9 Our findings: Right to health care - a gap in expectations

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The guideline on gender incongruence pays great attention to the patients' right to health care. The right to necessary health care from the municipal health and care services and the specialist health service is laid down in the Patients' and Users' Rights Act. The concept of "necessary health care" is interpreted as giving a right to (necessary) health care of an acceptable standard based on an individual assessment of need. The scope and level must therefore be assessed specifically on the basis of a health professional assessment of the patient's needs.

The requirement of soundness should always be decisive in assessing the patient's right to healthcare. The right can be related to the municipal health services and to the specialist health services.

The national professional guideline is not clear on the level of assistance to be provided once a medical assessment of need has been made. It is left to the service to define who is entitled, what they are entitled to and when they are entitled to different health services. What is considered specialist health care and what services can be provided by the municipal health service is also not clearly defined. This is more or less left to the services to define based on an assessment of justifiability.

In order to be entitled to healthcare from the specialist health service, some specific requirements must be met. Firstly, the right is linked to a medical assessment of the patient's need for specialized health care. The guideline does not say anything about what should be included in a medical assessment of the need, but that it must be based on a proper assessment of the patient. The guideline states that gender incongruence in itself does not provide grounds for referral to the specialist health service, but there may be a risk of developing a mental disorder. People with gender incongruence may have gender dysphoria, a condition that causes psychological pain, discomfort or other complaints that require health care. It is the individual's need that determines whether they are entitled to health care and the level of care they should receive.

The Prioritization Regulations elaborate on the assessments that are relevant for determining who is entitled to necessary health care from the specialist health service. In the individual assessment of the patient's entitlement, the expected benefit of the health care must be assessed. The expected benefit of the healthcare is assessed on the basis of whether evidence-based practice indicates that

the healthcare can increase the patient's life expectancy and/or quality of life. It must be assessed whether the health care product can increase the probability of: survival or reduced

loss of function, physical or mental improvement of function, reduction of pain, physical or mental discomfort, cf. the Priority Regulation.

As described above, little is known about the long-term effects of puberty-delaying treatment and gender-affirming treatment with hormones. There is a need for more research to be able to say something about short- and long-term effects. It is therefore also difficult to say anything about the expected benefit of the treatment as long as we do not have a sufficient knowledge base.

The right to necessary health care does not include experimental or test treatment, cf. Circular I-4/2019. Experimental treatment means all treatment where efficacy and safety have not been sufficiently documented for the treatment to be included in the ordinary treatment offer. Investigational treatment covers both treatment tested in clinical trials and treatment provided outside clinical trials, but the general rule is that investigational treatment should be provided through clinical research studies. The national principles allow for treatment that is not based on sufficient documentation to be given to individuals outside clinical trials in exceptional cases when this is professionally justifiable. This is stated in the Directorate of Health's guidelines for investigational treatment. It also states that although the principles for experimental treatment were developed for the specialist health service, they can also be used as a basis for the use of experimental treatment in the municipal health and care services.

This means that there is room for maneuver to offer investigational treatment, but it is a fundamental prerequisite that the offer of investigational treatment is assessed as justifiable. The justifiability requirement is a legal standard that changes in line with medical and technical developments, but the core is linked to what is defined as established treatment at any given time. When there is no established treatment option, it is particularly important to have a safe framework for the treatment. Treatment must then take place within a predictable framework and contribute to increasing knowledge. This is particularly important for the group of teenagers with gender dysphoria who are increasingly seeking the health services for puberty delaying and gender affirming treatment where the research-based evidence base is inadequate.

It is the health authorities that decide what should be available in the service. This is based on a thorough assessment of the available knowledge about the service. Knowledge is obtained, among other things, through HTAs. A full HTA involves a comprehensive systematic assessment of new or established methods in which efficacy, safety and/or cost-effectiveness are reviewed and assessed. The assessment often also includes questions concerning ethical, legal, organizational and societal consequences.

The national guideline on gender incongruence does not use the concept of experimental treatment and bases the right to necessary specialist health services on experience-based knowledge. This is not consistent with other help provided by the specialist health service. The prioritization regulations stipulate that the patient should benefit from the health care and that the assessment of benefit requires evidence-based practice. The national guideline also points out that evidence-based practice is inadequate and highlights a prerequisite when describing the main elements of evidence-based practice:

> *"It is possible to develop evidence-based recommendations with more emphasis on clinical experience and user knowledge while awaiting research-based documentation, as has been done in this guideline. This assumes that health care will be followed by systematic collection of data for research. The basis for making clinical decisions will thus be better in the time to come."*

This lack of connection between the right to health care and ambiguities in the evidence base means that the health authorities must make a thorough assessment of the justifiability in the light of the available evidence base. They must make this assessment before deciding which services to provide. It will therefore be demanding for the regions to put in place an assistance and treatment

Gender-affirming treatment is ongoing among different actors in Norway. No national register has been established, nor have there been specific requirements or resources allocated for follow-up research with systematic data collection. The knowledge base is thus not strengthened to make better clinical decisions locally at the individual practitioner, regionally or nationally. By defining treatment with puberty blocks, gender-affirming hormone therapy and surgery for children and adolescents as experimental treatment, there will be stricter requirements for a predictable framework for the help. This will contribute to safer and more predictable services. The framework will also contribute to increased knowledge.

