BMJ Paediatrics Open

Multidisciplinary teams caring for people with variations of sex characteristics: a scoping review

Martin Gramc ,[1] Jürg Streuli,[2,3] Eva de Clercq[2]

To cite: Gramc M, Streuli J, de Clercq E. Multidisciplinary teams caring for people with variations of sex characteristics: a scoping review. *BMJ Paediatrics Open* 2021;**5**:e001257. doi:10.1136/bmjpo-2021-001257

Received 10 August 2021
Accepted 27 October 2021

[1]Institute of Biomedical Ethics and History of Medcine, Universität Zürich, Zurich, Switzerland
[2]University of Zurich Institute of Biomedical Ethics History of Medicine, Zurich, Switzerland
[3]University Children's Hospital and Children's Research Center, Switzerland, University Children's Hospital, Zürich, Switzerland

Correspondence to
Dr Martin Gramc; martin.gramc@ibme.uzh.ch

ABSTRACT

Background In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient-centred care embedded in ethical principles of self-determination and child participation. But there is little evidence that successfully MDTs have been implemented in clinical practice.

Methods and aims A scoping review was conducted to identify studies that address the collaboration and decision making process of MDTs providing care of people with VSC to identify ideal and actual (1) team composition; (2) models of collaboration and (3) ethical principles that MDTs follow. Six databases were systematically searched: CINAHIL, Medline, Psychinfo, Scopus, Socindex and Web of Science. No restriction was placed on the type of methodology used in the studies. To frame the research, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used.

Results The MDTs in the literature include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in MDTs lacks cooperation as one team member sets the tasks of the team while each professional works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC.

Conclusion The care of people with VSC described in the papers is medically oriented as the team members are mainly medical professionals working separately. MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent. There was no mention of adult care and lack of inclusion of patient's perspective in the care process. The future research should do more empirical research of MDTs.

What is known about the subject?

- Since the introduction of Chicago consensus statement multidisciplinary teams (MDTs) have been integrated in treatment of people with variations of sex characteristics (VSC). However, the implementation of MDTs in literature is unclear: there is no information on the composition of teams, collaboration processes and ethical framework.

What this study adds?

- The study provides a literature overview on the collaboration and composition of MDTs. It fills the gap in the literature by showing that collaboration in MDTs is poor, that medical professionals dominate over other healthcare professionals, that psychosocial care is secondary to medical treatment and that ethical frameworks excluded the voices of people with VSC.

INTRODUCTION

Variations of sex characteristics (VSC) demand a multidisciplinary care approach,[1] because human sex is determined by multiple factors[2]: genetic, gonadal, hormonal, phenotypic and psychological sex. The need to bring together a broad range of healthcare professionals to provide care for people with VSC has been recognised also by the Chicago consensus statement of 2006.[3 4] The consensus statement has introduced new guidelines for the care of people with VSC and their families. These recommendations include: (1) the provision of long-term multidisciplinary care (including psycho-social support), open and ongoing communication, the deferral of early cosmetic surgeries until the age of informed consent and the use of a new medical umbrella term differences of sex development (DSD).[3 4] According to the consensus statement, multidisciplinary teams (MDTs) are to include: (paediatric) endocrinologists, urologists, surgeons, psychiatrists/psychologists, gynaecologists, geneticists, neonatologists; and if available: social workers, nurses and medical ethicists.[3] The MDT should educate other healthcare professionals involved in the treatment of people with VSC, communicate with family members under supervision of a (health) care professional and develop a plan for

clinical management.[3 5 6] Care should be patient-centred and focus on children's growing capabilities to participate in decisions regarding their health and thus pose a limit to parental authority.[2]

The updated consensus statement of 2016 seemed to recognise this important paradigm shift in children's rights by considering shared decision-making as 'the crux of patient-centred care'. Healthcare experts should share their knowledge but also their uncertainties in care and outcomes with patients and families and give them enough time and support to make fully informed decisions.

