themselves as individuals. But I don't use it, so if the patient spontaneously calls themselves intersex, so I'll play with it, but I don't use it spontaneously, I don't like the word at all. But there are patients who really like to place themselves in between.

3 Avoiding labels

Physician 2: I tend not to use any label because it doesn't really help. So I don't use any label even when I talk to parents, I try to stress the fact that the child is okay. (...) for the scientific part, you need to use labels. So I do use differences of sex development which allows me not to change the acronym, or variants or variations (...).

4.4. Interdisciplinarity, still a long way to go

The challenges with the transition from paediatric to adult healthcare services shows how important interdisciplinarity really is. All participants argued that multidisciplinary teams (MDT) are essential in the care of intersex patients given the complexity and the rarity of these conditions. Still, they believed that there was still much room for improvement.

Some argued that gaps in multidisciplinary care are more outspoken in smaller centers and within adult healthcare settings. To address these shortcomings, a national network should be established which, according to the participants, is currently missing in Switzerland. One physician expressed the wish for more international exchange in order to provide the highest quality of care to her patients. [4.1]

The respondents identified various barriers to the implementation of MDT and the creation of a network within Switzerland. A first important perceived obstacle was related to the often closed mindset of HCPs. Participants admitted how demanding it was for them to challenge their perspectives and to listen and integrate the viewpoint from other professionals, in particular then from psychologists and ethicists. [4.2]

The failure to recognize psychologists and ethicists as essential members of MDT was according to one of our participants not just the fault of physicians, but part of a deeper, structural problem. Recognizing her own limits, she actively sought for support to care for her patients, but money was time and again a stumbling block. [4.3]

Another important structural challenge to the creation of multidisciplinary collaboration seemed to be hospital funding. Various participants reported that among physicians there is often a certain reluctance to collaborate with HCPs from other hospitals out of fear of losing patients. This seemed especially to be the case for those working in smaller centers with less experience with VSC.

According to our respondents the importance of multidisciplinary collaboration in the care of intersex persons was closely connected to the shift in the medical management of VSC from a purely somatic to a more holistic and patient-centred care approach.

4.5. Towards a new care paradigm?

According to our respondents the importance of multidisciplinary collaboration in the care of intersex persons was closely connected to the shift in the medical management of VSC from a purely somatic to a more holistic and patient-centred care approach.

4.5.1. Past vs present medical practice

All participants agreed that the medical care of patients has changed drastically compared to the past and most of them seemed to welcome

this change, in particular the tendency to postpone elective surgery until the child is old enough to participate in shared-decision-making. A few HCPs were more supportive of surgery but only if the decision was taken in collaboration with the entire treatment team and the parents. Participants argued they would never take such a decision on their own. [5.1] HCPs with long-term experience in VSC also addressed the change in their own care practices and some felt guilty about past actions. [5.1]

4.5.2. Perceived challenges and recommendations

Several participants reported that parents are often in favour of early surgical interventions. Anticipated social stigma was considered a major obstacle to deferring elective surgery together with families' cultural and religious background [5.2]. To combat stigma, many physicians considered it important to raise more awareness and openness towards intersex in society. Schools were often seen as critical venues for understanding and practicing tolerance. Still, one participant argued that education about sex, gender and sexuality is often met with a lot of objection from parents and thus difficult to implement. [5.2] One participant argued that concern for anticipated societal stigma is often misplaced and that children are much more tolerant toward diversity than adults think. [5.2]. It was rather parents' obsession with "normality" that according to our participants lead to the decision of early surgery. They reported, in fact, that parents often ask HCPs to do everything to ensure that their child looks "normal". Participants mentioned various strategies that they had used to challenge parents' reasoning process. First, they try to make parents reflect on what "being normal" really means. For this reason, when talking with families, they prefer to use the word variation rather than difference in order not to set the child apart from other children without VSC. Second, they also reported that they try to re-assure parents that if they or their child would encounter problems in the future, they can always come back to their initial decision and start treatment or have surgery. [5.2] Another important strategy used by HCPs to combat parents' preference for early interventions was related to diagnostics. Some participants in fact believed that finding an accurate diagnosis which is made in a timely manner is crucial to provide the best possible care as it allows HCPs to somehow predict the future and thus provide families the best possible care. [5.2] One participant even considered the option of not including the surgeon in multidisciplinary consultations, but feared that this could be counterproductive as parents often seem to consider surgeons to be the most authoritative HCP when it comes to the decision to have a surgical intervention or not. [5.2]

Despite their attempts to discourage parents to choose for early surgery, some HCPs argued that the decision "not to operate" was only possible for a certain type of family in which parents are highly educated and receive a lot of support from their surroundings to counter social stigma. HCPs observed this fear of future potential prejudice, stigma, and discrimination not only

in parents, but also in themselves. Some were very open about their own values and assumptions on sex, gender and sexuality and on how they might impact the care of their patients. One participant described his own difficulty of not considering VSC as a medical condition. Another physician admitted his struggle with accepting non-binary gender categories. [5.2]

4.6. What's in a name

The shift in the medical management of intersex has gone hand in hand with an important change of terminology. All care providers agreed that the term DSD is very broad.