Different expectations

Our investigation indicates that there is a gap between what the guideline outlines and what is possible given the current available services and knowledge base. When the national guideline states that people with gender incongruence are entitled to health care, without the evidence base being well documented and without a good overview of any negative aspects of the treatment, an expectation is created among patients that the services can hardly meet.

This relates both to expectations of the health service and its organization. Parts of the patient population have an expectation that the right to treatment should be fulfilled on the basis of a subjective need. It thus becomes a source of frustration when the Norwegian health system is organized in such a way that requirements for expected benefit, efficacy and safety are what trigger the type of help and treatment.

For many people with gender incongruence, it can be difficult to know what the right help and treatment options are. Here, as elsewhere in the service, the GP will first have an important function in helping the person to find the right health care and then as support during the treatment and after the treatment is completed. The GP has a gatekeeper function in the Norwegian health service, and this is important for patient safety in order to avoid overtreatment, among other things. In our study, we see that some actors in this field use the gatekeeper model as an argument for discrimination. The role of the GP in relation to access to specialist health services applies across patient groups. The role can be challenging to manage, especially when unclear frameworks or criteria for treatment meet clear patient expectations. There is a need to clarify the framework for care and treatment and to align expectations.

Health personnel have also told us that it is difficult to relate to the expectations of rights in a field where they are faced with difficult ethical considerations between "doing good" versus "doing no harm". Ukom has been told by health personnel that gender incongruence is a field that many are reluctant to enter because of the fear of doing more harm than good.

In summary

We see that when the evidence base is insufficient, the right to health care creates conflicting expectations and demands. One consequence of this is that some patients feel that they are not seen and heard. There is a great need to harmonize expectations and opportunities in patient care for children and adolescents with gender incongruence and gender dysphoria. It must then be considered whether the interventions require a framework that meets the requirements for experimental treatment.

It is important to make the necessary clarifications at system level to reduce the gap between expectations and practice. Expectations that are not met are burdensome for patients and their families and create ethical dilemmas for those working in the service.

10 Our findings: Performance climate and interaction

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Discrimination and the fight for rights has been an ongoing issue within the trans community. Patient and family organizations and professionals have been active in advocacy work, demanding better patient services and various measures to prevent discrimination against trans people in the health services. This has gone hand in hand with important work aimed at promoting the rights of trans people in all sectors of society.

Performance climate and development of health services

Diversity and inclusion are also key issues in the ongoing debate about the treatment of people with gender incongruence and gender dysphoria. The debate about whether the health service is inclusive and what constitutes good practice is ongoing in the media, social media and within the health service. In our review of the debate, we see that it is sometimes unbalanced and highly polarizing.

This leads to several simplistic messages that are very unfortunate for the field of gender incongruence in terms of establishing a comprehensive and equal health service for those in need of help and treatment.

A climate of expression has developed that is characterized by polarization and harsh, judgmental language. The Freedom of Expression Commission, which delivered its report in 2022, highlighted the debates on gender diversity and gender expression as an area where social condemnation can be high for those who choose to express themselves.

"Those who enter the debates risk being labeled as phobic, prejudiced, hostile or reactionary"

THE FREEDOM OF EXPRESSION COMMISSION

Furthermore, the Freedom of Expression Commission writes that this will limit the real freedom of expression for others, including those who wish to contribute new or different perspectives, facts and opinions. Empathy, the ability to put oneself in the shoes of others, requires a common space for conversation where everyone has the opportunity to participate.

Our report points out that work remains to be done to put in place a differentiated health service that addresses the different needs of gender incongruence. A health service must embrace the gender diversity that exists in society. To succeed in this, it will be important to establish a climate of cooperation in order to further develop the health services. Our survey shows that parts of the current dialogue from some actors are characterized by ideology and an us-versus-them rhetoric. Ukom is concerned that the current discourse and level of conflict inhibits rather than promotes the development of sound health services and treatment options.

In recent decades, there has been a major focus on and further development of patient, user and family participation in the health service. We believe that in the future it is important to use the established systems and methods that have been developed nationally and internationally as a framework for cooperation. User participation at system level can contribute to increased accuracy and quality, both in service development and research. The Norwegian Directorate of Health is working to develop national professional advice for user participation in the field of substance abuse and mental health, with the aim that these can eventually be further developed for the entire health and care service. The project highlights these benefits at the system level:

- User and family knowledge is understood and used as an equal area of knowledge in service development, implementation and evaluation at system and service level.
- User and carer organizations, user-run centres, experience consultants and other patient and user voices have a common understanding of each other's roles and responsibilities.
- Staff and managers in the services facilitate increased user and family involvement.