A crucial aspect of this patient-centred, individualised care approach is the endorsement by the Chicago consensus of healthcare teams that are composed of different provider types. Such teams can be multidisciplinary, interdisciplinary and transdisciplinary depending on the degree of collaboration.[4] The Chicago consensus does not specify which MDT would be the most appropriate. However, the 2016 update defines types of collaboration in detail. In MDTs two or more team members work simultaneously but separately; interdisciplinary teams involve the joint work of professionals from different disciplines sharing knowledge and skills to address a common problem and in transdisciplinary teams various disciplines are brought together to create new ways of solving problems and share responsibility of care.[5] Although Lee and colleagues[5] explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Studies suggest that regular MDT meetings may result in active deferral of early cosmetic surgeries.[7] On the one hand, data seems to suggest that the majority of teams in Europe accept the MDT approach while other studies portray a less optimistic situation. Moreover, empirical data on the actual functioning of MDT, their collaboration with patients and families as well as their efficacy remain poorly documented.[8 9] It is often unclear, in fact, who is actually included in the team, what the role of each team member is, how various healthcare professionals collaborate, how people with VSC and their families are involved in the decision-making process regarding their health and what impact MDT have on care management and patient well-being.

The following paper aims to critically examine the existing scientific literature on the composition of MDT in the care of people with VSC, to describe the implementation of MDTs in the care of people with VSC.

For this purpose, the manuscript aims to identify ideal and actual (1) MDT composition; (2) models of collaboration and (3) ethical principles that guide MDTs. It further aims to identify possible barriers to the adequate implementation of MDT and examine any assessments of their impact on the care of persons with VSC. Finally, the review aims to identify possible gaps in the existing research on MDT.

METHODS

Given the broad aim of the research question, a scoping review was conducted to provide an overview and critical analysis of the existing literature on MDT caring for people with VSC. We searched the following databases: CINAHIL, Medline, Psychinfo, Scopus, Socindex and Web of Science. The research terms were selected after discussions within the research team and extensive background reading on the topic (see table 1). Inclusion criteria were: published in peer-reviewed journals between 2006 and 2021, written in English, German or French. A 15-year publication window was chosen to capture all studies that were published after the publication of the Chicago consensus statement of 2006. In line with scoping reviews, no restriction was placed on the type of study (theoretical, intervention, quantitative, qualitative or mixed-method). However, book chapters, literature reviews, expert reports, commentaries, conference abstracts and books were excluded. Given that in the medical community the acronym DSD is prevalent, we used it as a search term together with intersex. Terms such as 'diverse sex development' and 'variations of sex development' were not included in the search query because although these research terms are often relevant for affected persons and activists, they are not yet ingrained in the scientific literature and the preliminary searches gave no additional results when using these terms.

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines[10] (see figure 1). The combined research of 6 databases gave 415 results and 1 article was added through other sources. After deduplicating (using Zotero) 251 units remained and were further screened on the basis of title and abstract. The articles that referred to intersex or DSD, but did not refer to MDT were excluded. The screening process of the first author was checked and unified with the second author, who confirmed which articles were eligible based on the abstract. The first screening gave 35 results. After that the references of the already selected studies were checked to identify additional studies. This resulted in a final sample of 37 units. In the next step, the first and second authors then read the full-text versions of these articles. Twenty-five records were excluded because they only loosely referred to MDT and either (1) failed to list which healthcare professionals are part of MDT; (2) made no reference to MDT collaboration models; (3) almost exclusively focused on the clinical management or psycho-social care of people with VSC; (4) or discussed the role of only one MDT member, without any description of their collaboration with other team members.