Some saw advantages in working with a term that is not too narrow, but at the same time they all felt that the term risks losing meaning as in their experience the diagnoses are so different that it is hard to make general statements. [6.1]

All participants agreed that it was important to avoid the word “disorder” with patients and families as they considered it stigmatizing and pathologizing. Some HCPs preferred the term “variation”, others used also “difference” or their respective acronyms, also when talking with colleagues. None of the physicians seemed to use the word intersex, but they recognized that their patients might identify with this term and they respected that. [6.2]

One respondent preferred to avoid labelling altogether, and only used labels at scientific gatherings or in academic publications. [6.3]

5. Discussion

The Consensus Statement and its update [1,11] have called for the integration of psycho-social support in the care of intersex persons. Research, however, has revealed an important gap between these intentions and available mental health services for children and adults with VSC and their families [19,20]. The present study offers an important contribution to the existing literature on support services by examining the perspective of HCPs who care for intersex youth in Switzerland. Our study results reveal a certain discrepancy between participants' willingness to shift toward a more holistic paradigm of care (including also psychosocial care) and the unconscious tendency to both medicalize and de-medicalize youth with VSC; a propensity that undermines a more holistic approach to care. In the following, we discuss this apparent contradiction in relation to HCP's difficulty in managing medical uncertainty and raise concern about the current rhetoric of changed clinical practice.

Medicalization is often defined as the process by which some aspects of human life that were not considered pathological, are turned into medical problems [27]. Medicalization is generally considered to have widespread negative effects, certainly within the context of VSC, given the long-term history of irreversible normalizing medical interventions on intersex bodies.

De-medicalization is commonly described as the mere opposite of medicalization, but is often left undertheorized. Moreover, research increasingly shows that medicalization and de-medicalization can operate at the same time [28,29]. Our present research seems to support this finding and to illustrate that both of these processes might have negative implications for intersex youth.

In line with the Consensus, our study participants seemed very supportive towards the importance of open and on-going communication with patients and their families, multidisciplinary care teams, psycho-social support and the deferral of aesthetic surgeries until the age of informed consent. Those with longer work-experience often looked back critically at their own actions. These regrets focused mainly on early, irreversible, non-therapeutic surgeries and internal power hierarchies among different healthcare provider types. Moreover, out of concern that it might pathologize, participants tended to avoid the acronym DSD when talking with patients and their families. Thus, contrary to the Consensus, they seemed quite conscious of the stigmatizing effect of language. In fact, in their communication with families, some healthcare professionals encouraged parents to critically reflect on their pursuit of a “normal” child.

At the same time, participants appeared to be well aware of the difficulty of implementing a holistic and de-medicalized model to care and reported multiple barriers of different nature, including structural (e.g. lack of funding and staff, hospital culture), and societal (e.g. binary sex/gender categories, stigma) obstacles together with physician (e.g. lack of specialization; lack of interest) and patient/parent-related (e.g. lack of time, anticipated stigma) ones. To address some of these barriers, HCPs advocated for specialized medical training, awareness raising in schools and society at large.

Many of the reported barriers seem to be amplified in the case of AYA with VSC, a group with intrinsic physical, cognitive, and emotional developmental specificities. In fact, various participants reported on the difficulties in organizing the transfer of their AYA patients to adult providers. This finding is in line with other research that shows that transitional care for intersex youth – like for other AYA with chronic health conditions – often fails due to the absence of specialized AYA care centres in smaller countries, the system differences between paediatric and adult healthcare settings and the fact that physicians caring for adults lack adequate preparation in AYA healthcare [30,31]. This might explain why our sample included only one adult-care provider with expertise in VSC and why this physician expressed great concern about their colleagues' reluctance to engage with intersex patients because of the social and ethical complexities surrounding these variations.

At the same time, the assertion – made by many of our child-care providers – that intersex youth are not that different from other AYA with regard to questions and concerns about sexuality and relationships might be problematic as well because in their desire to de-medicalize, they might actually overlook the real-life concerns of their patients. Research [10,15,32,33] in fact suggests that, contrary to what many of our participants argued, sexual health and fertility are often major issues for young people with VSC. Underestimating these needs might have a negative impact on the doctor-patient relationship and further complicate the transition process [10]. Furthermore, as suggested by previous research [32,34,35] MDT members should promote patient's sexual agency by explicitly challenging social norms regarding the body and what is “normal” sex. However, this is only possible if they are consciously aware of their patients' concerns.

Psycho-social care is crucial to attend to the unique needs of AYA with VSC [35]. The importance of mental health services was recognized by our participants, but they listed a series of important challenges to their proper implementation, including the lack of MDT in adult care settings. This is consistent with the findings of other studies that show that psycho-social care is mainly provided to parents and that the availability of specialised staff is more advanced in paediatrics than in adult care [21]. As a result, AYA with VSC risk experiencing discrimination during consultations and this in turn might lead to dropout from care especially during the transition period [36].