These points are also good for highlighting some of the conditions for a genuine and respectful climate of cooperation:

- Stakeholders have a responsibility to see each other as equal partners with important knowledge to develop services.
- Stakeholders have a responsibility to establish a common understanding of each other's
- roles and responsibilities. The service is responsible for facilitating increased user and family involvement.

Effects of a harsh climate of expression

We have found that the debate taking place in the media and on various social networks affects those with gender incongruence and gender dysphoria, their families and those working in the field. The debate is characterized by sometimes major and fundamental differences of opinion. Particularly prominent is the discussion about what treatment should be offered to young people with gender

incongruence and gender dysphoria.

We have found that the debate and disagreements affect four areas in particular that can compromise patient safety. It affects:

- the relationship between patient and carer/treatment provider
- access to information
- participation in the debate
- recruitment/engagement in the field

Relationship and alliance building between the therapist/helper and the person seeking help/treatment can be affected by disagreements and differing expectations. Conversations and assessments that help to find the right help for the individual require a safe and open climate for expression. It is demanding to build security, trust and alliances in a landscape of uncertainty, distance and fear. We find that within gender incongruence, both trust in therapists and in treatment institutions is affected by a debate about what is good practice in the treatment of gender dysphoria.

In general, it can be difficult for children and young people to find relevant health information. In particular, it can be difficult for children and young people to deal with conflicting messages from professionals and from discussions on the topic in social media. At times, we see that messages about help and treatment for gender incongruence are not very nuanced, and it is difficult to get an overview of the risks and benefits of the treatments.

"We don't talk about side effects very much. There's talk of "as long as I get hormones, my body will go in the direction I want". I think it's important that we have a balance here. The fact that you have side effects, or that you are struggling, does not mean that this is wrong."

REPRESENTATIVE PATIENT ORGANIZATION

"We also need to look at hormones. It can create pleasure and serious side effects. Blood clots and so on. There are also many people I meet who don't understand the seriousness of side effects. This is something that not only affects you on the outside, but also on the inside"

REPRESENTATIVE PATIENT ORGANIZATION

The use of harsh and judgmental language carries the risk that some people may be reluctant to participate in public debate. For some, it may be too challenging to participate and express themselves because they have opinions that they know will not be tolerated by everyone. In this climate of expression, the cost of participating in public discourse with opinions or expertise may be too high.

"So polarized a debate that even as a patient, I risk being verbally trampled - caught in having to choose sides. Like a divorce debate."

PREVIOUS PATIENT ASSESSMENT/TREATMENT GENDER INCONGRUENCE

Recruitment of clinicians and researchers to the field is affected by the debate. The fierce debate may also make practitioners reluctant to work in the field for long periods of time. Professional disagreement and lack of consensus can also increase the burden on practitioners, and a pressured work environment can compromise patient safety.

"This is a very demanding field to work in. Unfortunately, the polarization means that we just stand and bump into each other instead of improving the field. I have a friend who works in the BUP system, and in relation to this topic she says: I go to work, and almost no matter what I do, I make mistakes."

TREATMENT

"Polarization is blocking research."

PRACTITIONER AND RESEARCHER

Fear

The word fear has been repeated by several stakeholders in our survey. Children and young people are afraid of not being believed and understood, and many are afraid of not getting the help and treatment they need. We have been told by several young people who are being examined for gender incongruence that they answer what they think is expected. Young people also share their experiences on social media, and they can get information on how best to respond in order to access gender-affirming treatment.

Relatives are afraid that their child will not receive the right health care, and they point to the many influences, complexities and climate of expression that make this particularly difficult. Relatives also report that they are afraid to express their concerns and uncertainty about the invasive treatments for fear of being labeled as transphobic. They express that they want to be supportive and caring. Relatives also mention that friends and close family members may avoid asking critical questions to

their young person for fear of hurting their feelings.

Practitioners report that they are afraid of offending, afraid of ignoring other illnesses or giving treatment for which they are not fully aware of the effects or consequences, and in particular they are afraid of causing harm or not providing proper health care. They express concern about overtreatment, for example, starting hormone treatment unnecessarily or too quickly, or the treatment period with puberty blockers being too long. They also express concern about malpractice, for example when they have to take over the assessment, treatment and follow-up of children and young people who have started treatment on their own or with other practitioners on varying grounds. One practitioner in the field has recently lost his license for various reasons, and media coverage has conveyed much fear in this regard.
Professionals with different perspectives at different levels of the health service report that they receive harassment and threats, but in conversations with Ukom, these different actors have been primarily concerned with patients, patient safety and soundness. Although the conditions can be demanding, practitioners in the health service also report a lot of support and good patient relations. Several patient organizations and professionals also express concern about undertreatment and the consequences of this if the decentralized service is not put in place. Many are afraid that the outcome of the ongoing debate on accountability will be a reduction in treatment services.