The data from the selected 12 articles were extracted by making a Microsoft Excel spreadsheet, secured and available to all team members. The spreadsheet included sections for authors name, year of publication, country of origin, name of the journal, study design, data analysis, key findings, patient age cohort, intersex variation, medical management, psychosocial care, composition of

Table 1 Search query

Search terms	WoS	Scopus	Medline	CINAHIL	Psychinfo	Socioindex
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity")	8312	7018	2287	466	930	331
(child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediatr* OR boy* OR girl* OR neonat* OR adolescent*)	4 111 869	2 875 699	1 258 637	523 079	541 804	132 823
(ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management)	12 727 466	1 520 839	3 237 731	1 270 357	986 407	986 407
(multidisciplinar* OR interdisciplinar* OR interprofession* OR multilateral OR transdisciplinar* OR transprofession* OR holis*)	345 970	343 642	116 958	57 007	48 329	11 091
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity") AND (child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediatr* OR boy* OR girl* OR neonat* OR adolescent*) AND (ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management) AND (multidisciplinar* OR interdisciplinar* OR interprofession* OR multilateral OR transdisciplinar* OR transprofession* OR holis*)	189	102	82	26	14	2

the team, approaches to collaboration, conceptual issues, ethical framework.

PATIENT AND PUBLIC INVOLVEMENT STATEMENT

No patients were involved in conducting this study.

RESULTS

General characteristics of included studies

Out of the final 12 articles, 6 were theoretical,[11–16] 5 were empirical[17–21] and 1 was a mixed-method study.[9] One-third (4) of the articles were published in the UK,[9 11 12 18] the other third in the USA[13 15 17 20] and the remaining third came from Switzerland and Germany,[21] Sweden and UK,[19] Australia[16] and Germany[14] (see tables 2 and 3).

Only two empirical studies[17 18] addressed MDT in relation to a specific VSC: CAH and 46, XY DSD. Other studies either referred to a wide array of VSC[11–14 20]: or provided no specification[9 15 16 19 21] (see table 2).

The majority of studies discussed MDTs in relation to infants and children.[12–15 17–21] Two studies referred to children and adolescents[9 16] and only one focused exclusively on adolescents.[11] Overall the focus on adolescents was limited and none of the papers discussed MDT in relationship to adults (see table 2).

Except for[17 19] most studies referred to VSC in terms of disorders/differences of sex development and used the acronym without any critical reflection or explanation of it.[9 11–16 18 20 21] Two papers explicitly referred to VSC as a pathology.[11 16]

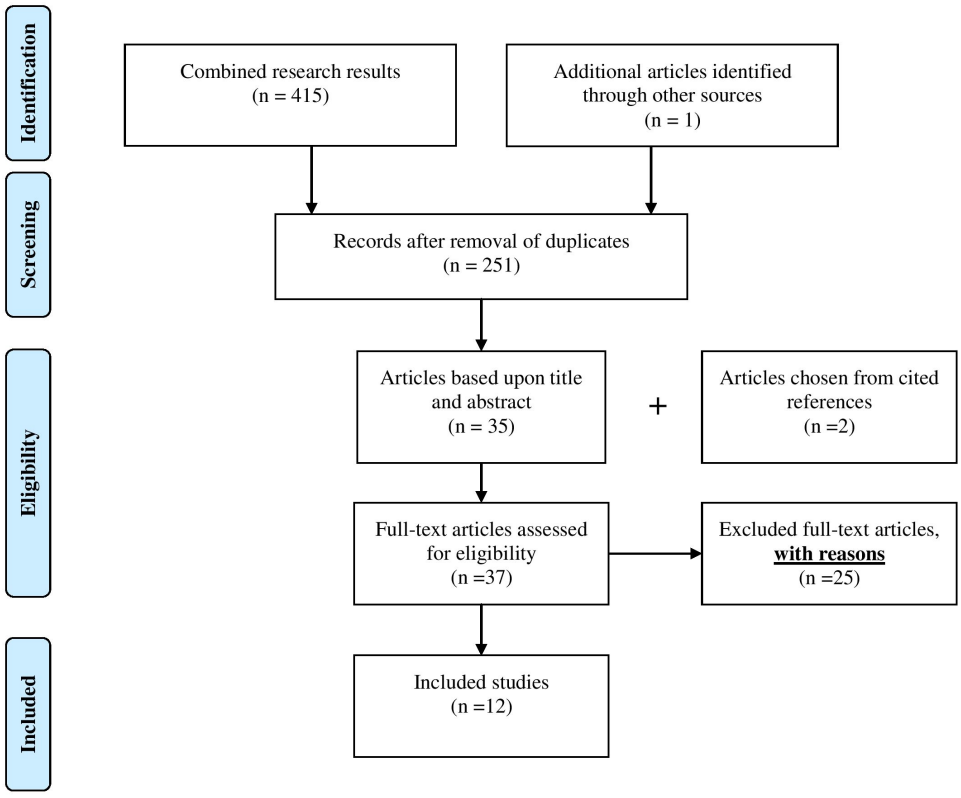

Figure 1 Search process using Preferred Reporting Items for Systematic Reviews and Meta-Analyses systematic review of literature.

