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RESEARCH ARTICLE



Waiting for and in gender-confirming healthcare in Sweden: An analysis of young trans people's experiences

Väntar på och inom könsbekräftande vård i Sverige: En analys av unga transpersoners erfarenheter

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ABSTRACT

The role of waiting and temporality has been explored in relation to gender-confirming healthcare for adults. However, young people's experiences have been lacking, both in previous research and in the public debates on young trans people's access to gender-confirming medical procedures. This paper explores young trans people's experiences of waiting for and in gender-confirming healthcare in the Swedish context. The analysis draws on 16 semi-structured interviews with young trans people (16–25 years old). The analysis was done using thematic analysis and conceptual work on 'waiting' and 'youth'. The participants described waiting as one of the most challenging aspects of their encounters with the gender-confirming healthcare, and the findings also show that this waiting has consequences for youth's mental health and social life. Social workers can have an important role in providing psychosocial support in times of waiting.

ABSTRAKT



Väntan och temporalitet har utforskats och diskuterats tidigare i relation till könsbekräftande vård för vuxna. Ungdomars egna erfarenheter har dock saknats, både i tidigare forskning och i samhällsdebatten om unga transpersoners tillgång till könsbekräftande vård. I den här artikeln utforskar vi unga transpersoners egna erfarenheter av att vänta på och inom den könsbekräftande vården i Sverige. Analysen bygger på 16 halvstrukturerade intervjuer med unga transpersoner (16–25 år). Analysen gjordes med hjälp av tematisk analys och inspirerades av teoretiska arbeten kring 'väntan' och 'ungdomstid'. Väntan beskrevs av deltagarna som en mycket central fråga i deras möten med vården och som en av de mest utmanande aspekterna av att försöka få tillgång till könsbekräftande vård. Analysen visar också att väntan på och inom den könsbekräftande vården får konsekvenser för unga transpersoners psykiska hälsa och sociala liv. Socialarbetare kan ha en viktig roll i att ge psykosocialt stöd i väntan på vård.

KEYWORDS

Transgender; waiting; temporality; social work; gender dysphoria

NYCKELORD

transpersoner; väntan; temporalitet; socialt arbete; könsdysfori

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Background

The number of young people that seek gender-confirming healthcare has rapidly increased in the last couple of years, both in Sweden (Frisen et al., 2017) and internationally (Cartaya & Lopez, 2017). This has resulted in longer waitlists to get access to hormones and surgery but also to academic discussions and a heated public debate about when and on what grounds trans youth ought to be able to access gender-confirming healthcare, a debate that echoes debates in other parts of the world where trans youth care is an established medical practice (Steensma & Cohen-Kettenis, 2018; Temple Newhook et al., 2018). In Sweden, concerned parents and medical professionals have argued that young trans people's access to gender-confirming care ought to be delayed, to give both care seekers and medical professionals more time to think decisions through (see, for example, Gillberg et al., 2019; Motion, 2020/21:598).

The emphasis on temporality is not a new phenomenon in research on trans lives. Previous research has shown that a focus on temporality in general and waiting in particular are highly present in care-seekers' experience of gender-confirming healthcare (e.g. waiting lists, length of evaluation) (Bertilsson Rosqvist et al., 2014; Bremer, 2011; Linander, 2018; Pitts-Taylor, 2020; Shepherd & Hanckel, 2020; Tiseyra et al., 2021). Alm (2006, 2018) has argued that during the 1970s, when the Swedish healthcare system established a centralised practice for gender-confirming care, legislators and physicians discussed how to use waiting time as a diagnostic tool, to test care seekers' persistence and determination. Time is still used as a diagnostic tool within the gender dysphoria evaluation system in the sense that the evaluation relies on an estimation of the stability of the applicant's gender identity over time (Linander, 2018; Linander et al., 2020).

While studies in other countries have reported on long waiting lists within gender-confirming care for young people (Pullen Sansfaçon et al., 2019; Shook, 2020), to the best of our knowledge, a deeper analysis of how waiting for and in gender-confirming healthcare is experienced by young trans people in Sweden has not been done before. Previous studies have explored adult care-seekers' lived experiences of waiting (Bremer, 2011; Linander, 2018; Pitts-Taylor, 2020; Tiseyra et al., 2021). Adult care-seekers described waiting as consisting of frustration, distress, anxiety and feelings of powerlessness (Bremer, 2011; Linander, 2018; Linander et al., 2019). The despair brought on by the waiting can be detected in unsupervised use of hormones or trying to access hormones from private clinics, which in turn has been shown to provide faster access to tax-subsidised hormones (Linander et al., 2017; Shepherd & Hanckel, 2021). This highlights how the possibility to negotiate waiting times is an acquired ability that can be stratified along the lines of class or connections to the trans community.