In summary

The climate of expression in this field in the public domain affects the available information for children and young people with gender incongruence and gender dysphoria and their families. There is a massive impact on children and young people in different communities, also related to treatment and health services. There is a lot of fear and anxiety about getting it wrong from all sides. Different opinions about what is the right treatment can lead to difficult cross-pressures. Different emphasis and discussion of what is necessary at group level can confuse and undermine patient-provider relationships and a personalized approach for the person concerned.

We would like to emphasize that all actors have a shared responsibility for good coordination. The field needs to establish a constructive community for everyone involved in good health care for people with gender incongruence and gender dysphoria. This could make it easier for clinicians and researchers to seek out the field and, not least, for children and young people and their families to seek the help they need.

In addition, interested and affected parties need quality-assured information on the treatment options for gender incongruence and current knowledge on efficacy and safety. This information needs to be accessible and adapted to different target groups, including children and young people.

11 Our recommendations

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Our survey shows that there are major differences in the health services for children and adolescents with gender incongruence and gender dysphoria. Actors in the health services have different understandings of the knowledge base and different assessments of what constitutes acceptable health care. This has led to a situation with variation in the treatment offered, where patients may encounter different expertise and different approaches to assessment and treatment depending on which provider they seek help to manage their gender incongruence and gender dysphoria. It is now important to strengthen the help provided in the municipalities, the specialist health service throughout the country and the national treatment service.

We see that the national guidelines leave too much room for different interpretations, which has resulted in variations in the treatment offered to children and young people. When the authorities decide to grant a group the right to health care, this must be based on a thorough assessment of need, justifiability, cost and benefit. The guidelines must provide the services with the necessary guidance and be a tool for professional standardization that the services can use to ensure that patients receive appropriate and equal health care throughout the country. The evidence base for the treatment of gender incongruence and gender dysphoria is inadequate. This is particularly true for the teenage population, which accounts for a large part of the increase in referrals to the specialist health service over the last ten years. The stability of gender dysphoria that occurs or is expressed in the teenage years is not known. It is also true for patients with non-binary gender incongruence and gender dysphoria.

Against this background, UCOM's recommendations relate to revising the guideline, ensuring a safe framework for the treatment offered and measures to strengthen the evidence base. The recommendations will also ensure systematic data collection and promote follow-up research. It is important that children and young people with gender incongruence and gender dysphoria, including non-binary people, are properly cared for while health services are being developed.

1. Revising the national professional guideline on gender incongruence

Ukom recommends that the Ministry of Health and Care Services commission the Norwegian Directorate of Health to revise the national guideline on gender incongruence. The revision must be based on a systematic review of the evidence.

The following should be included in an audit:

- clarify which treatments can/should be done by primary care, what can/should be done at regional level and what should be done by the national treatment service clearer professional
- guidelines and recommendations for the content of the assessment
- clearer professional criteria for the initiation and completion of treatment
- concrete guidelines for clinical issues that may arise during the course of assessment

and treatment, including specifications on indications and contraindications clearer requirements for the follow-up of patients before, during and after the end of treatment

- clearer guidance on when and how relatives should be involved in the assessment and treatment process
- clearer guidance on how services should address issues of competence to consent in children and young people seeking treatment for gender incongruence and gender dysphoria
- clearer guidance on the skills required by services to assess and treat children and young people with gender incongruence and gender dysphoria
- clearer guidelines for the care of all people with gender incongruence and gender dysphoria, regardless of whether or not highly specialized treatment is appropriate

A systematic review will also contribute to a common platform, language and terminology for the different actors involved in the field. A systematic review can build on recent reviews from abroad.

2. Ensuring a safer environment for the treatment of children and young people

In order to improve the basis for making clinical decisions, it is a prerequisite that health care and treatments are followed by systematic collection of data for quality assurance and research. Clinical research aimed at improving quality and patient safety is in line with the National Action Plan for Clinical Trials and is necessary in this field. This will help to ensure a safe framework for the treatment and follow-up of children and young people until the knowledge base on efficacy and safety is sufficiently documented.

Ukom recommends that puberty blockers and hormonal and surgical gender affirming treatment for children and adolescents be defined as investigational treatment. This is particularly important for teenagers with gender dysphoria.

3. Strengthening the knowledge base - National Medical Quality Registry

Our findings show that the knowledge base is insufficient, and we therefore make several recommendations that together will help to strengthen the knowledge base.

We believe that there is a need to establish a medical quality registry with national status. We consider that the treatment of children and adolescents with gender incongruence and gender dysphoria meets the criteria for establishing a national medical quality register. According to the Norwegian Directorate of Health's national guidelines for approval of medical quality registers for national status, a lack of professional consensus on diagnostics and treatment may be grounds for prioritizing the establishment of a medical quality register with national status.

Ukom recommends that the Ministry of Health and Care Services consider whether a national medical quality register should be established for the treatment of children and adolescents with gender incongruence. Necessary measures must be taken to ensure that such a national quality register can be established, operated and financed in order to contribute to an overview, improve quality and reduce unjustified variation in patient treatment.