Ideal and actual composition of MDT

According to most theoretical studies MDT ideally consist of an endocrinologist, an urologist and a surgeon.[11–16] Some papers also include geneticists,[11–14] psychologists,[11–15] gynaecologists[12–14 16] and radiologists.[11 13 14]

However in practice, the core team was composed of endocrinologists,[9 17–21] accompanied almost always by urologists/surgeons,[9 17 19–21] geneticists,[9 18–20] gynaecologists[9 19–21] and psychologist/psychiatrists.[9 19–21]

The vast majority of articles considered multiple methods of medical management as being the task of MDTs: genetic testing (including karyotyping), biomedical assessment (such as hormone levels, blood and urine tests), genital surgery and ultrasounds.[11–14 16–21] Less than half of the papers suggest that in the MDTs each specialist is singularly responsible for the medical management.[11–14 17] Half of the papers did not specify the responsibility for medical management.[9 16 18–21] Only one paper[15] argued that specialists should talk to each other about their medical tasks and collaborate with coordinator.

Next to medical management, psychosocial care was considered by six articles to be a key task of MDT. This role was mostly ascribed to psychologists.[9 11–13 16 19] In only one paper psychosocial care was said to be provided by all the members of the team.[21]

Most studies focused on the importance of psychosocial support for parents to help them cope with their child being intersex.[11 13 16] Psychologists should provide them information, connect parents to support groups[13 16] and function as mediators between parents and healthcare professionals to facilitate the decision-making process.[12 13] Ahmed and colleagues[11] argued that psychosocial support ought to be provided to people with VSC in general to help them cope with the whole process. Only one empirical study[19] focused on psycho-social support as part of MDT. The authors found out that in the initial phases of the multidisciplinary care psycho-social counselling is secondary to medical treatment. What is more psychologists rarely collaborate with medical professionals and the former take on reconciliatory role between medical professionals, patients and parents in the last stages of the care process.

Models of collaboration and barriers

In most studies,[11–21] the model of collaboration—multidisciplinary, interdisciplinary or transdisciplinary—was not explicitly mentioned. Still most of the papers seemed to indicate a multidisciplinary approach in MDTs described as the simultaneous but independent contribution of two or more team members. Two empirical studies[19 21] and the mixed-methods study[9] show that although participants referred to their team as an MDT or even interprofessional, their responses reflect a disintegrated approach.

In most studies, interaction among team members was mediated by a team coordinator who was responsible for delegating and reviewing tasks.[11–18 20] The