Peer-support can be an important ally for intersex youth to validate their experiences and overcome feelings of social isolation. Although in principle many respondents seemed to value the role of peer-support in the empowerment of their patients, in practice they found it challenging to organize this peer-matching. They were for example concerned about privacy and confidentiality issues and time management. However, it would be sufficient to ask families and AYA's whether they agree to share their contact details with other patients and be willing to provide advice to peers. Besides structural and ethical reasons, this hesitancy about peer-matching was often motivated by the observation that every situation is too particular and individual to allow people to connect. Fear of adverse outcomes in the case of peer-matching can also be found in the oncology context [37] and highlights healthcare professionals' inability to accept uncertainty. Careful peer-matching, i.e. matching based on same diagnosis, treatment, age, etc., is, to a certain extent an expression of providers' desire for medical control and thus a form of re-medicalization which risks to deprive AYA from a unique source of support as the “perfect” match rarely exists. Studies with intersex AYA show that they themselves favour low-threshold peer support and counter the importance of the same VSC diagnosis [24]. Many of the barriers cited by our participants were thus more

perceived than real. Surprisingly, only one participant considered the option of online peer support communities. They admitted to be rather ignorant about specific sites or social media channels for peer support. Due to this unfamiliarity, HCPs risk missing out on important opportunities to provide AYA tailored support.

Intolerance towards uncertainty could also be scrutinized in participants' emphasis on the importance of providing a prompt and accurate diagnosis of the underlying cause of VSC in order to improve counselling and guide decision-making. The development of new diagnostic tools has optimized diagnostics to a major extent, but has also created new medicalized categories, grounded in genetics, that seem to allow for objective treatment decisions. As such, the focus on diagnosis tends to favour action over deferral of correctional surgeries and thus risks to harm intersex individuals. This might explain why despite increased scepticism, in many countries such surgeries continue to be performed [12,18]. More work is needed to help physicians cope with medical uncertainty and discuss it with patients and families as disclosure of uncertainty is essential for true shared decision-making and patient-centred care [38–41]. However, this requires a change, not only in the culture of medical practice, but also in that of medical education where the overriding focus – as shown by our results – still seems to lie on curing uncertainty rather than accepting it [42].

The wish to hold a position of medical control was also reflected in the sceptical attitude of most participants with regard to the function of support and advocacy groups in the care of intersex persons. Although it would be highly beneficial for intersex youth if non-medical perspectives would be taken into account, at present non-medical partners are hardly included in the MDT [20,21]. Likewise, in line with other studies [18] our results suggest that the representation within the MDT of different types of care professionals (e.g. social workers, psychologists and ethicist) is not yet a reality in many Swiss hospitals. Endocrinologists and surgeons are often still the key caregivers. Such a one-side clinical perspective within MDT, however, can reinforce the risk of re-medicalization of intersex bodies, with this difference that decisions in favour of early surgery have greater justificatory power compared to the past since they have been taken not by one, but by multiple providers [8]. We should not forget in fact that clinicians' definition of the "medically necessary" might be grounded in (implicit) normative understandings of sex and gender [43]. Hence the establishment of a MDT is no guarantee for the postponement of early elective interventions. Deeper structural changes to the hospital culture might be required for this, although maybe nobody would go so far as one of our participants who argued provocatively for the exclusion of surgeons from the MDT.

Finally, the claim made by some HCPs that intersex advocacy and activist groups have somehow lost their reason for existing because of changed medical care is deeply worrisome given the substantial gap between the post-consensus rhetoric of change and actual clinical practice.

6. Limitations

Our results are not generalizable to all healthcare professionals caring for AYA with VSC. The modest sample size, the specific Swiss context and the absence of gynecologists, psychologists and psychiatrists in our sample render such a generalization impossible. Our difficulty in recruiting mental health professionals indicates their lack of involvement in the care of persons with VSC.

7. Conclusion

Our study captures unique insights into the attitudes of clinical providers with regard to existing support services for intersex youth in Switzerland. The results of our study provide additional, empirically supported input to improve the care of AYA with VSC. Swiss HCPs involved in the care of AYA with VSC worked to implement a holistic approach to care, but their intentions were often undercut by processes of de- and re-medicalization. Our findings suggest that HCPs need to come to see medical

uncertainty not only as a threat but also as an opportunity. Accepting uncertainty means taking on a stance of self-doubt which in turn might lead to more openness to collaborate with non-clinical partners and advocacy groups, promote low-threshold peer-support and engage in shared decision-making with patients and families. These changes can be supported by specific training in the medical context as well as opportunities for self-reflection. Besides that, structural changes in hospitals are needed to implement the intended psycho-social care approach for AYA with VSC. Finally, it would be extremely valuable to conduct this research in other healthcare settings and to involve more and different types of HCPs.

Contributions

This study was conceived by EDC. Interviews were conducted by EDC. Coding, analysis and interpretation were performed by NR and EDC. Both authors contributed to the creation of this manuscript and reviewed it prior to submission.

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Declarations of interest

The authors have no conflict of interest

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