12 Procedure for the survey

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In the spring and summer of 2022, Ukom received two reports of concern from relatives of adolescents and young adults with gender incongruence. The reports of concern provided the basis for going into the topic of gender incongruence in more detail. We have not examined a specific patient history, but we have gathered information from various people with gender incongruence and gender dysphoria. In line with the guidelines in the Act on the National Commission of Inquiry for the Health and Care Services, we have omitted all personal names in the report.

Information base

Our assessments are based on information from interviews, dialog meetings and public documentation. We have obtained the status of treatment of gender incongruence from the four regional health authorities. We have reviewed statistics, professional literature, research and followed available public debate and media coverage. We have shared experiences with the Healthcare Safety Investigation Branch (HSIB) and their report on the same topic.

We have also engaged with various experts and resource persons at different stages of the process.

Collection of data

We initially started a mapping exercise on the topic. The review and systematization of the collected written documentation was the starting point for some main themes and questions we wanted to elucidate further in interviews and dialogue with various stakeholders.

Conversations and semi-structured individual interviews were conducted with four patients and two relatives. These were people who had personal and family experience with gender incongruence and gender dysphoria.

Our interviews are based on the K.R.E.A.T.I.V. method, which aims to obtain the most reliable information possible from the informants.

During the information gathering phase, we held dialogue meetings with the following patient, user, next of kin and interest organizations: FRI - The Association for Gender and Sexuality Diversity, Genid, Harry Benjamin Resource Center (HBRS) and the Patient Organization for Gender Incongruence (PKI).

We also held dialog meetings with different treatment environments and levels: The National Treatment Service for Gender Incongruence (NBTK) at Oslo University Hospital HF, the Health Center for Gender and Sexuality (HKS) in Oslo Municipality and the four regional health authorities (RHF) through their technical directors and staff. In addition, we had meetings with the Directorate of Health (Hdir), the Norwegian Board of Health Supervision (Htil) and the Norwegian Institute of Public Health (FHI). In total, we had 11 meetings during this phase, where we presented topics and

presented concerns reported to Ukom.

The different actors decided who and how many people they wanted to bring to the meeting. Some of the meetings were fully digital, some of the meetings were physical, and some of the meetings were hybrid meetings with a large variation in the number of participants. In one hybrid meeting, not everyone who was connected digitally attended the entire meeting.
The interviews were in principle semi-structured with an emphasis on open, exploratory questions. All meetings began with a presentation by Ukom and ended with an open discussion afterwards. Meeting participants chose what they wanted to comment on or raise first. Ukom had a list of topics we wanted to highlight. At meetings with many participants, it was necessary to actively manage the meeting to ensure that more people were allowed to speak and that the desired questions were answered. At other meetings, where only one or a few people attended, they were allowed to speak more freely as long as the requested topics were covered. No audio recordings were made, but notes were taken. The meetings were always attended by several people from Ukom with different professional backgrounds.

We also held five exploratory discussions with professionals with legal, medical, sexological and administrative expertise. In addition, we consulted with people with experiential and relevant professional expertise as needed.

Analytical work

We have sorted and analyzed the collected data to find possible connections, influences and causes of what may constitute a patient risk in the health services for children and adolescents with gender incongruence and gender dysphoria. When we enter a topic to shed light on patient safety, the picture will be complex and the causes of possible risks will be interdependent.

Ukom uses security methodology to identify underlying causes at the system level. As a basis for those parts of the analysis, we have used the Sociotechnical approach, with MTO (human-technology-organization) keywords and methodology, AcciMap methodology, causal maps, actor maps and influence diagrams. This methodology highlights how relationships at different organizational levels influence each other. This approach provides a holistic understanding of possible causal relationships at different levels. We looked at how different services and systems relate to each other, and we have formulated and tested hypotheses along the way.

Validity requirements

In order to come up with recommendations that could be useful for this field and this group of patients, we have conducted dialog meetings and anchored our findings with all stakeholders who have provided us with valuable feedback and input.
During the course of the survey, we have also received useful input from UCOM's reflection panel.

All informants have been given the opportunity to review any quotes we have used.

All are anonymized. Those quoted have been involved in shaping how they are referred

to. Stakeholders involved have also been presented with findings and themes for

recommendations.

Furthermore, findings and draft recommendations have been discussed with informants, user organizations, other interest groups, professional organizations, businesses and professional communities in both the clinical and research fields, the administration, authorities and individuals with special knowledge of the topic.

In this phase, we conducted 11 dialog meetings with the following bodies:

- Norwegian Nurses' Association (NSF)

- Norwegian Psychological Association (NPF)
- The Norwegian Medical Association (DNLF) Patient
- Organization for Gender Incongruence, PKI
- Association for Gender and Sexuality Diversity Free, with Queer Youth

- Gerd Norway
- Patient organization and user organization Harry Benjamin Resource Center
- National Association for Relatives in Mental Health
- Mental health
- Patient and user representatives
- National Treatment Service for Gender Incongruence
- (NBTK) Health Center for Gender and Sexuality (HKS), Oslo
- Municipality The regional health authorities
- Directorate of Health
- Norwegian Board of
- Health Supervision
  Norwegian Institute of
  Public Health (NIPH)

In total, we held 27 meetings with various stakeholders during the survey. In these meetings, we have openly discussed the issues and findings and asked for input. In addition, we have allowed for written input afterwards, which several stakeholders have taken advantage of.