Table 2 Included theoretical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Ahmed *et al*[11]	2016	UK	Theoretical	Adolescents	Clinical psychologist should examine early emotions of people with VSC, facilitate adjustment of parents to new-born, informed decision-making process	Endocrinologist, surgeon and/or urologist, clinical psychologist/ psychiatrist, radiologist, nurse and neonatologist	Paediatric endocrinologist should take the role of coordinator of sex assignment and decision-making process	Multidisciplinary	Informed consent
Brain *et al*[12]	2010	UK	Theoretical	New-borns	Psychologist as mediator between physicians and patients	Endocrinologist, (paediatric) urologist/surgeon, gynaecologist, psychologist, biochemist, clinical/ molecular geneticist, ethicist	Psychologist has the crucial role, manages the process of communication between physicians and families	Multidisciplinary	Informed consent and decision-making
Gomez-Lobo[13]	2014	USA	Theoretical	Infants, children, adolescents	Psychosocial support should cover family support and facilitation of the decision-making process regarding medical treatment	Physician, endocrinologist, nurse, counsellors, geneticist, paediatric urologist, surgeon, radiologist, bioethicist, gynaecologist—focus in this article	A team coordinator is important in the creation of the service as well as ongoing functioning of the team and the team should educate other healthcare professionals	Multidisciplinary	Shared decision-making
Hiort *et al*[14]	2014	D	Theoretical	Infants, children	/	Endocrinologist, surgeon/urologist, psychologist, gynaecologist, geneticist, molecular biologist, radiologist, pathologist, biochemist	Patient navigator coordinates communication between patients/families with the team	Multidisciplinary	Informed consent
Moran and Karkazis[15]	2012	USA	Theoretical	Infants, children	Psychiatrist, and/ or social worker can provide early and ongoing psychosocial care and access to support resources for parents and patients	Paediatric endocrinologist, a paediatric urologist and/or surgeon, and a psychologist, psychiatrist, and/or social worker	The development of a team requires coordination in the planning, implementation, and functioning stages, and a team coordinator	Multidisciplinary	Shared decision-making

Continued

Table 2 Continued

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Vora and Srinivasan[16]	2010	AU	Theoretical	Neonates, children, adolescents	The (clinical) psychologist can aid in assessing the parents' and young person's understanding of information discussed and provide family support in a culturally sensitive manner	Endocrinologist, urologist, gynaecologist	The biomedical assessment is most often coordinated by the paediatric endocrinologist	Multidisciplinary	Informed consent?

VSC, variations of sex characteristics.

coordinator was usually one of the following specialists: endocrinologists,[11 16 18] geneticists,[20] a physician,[13] social worker[15] or psychologist.[12] Only in the study of Streuli and colleagues[21] the MDT collaborated and cooperated with patients and parents without the mediation of a coordinator.

In most empirical[17–21] and theoretical[11–16] articles the model of collaboration was not explicitly mentioned but most of the papers seem to indicate that MDTs take a multidisciplinary approach insofar the teamwork was described as the simultaneous and independent contribution of two or more team members. Only the mixed-methods study of Sanders and colleagues[9] included an interprofessional team approach where patients, parents and members of the MDT actively cooperate in the treatment process in order to cocreate knowledge and improve the care of people with VSC and help parents cope with their child's condition.

As Liao and Roen[19] pointed out medical professionals have more important role than psychologists whose work is seen as non-intervention because it is not medical and it is as such often side-lined.

The most often mentioned barriers to multidisciplinary collaboration were lack of financial, organisational and financial resources at hospitals and care centres for MDTs to be implemented and registered.[11–14 18] The key barrier to collaboration, for example, formation of MDTs in these centres is the lack of specialists.[9 12 13 18] One-fourth of the papers[9 12 21] stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process because sharing information can be distressing to parents to the point where they cannot participate in the shared decision-making process.

Two papers[14 20] pointed out the difficulties of diagnosis referred to as the time of diagnosis and the precise determination of VSC. The lack of cooperation between medical professionals and psychologists and prevalence of medicalised approach was highlighted as a barrier in one case.[19] Only one study[21] pointed out the emotional distancing and difficulties of medical professionals to distinguish facts from assumptions as obstacle to collaboration process. One-fourth[15–17] of the papers did not specify any barriers to collaboration process.

Ethical principles of MDTs

The most commonly cited ethical principles were informed consent,[11 12 14 16] and shared decision-making.[13 15 17 18 20 21] However, only a minority[9 11 12 17] of papers provided an account of implementation of these two ethical principles. The papers[9 11 12 17] stated that parents needed to be educated about the condition of their child and that parental fears need to be considered in the decision making process. Yet there was a lack of mention of how patients themselves growing up should be educated about their condition and actively involved in the decision-making process. Only two papers mentioned the involvement of patients in the decision making process.[11 15] Two papers[13 20] emphasised that the