13 Glossary of terms

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This list is taken from Bufdir's Lhbt+ glossary. The terms can be defined in several different ways, and the terminology in the field is constantly evolving. Therefore, some terms may be inclusive to some, but alienating to others.

Non-binary

A person who does not feel that they fit into the categories 'male' or 'female'. Being non-binary is about gender identity and not about what the body looks like. Some non-binary people identify as something in between female and male, others do not identify by gender. In society, gender is often divided into two categories, girl and boy. This division does not apply to everyone

Gender

Gender is often a fundamental aspect of a person's identity. Societal norms play a large part in defining what is typically female and male. What is seen as male and female varies throughout history and between cultures.

Gender can be understood as three different aspects: biological gender (the body you are born with), psychological gender (the gender you feel you are) and social gender (the gender others perceive you as and into which you are socialized).

It is commonly thought that there are two genders, male or female. However, there are people who do not feel at home under these two categories. Therefore, in some countries there is a possibility to register as a gender other than male or female.

- **Biological sex:** Biological sex is made up of biological factors such as external and internal genitalia, genes, chromosomes and sex hormones.
- **Legal gender:** Society's official registration of gender. Legal sex is the sex with which you are registered in the National Population Register. Legal gender does not necessarily correspond to social gender. The Act on Change of Legal Gender came into force in 2016. Under this law, you decide for yourself whether you are listed as a woman or a man in the National Population Register. If you are 6 years old or older, you do not need a medical certificate to change your legal gender. The law applies to people who have reached the age of 16, but people aged between 6 and 16 can apply to change their legal sex with the permission of their parents. Children under the age of 6 can have their legal sex changed if they have a congenital, uncertain somatic gender development. The condition must be documented by a health professional. It is the tax office that decides on the change of legal gender status and assigns a new national identity number.
- **Social gender:** The gender others perceive you as and into which you are socialized.

Gender identity

Gender identity refers to a person's internal experience of being female, male, both female and male, or neither. Most people identify with the sex they were assigned at birth, but not all. Perceived gender can be used as a synonym for gender identity.

Gender expression

A gender expression is the way we identify ourselves as either female, male, feminine, masculine or outside of society's two-gender norm. Although most people present themselves in a gender expression that is perceived as clearly male or clearly female, some people have a gender expression that breaks the dichotomy between male and female.

Gender affirmative action

Health care that helps confirm a person's gender identity. For people who experience discomfort with the mismatch between biological sex and gender identity, this healthcare can be important to improve their quality of life. It may include psychosocial support/care, assistive devices (such as wigs or voice training), sex hormone supplementation or surgical procedures (such as breast removal or vaginal reconstruction). Gender-affirming treatment helps to alleviate gender dysphoria and to enable a person to function in accordance with their gender identity.

Gender dysphoria

Gender dysphoria is a medical term for discomfort caused by a mismatch between a person's gender identity and the sex assigned at birth and the gender role associated with this. Gender dysphoria is a term within the gender incongruence spectrum. People who experience gender dysphoria may wish to undergo gender-affirming treatment to align their body with their gender identity. Not all trans people experience gender dysphoria

Gender incongruence (transgender people)

Gender incongruence is the persistent experience that the gender assigned at birth does not match the gender you perceive yourself to be. People with gender incongruence are often referred to as transgender people. Not all people who experience gender incongruence define themselves as transgender. Gender incongruence is also a diagnosis that replaces all diagnoses that previously began with
"trans"- and is explained as a mismatch between perceived gender and the gender assigned at birth.

Gender characteristics

Sex characteristics refer to the biological or bodily aspect of gender, i.e. physical features, sex chromosomes, sex hormones and genitalia. Individuals with variation in bodily sex development are born with a combination of sex characteristics that vary to a greater extent than we traditionally associate with male and female bodies. Sex characteristics can be divided into primary and secondary sex characteristics:

- **Primary sex characteristics** include sex chromosomes (e.g. XX, XY, X, XXY), external genitalia (e.g. head of penis, foreskin, clitoris, labia, vulva), gonads/sex glands (testes and ovaries), hormones (estrogen and testosterone) and internal reproductive organs (e.g. uterus, fallopian tubes, prostate).
- **Secondary sex characteristics** are characteristics that develop later in life, often around puberty, and can be linked to hormonal development. These may include body and facial hair, menstrual cycle, breast development, height, muscle distribution and body fat

Gender diversity

Gender diversity refers to the fact that there are many ways of being a woman/man or boy/girl, including gay, straight, lesbian, bisexual and transgender people. The term also opens up the possibility that there are more gender identities than woman and man. The term can help to create space for different gender expressions,
-preferences and identities without categorizing.

LGBTQ

Lhbtiq is an abbreviation for lesbian, gay, bisexual, transgender, gender variant/intersex and queer. The term Lhbtiq encompasses terms related to sexual orientation (lhbq), gender identity (t) and gender characteristics (i).
The term "people who transgress gender and sexuality norms" is the most precise and least exclusionary term for this group.

Minority stress

Minority stress is the additional burden that individuals from stigmatized groups face because of their minority position.

Gender and sexuality norms

Norms are unwritten rules, thoughts and ideas that a society, and we who live in it, take for granted. Norms create expectations of how we should behave and what we should be like and involve ideas about what is positive and what is negative. Norms vary between societies and cultures and can change over time. Gender norms are widespread beliefs that assume that everyone identifies with the gender they were assigned at birth and that our behavior and how we express ourselves corresponds to this gender. Norms of sexuality revolve around expectations about who we are attracted to, fall in love with, have sex with, how we have sex and what turns us on. In a heteronormative society, it is assumed that everyone is heterosexual

Skewed

Skeiv is a Norwegian translation of the English term 'queer'. Many people use "queer" as an umbrella term for anyone who breaks gender and sexuality norms, or as a synonym for lhbtiq. For others, 'queer' is an identity that challenges and transcends the categories of heterosexual, lesbian, gay and bisexual and involves a critique of society's heteronormativity. Queer is also used by people who feel that they do not fit into society's division of people into two genders. Not everyone is comfortable with the word 'queer' being used about them.

14 Ukom's mission

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The National Commission of Inquiry for the Health and Care Services (Ukom) is an independent, governmental body tasked with investigating serious incidents and other serious matters in the health and care services in Norway.

Ukom will investigate the course of events, causal factors and causal relationships. The purpose of the investigations is to improve patient and user safety through learning and prevention of serious incidents.

Ukom does not take a position on civil or criminal guilt and liability.
Ukom decides which serious incidents or serious circumstances are to be investigated, the timing and scope of the investigation and how it is to be carried out.

The surveys are carried out in consultation with stakeholders, i.e. health and social care professionals, patients, users and relatives.

The reports from Ukom are public and do not contain references to individual names and addresses. It is assessed in each individual investigation whether reference is made to the location of the incident.

Ukom's activities are authorized in the Act on the National Commission of Inquiry for the Health and Care Services of 16.06.2017 no. 56.

15 Reference list

Published on March 9, 2023 Last updated on March 9, 2023

We have reviewed a large body of literature and we refer here to a selection of references. This is not a systematically complete list of available literature and references. We have included references highlighted by resource persons with expertise and through dialog meetings.

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Pubertal Suppression, Bone Mass, and Body Composition in Youth With Gender Dysphoria

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abstract

BACKGROUND AND OBJECTIVES: Puberty onset and development contribute substantially to adolescents' bone mass and body composition. Our objective with this study was to examine the effects of gonadotropin-releasing hormone agonists (GnRHa) on these puberty-induced changes among youth with gender dysphoria (GD).

METHODS: Medical records of the endocrine diversity clinic in an academic children's hospital were reviewed for youth with GD seen from January 2006 to April 2017 with at least 1 baseline dual-energy radiograph absorptiometry measurement.

RESULTS: At baseline, transgender females had lower lumbar spine (LS) and left total hip (LTH) areal bone mineral density (aBMD) and LS bone mineral apparent density (BMAD) *z* scores. Only 44.7% of transgender youth were vitamin D sufficient. Baseline vitamin D status was associated with LS, LTH aBMD, and LS BMAD *z* scores. Post-GnRHa assessments revealed a significant drop in LS and LTH aBMD *z* scores (transgender males and transgender females) without fractures and LS BMAD (transgender males), an increase in gynoid (fat percentage), and android (fat percentage) (transgender males and transgender females), and no changes in BMI *z* score.

CONCLUSIONS: GnRHa monotherapy negatively affected bone mineral density of youth with GD without evidence of fractures or changes in BMI *z* score. Transgender youth body fat redistribution (android versus gynoid) were in keeping with their affirmed gender. The majority of transgender youth had vitamin D insufficiency or deficiency with baseline status associated with bone mineral density. Vitamin D supplementation should be considered for all youth with GD.

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Dr Navabi conceptualized and designed the study, collected data, conducted initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Dr Tang conducted the analyses and reviewed and revised the manuscript; Dr Khatchadourian reviewed and revised the manuscript; Dr Lawson conceptualized and designed the study, coordinated and supervised data collection, and critically reviewed and revised the manuscript for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THIS SUBJECT: Despite short-term efficacy and safety of gonadotropin-releasing hormone agonist (GnRHa) to suppress puberty in youth with gender dysphoria, evidence on the potential impacts of GnRHa monotherapy on bone mass accrual and body composition and the role of vitamin D status is limited.