Table 3 Included empirical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Chawla *et al*[17]	2019	USA	Empirical	An infant	Psychosocial support was provided: risk and benefits including the psychological consequences of having atypical genitalia were reviewed with the family	Endocrinologist, urologist, and paediatric, surgeon, clinical coordinator	Clinical professional coordinates the team and shared decision-making process	Multidisciplinary	Shared decision-making
Kyriakou *et al*[18]	2016	UK	Empirical	Children	/	Paediatric endocrinologist, clinical geneticist, paediatrician, neonatologist, adult endocrinologist	Paediatric endocrinologist has the central role in the team	Multidisciplinary	Informed consent
Liao and Roen[19]	2019	UK, SE	Empirical	Children	Psychologists' role is pushed aside in the begging of examination. The psychologist sometimes mediates the emotional mess to prevent patients from disengaging with the service	Gynaecologists, urologists, paediatric surgeons, endocrinologists, geneticists, psychologists and nurse specialists	Team means a collection of specialists—there is no real collaboration, it is rather multi-professional	Multidisciplinary	/
Parisi *et al*[20]	2007	USA	Empirical	Infants, children	Psychosocial support for families: parents are given pragmatic, age-appropriate recommendations for disclosure of a diagnosis of a DSD to a child in an honest, non-stigmatising manner	Specialists in medical genetics, cytogenetics, gynaecology, and reproductive endocrinology and the paediatric specialties of urology, endocrinology, adolescent medicine, and psychiatry	The role of geneticists is highlighted and in the initial stages coordinates the team	Multidisciplinary	Shared decision-making
Sanders *et al*[9]	2017	UK	Mixed method	Children, adolescents	The nurse and psychologists are information exchange agents acting in an advocacy role	Endocrinologist and geneticist were always present. In 9 out of 10 clinics urologist and psychologist. Gynaecologists were present in seven clinics, nurse attended three clinics, one site had a nurse as a consistent and integral member of the team	Patients are also educators: general discussions about which topics or concerns were likely to be raised in clinic as issues based on connection to families helped professionals to 'really think about what's going to happen in a consultation'	Interprofessional	/

Continued

Table 3 Continued

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Streuli *et al*[21]	2012	CH, D	Empirical	Children	Psychosocial care is shared and provided or at least considered by all MDTs	Paediatric endocrinologist, psychologist, specialist in sexual medicine, child and adolescent psychiatrist, paediatric surgeon, social worker, study nurse, gynaecologist, neonatologist, member of a support group	The team members collaborate with each other, family and the patient	Interprofessional (only pro forma), in reality it is multidisciplinary	Shared and information based decision-making process

DSD, differences of sex development ; MDT, multidisciplinary team.

communication between MDT and parents/patients in the process of making an ethical decision should be open and should include the concerns of parents, but not children.

DISCUSSION

The scoping review identified 12 studies that either empirically or theoretically provided an account of MDTs caring for patients with VSC. Almost all articles stressed the importance of MDT, but under closer examination the exact nature of collaboration remained unclear. The prevalent approach seemed to be multidisciplinary, that is, collaboration in which different care providers work simultaneously but separately. The papers rarely elaborated on implementation of multidisciplinarity let alone critically examine it.

Research on MDT in other healthcare contexts suggests that it is not enough to have a unit of different healthcare professionals working together,[22 23] but the responsibility, knowledge and authority should be flexibly shared and team members should believe in cooperation.[22 24–26] However, the studies in our scoping review failed to address these suggestions as there are no indicators to assess the impact of the MDT which could lead to improved care for people with VSC.

The teamwork is usually coordinated by an endocrinologist, physician, and in a few instances by a psychologist, even though this was not always empirically assessed, because the exact nature of the relationships within the teams and their working practices were not revealed. The papers clearly demonstrate the dominance of medical professionals over other healthcare experts and psychosocial care in the core teams which necessarily include endocrinologists, urologists and surgeons and to lesser extent psychologists, social worker and ethicist.

Our scoping review confirmed the findings that tend toward a more medical-oriented structure (predominance of doctors in the teams) of MDTs leads to poor collaboration and efficacy.[26 27]

This was also partly confirmed by data on psychological support which is thought of and provided in terms of ‘alleviating emotional distress of parents facing the fact that they have a child with VSC’. Psychological support is provided to mediate relations between families and medical professionals, but it is seen as an addition to the treatment provided by medical professionals.

The account of psychological support revealed absence of child-centred approach and a lack of combined child centred approach with family-oriented care as there was no mention of what kind psychological support is provided for people with VSC, but only for their families. This was reverberated in ethical principles as only two papers mentioned that the decision making process and informed consent should include people with VSC. This might be since the majority of papers focused on infants and children, however these studies failed to address the role and implementation of shared decision making for

them. The studies also did not refer to care of adults and transition of care from adolescence to adulthood.

The lack of inclusion of patients' perspective and preferences in the treatment of people with VSC and shared decision making process in the examined literature is consistent with previous findings. According to these findings, healthcare professionals stated that patient's perspectives should be an important part of the meetings of the MDT, but do not consider it beneficial to the meetings of MDTs.[27] It is seen to be at the odds with professionals standards, and what is more medical professionals conflate shared decision making process with informed consent or there is no awareness of the former term.[28]

Although some papers aimed to advocate for approach according to which teams educate their patients and even learn from them—the interprofessional approach which seems to de-hierarchise the knowledge relations between patients and medical professionals—they remain a minority within the current literature on medical collaboration in MDTs working with people with VSC.[9]

LIMITATIONS

The scoping review explored the existing literature on MDTs examining the collaboration processes and ethical frameworks. Some relevant studies might have been overlooked due to exclusion/inclusion criteria, for example, conference abstracts and grey literature might have provided information from patients on the MDTs. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore we propose the following suggestions for future research: investigating the role of the healthcare professionals in the teams in the decision making process; examining the nature of relationship between patients and MDTs; examining the lack of care for adults and transition; more research on how MDTs can actually work together; researching new models of collaboration within the MDTs and how they relate to ethical dilemmas working with people with VSC: informed consent versus competence and capacity of children and young people of children and their rights to participate in their treatment.

CONCLUSION

The scoping review revealed that teams caring for people with VSC are seemingly multidisciplinary. The collaboration among them lacks cooperation and synthesised discipline approach as one team member—usually a medical professional (an endocrinologist, a geneticist or a physician), rarely a psychologist or a social worker, coordinates the management process while the rest of the team members seem to work separately. Only a minority of team members come from disciplines such as social work or psychology. The most frequently cited ethical principles are shared decision making and informed consent, but both tend to focus on parents rather than on patients. Future studies should pursue empirical research on MDT by examining in detail the process of shared decision making between MDT, parents, adults and children.

Contributors MG, EdC and JS planned the study. MG as the guarantor took the lead in performing the data analysis, writing the manuscript and doing the scoping literature research. EdC contributed to data analysis, supported the literature research and refined the original manuscript by critically revising it. JS supervised the data analysis and the preparation of manuscript. All authors critically reviewed the final draft of the manuscript.

Funding The authors would like to thank Research Executive Agency (REA)—European Commission for their financial support (859869—INIA).

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study does not involve human participants.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. Not applicable.