WHAT THIS STUDY ADDS: GnRHa monotherapy for gender dysphoria negatively affected bone mineral density without changes in BMI *z* score. Transgender youth fat redistribution (android/gynoid) and transgender females lean body mass and total body fat changes were in keeping with their affirmed gender. Most transgender youth had low vitamin D levels at baseline.

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The number of youth with gender dysphoria (GD) seeking gender-affirming care has increased significantly.[1–4] Endocrine Society[5] and World Professional Association for Transgender Health[6] guidelines recommend gonadotropin-releasing hormone agonists (GnRHas) for puberty suppression in youth with GD who are in Tanner stages 2 to 5. Efficacy and safety of GnRHa to arrest pubertal development in central precocious puberty is well described[7] with short-term efficacy and safety of GnRHa in youth with GD.[8,9] However, there are concerns about puberty suppression effects on bone mass accrual of youth with GD[5,8–11] because sex steroids are fundamental for bone acquisition during puberty and maintenance of bone mass in adulthood.[12,13] In small studies, researchers have found that GnRHa in youth with GD are associated with decreased bone mineral density (BMD) *z* scores and bone turnover markers.[11,14–17] Periodic monitoring of BMD by dual-energy radiograph absorptiometry (DXA) in youth with GD is currently recommended by the Endocrine Society[5] and International Society for Clinical Densitometry.[18] The scarcity of evidence on effects of GnRHa on bone health and body composition of youth with GD motivated us to retrospectively review all youth with GD managed at the endocrine diversity clinic of the Children's Hospital of Eastern Ontario (CHEO). In addition, we aimed to characterize vitamin D status of youth with GD and its relationship with bone health, as well as assess efficacy of supplemental vitamin D with 1000 to 2000 IU daily.

METHODS

Study Subjects

Medical records of the 198 youth <18 years of age seen at the endocrine diversity clinic at CHEO from January 2006 to April 2017 were retrospectively reviewed, and the 172 youth (86.9%) with at least 1 DXA measurement were included in this study. To allow a minimum follow-up time of 18 months, the study population's medical records were last reviewed in January 2019. GD diagnosis was based on adolescent medicine specialist assessments, which typically preceded the referral to the endocrine diversity clinic.

CHEO Endocrine Diversity Clinic Management of Youth With GD

Our center uses the GnRHa formulation of leuprolide acetate, historically starting with 3 doses of 7.5 mg intramuscularly every 4 weeks, followed by 11.25 mg intramuscularly every 12 weeks after confirmation of puberty suppression clinically and biochemically. GD management includes areal bone mineral density (aBMD) measurements by DXA with Lunar Prodigy system, and aBMD *z* scores are determined on the basis of birth-assigned sex, age, and ethnicity. Lumbar spine (LS) (L2–L4) and left total hip (LTH) aBMD *z* scores are usually assessed at baseline and every 12 months; however, youth with an aBMD *z* score below 2 SDs or significant drop (≥ 1 SD) in LS aBMD *z* score undergo BMD every 6 months and a lateral spine radiograph for vertebral fracture assessment. Youth with poor calcium intake are advised to take calcium carbonate 500 mg twice daily to meet the Institute of Medicine's[19] recommended dietary allowance. All youth are advised to take vitamin D 1000 to 2000 IU daily. Serum 25-hydroxyvitamin D (25OHD) levels are assessed at baseline and monitored every 6 to 12 months. Vitamin D status is classified on the basis of 25OHD level, with <30 nmol/L indicating deficiency, 30 to 50 nmol/L indicating insufficiency, and >50 nmol/L indicating sufficiency.[20]

Given the retrospective nature of the study and variable timing of baseline and follow-up DXA results relative to GnRHa initiation, pre-GnRHa DXA was defined as DXA scan within "−180 to +30" days of GnRHa initiation. Post-GnRHa DXA was defined as DXA scan at "≥ +180" days of GnRHa initiation, as long as this assessment was completed within 90 days of gender-affirming hormone initiation or GnRHa discontinuation.

Measurements

Birth-assigned sex, affirmed gender, Tanner stage at initial assessment, and anthropometrics (height and weight) at baseline and follow-up visits were retrieved from medical records. BMI *z* score was calculated on the basis of 2014 revised World Health Organization growth charts for Canada.[21]

Pre- and post-GnRHa DXA results were used to retrieve aBMD (grams per square centimeters) of LS, LTH, and total body less head (TBLH). Volumetric BMD was calculated as bone mineral apparent density (BMAD) (grams per cubic centimeters) at LS by using the method of Kroger et al[22] as "LS aBMD × [4/(π × width)]." LS BMAD *z* score was calculated on the basis of available reference for age-matched birth-assigned gender BMAD mean and SD.[23]

DXA is the most readily available and valid method of 3 compartmental body analyses.[24] In this study, we used pre- and post-GnRHa DXA results to extract the following variables: lean body mass (LBM) (kilograms), total body fat (TBF) (percentage), TBF (kilograms), regional fat mass ratios (ie, trunk/total, legs/total, and extremities/total), fat distribution in the form of android (fat percentage)