ORCID iD

Martin Gramc http://orcid.org/0000-0001-5378-8792

REFERENCES

1 Wiesemann C. Ethical guidelines for the clinical management of intersex. *Sexual Development* 2010;4:300–3.
2 Cresti M, Nave E, Lala R. Intersexual births: the Epistemology of sex and ethics of sex assignment. *J Bioeth Inq* 2018;15:557–68.
3 Hughes IA, Houk C, Ahmed SF, *et al*. Consensus statement on management of intersex disorders. *Arch Dis Child* 2006;91:554–63.
4 Pasterski V, Prentice P, Hughes IA. Impact of the consensus statement and the new DSD classification system. *Best Pract Res Clin Endocrinol Metab* 2010;24:187–95.
5 Lee PA, Nordenström A, Houk CP, *et al*. Global disorders of sex development update since 2006: perceptions, approach and care. *Horm Res Paediatr* 2016;85:158–80.
6 Cools M, Nordenström A, Robeva R, *et al*. Caring for individuals with a difference of sex development (DSD): a consensus statement. *Nat Rev Endocrinol* 2018;14:415–29.
7 InKomal A, Vora C, Bergmann P. Multidisciplinary team (MDT) review of management decisions in disorders/differences of sex development (DSD): experience of two paediatric tertiary hospital network 2016.
8 Prandelli M, Testoni I. Inside the doctor's office. talking about intersex with Italian health professionals. *Cult Health Sex* 2021;23:484–99.
9 Sanders C, Edwards Z, Keegan K. Exploring stakeholder experiences of interprofessional teamwork in sex development outpatient clinics. *J Interprof Care* 2017;31:376–85.
10 Shamseer L, Moher D, Clarke M, *et al*. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ* 2015;349:g7647.
11 Ahmed SF, Achermann JC, Arlt W, *et al*. Society for endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (revised 2015). *Clin Endocrinol* 2016;84:771–88.
12 Brain CE, Creighton SM, Mushtaq I, *et al*. Holistic management of DSD. *Best Pract Res Clin Endocrinol Metab* 2010;24:335–54.
13 Gomez-Lobo V. Multidisciplinary care for individuals with disorders of sex development. *Curr Opin Obstet Gynecol* 2014;26:366–71.

14 Hiort O, Birnbaum W, Marshall L, *et al*. Management of disorders of sex development. *Nat Rev Endocrinol* 2014;10:520–9.
15 Moran ME, Karkazis K. Developing a multidisciplinary team for disorders of sex development: planning, implementation, and operation tools for care providers. *Adv Urol* 2012;2012:1–12.
16 Vora KA, Srinivasan S. A guide to differences/disorders of sex development/intersex in children and adolescents. *Aust J Gen Pract* 2020;49:417–22.
17 Chawla R, Weidler EM, Hernandez J, *et al*. Utilization of a shared decision-making tool in a female infant with congenital adrenal hyperplasia and genital ambiguity. *J Pediatr Endocrinol Metab* 2019;32:643–6.
18 Kyriakou A, Dessens A, Bryce J, *et al*. Current models of care for disorders of sex development – results from an international survey of specialist centres. *Orphanet J Rare Dis* 2016;11:1–10.
19 Liao L-M, Roen K. The role of psychologists in multi-disciplinary teams for intersex/diverse sex development: interviews with British and Swedish clinical specialists. *Psychol Sex* 2021;12:202–16.
20 Parisi MA, Ramsdell LA, Burns MW, *et al*. A gender assessment team: experience with 250 patients over a period of 25 years. *Genet Med* 2007;9:348–57.
21 Streuli JC, Köhler B, Werner-Rosen K, *et al*. Dsd and professionalism from a Multilateral view: supplementing the consensus statement on the basis of a qualitative survey. *Adv Urol* 2012;2012:1–8.
22 Durand F, Fleury M-J. A multilevel study of patient-centered care perceptions in mental health teams. *BMC Health Serv Res* 2021;21:44.
23 Mayo AT, Woolley AW. Teamwork in health care: maximizing collective intelligence via inclusive collaboration and open communication. *AMA J Ethics* 2016;18:933–40.
24 Choi BCK, Pak AWP. Multidisciplinarity, interdisciplinarity, and transdisciplinarity in health research, services, education and policy: 3. discipline, inter-discipline distance, and selection of discipline. *Clin Invest Med* 2008;31:41–8.
25 Morley L, Cashell A. Collaboration in health care. *J Med Imaging Radiat Sci* 2017;48:207–16.
26 Saint-Pierre C, Herskovic V, Sepúlveda M. Multidisciplinary collaboration in primary care: a systematic review. *Fam Pract* 2018;35:132–41.
27 Rosell L, Alexandersson N, Hagberg O, *et al*. Benefits, barriers and opinions on multidisciplinary team meetings: a survey in Swedish cancer care. *BMC Health Serv Res* 2018;18:249.
28 Hayes D, Edbrooke-Childs J, Town R, *et al*. Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the theoretical domains framework. *Eur Child Adolesc Psychiatry* 2019;28:655–66.