Studies with both older and younger trans people have mainly focused on waiting *before* getting access to the gender dysphoria evaluation. Nevertheless, we know that waiting is prevalent also *in* the gender-confirming healthcare (Linander, 2018). Given that youth in itself is often portrayed as a transitional or liminal stage (Threadgold, 2020), this might affect the experiences of waiting for gender-confirming medical procedures. Consequently, in this paper, we aim to analyse how young trans people (16–25 years old) in Sweden experience and make sense of waiting for and in gender-confirming healthcare. By analysing young people's own experiences in dialogue with the theory on waiting and the current recommendations for care, we engage in a critical discussion about the dominant medical discourses on transgender youth within the Swedish healthcare system.

Swedish gender-confirming healthcare

Trans people who seek gender-confirming care are obliged to undergo a clinical evaluation (The National Board of Health and Welfare, 2015). To access the evaluating teams the care-seeker needs a referral, in some regions from general practitioners, in some from general psychiatry and for some teams, it is possible to write a 'self-referral'. Specific multidisciplinary teams are responsible for the evaluation and for referrals to medical procedures. The evaluation consists of psychological,

physical, social, and psychiatric assessments, in which social workers have an important and prominent role, alongside psychiatrist and psychologists; they often do the initial part of the evaluation that focuses on the psychosocial aspects. The length of the evaluation process varies and should, according to recommendations, be individually adapted (The National Board of Health and Welfare, 2015).

There are teams that specialise in adults, others that only evaluate individuals below 18 and one team that evaluates both children and adults. The National Board of Health and Welfare (2015, 2021) has published separate recommendations for the care for gender dysphoria for adults and for children and youth. People below 18 can access voice therapy, hair removal, puberty blockers and, in some cases, hormones. Access to breast surgery before 18 years old is generally restricted but can be deemed as therapeutically necessary in some cases. In March 2021, the hospital leadership at Karolinska (the hospital with the largest number of transgender youth care seekers per year) decided to stop all hormonal treatments for people below 18. Two other university hospitals have followed suit.

It is common that the evaluating psychiatrist writes an assessment to the Legal Advisory Board at the National Board of Health and Welfare, which is the agency that assesses applications for legal gender recognition and grants permission for genital surgery, in accordance with the Gender Recognition Act (SFS, 1972:119).

Conceptual framework

The conceptual framework for our analysis is inspired by Jeffrey's (2008) conceptualisation of waiting and Threadgold's critical perspectives on youth (2020). The choice of conceptual framework was done in an abductive way; after a first analysis of the interviews, we choose the conceptual framework, which in turn sensitised us to aspects and interpretations we had not put emphasis on before.

Three aspects of waiting are in focus. Firstly, Jeffrey (2008) stresses that power relations in society will position certain parts of the population, those already marginalised, as more likely to have to wait, for jobs, and for access to health care, etc. Previous research has shown that trans people's waiting for gender-confirming medical procedures is connected to a diagnostic practice in which the long-term stability of the care seeker's gender identity is evaluated by medical experts (Linander, 2018; Linander et al., 2019). For this study, specific discourses around youth are vital to understand these experiences of waiting. Within medicine and psychology, youth is often understood as a transitional period between childhood and adulthood (Threadgold, 2020). As such, youth is also often considered to be a risky or volatile period, when one does not really know what one wants or cannot foresee the consequences of the future (Threadgold, 2020). Such discourses can be detected in discussions about trans youth's access to gender-confirming medical procedures, both within medicine and in broader conversations in Swedish media and parliament (see, for example, Gillberg et al., 2019).

Secondly, we are interested in waiting as 'lost time' and as both passive and active. When describing waiting as 'lost time', Jeffrey (2008) especially mentions young people and how ...

... waiting often exerts a type of triple pressure: they [young people] are excluded from objects of desire, such as an education, marriage, and financial independence; they are incapable of moving into socially ascribed age-based categories, especially adulthood. (p. 956)

In a society that adheres to chronological time and to notions of success and futurity, waiting subjectify people as failures or 'left behind'. Jeffery argues that this notion of being left behind creates incitements for those that have to wait to engage in different activities. A concrete example of this, detailed in previous Swedish studies, is the practice among trans people to order hormones online to negotiate the waiting for access to tax-financed hormones (Linander et al., 2017). Jeffrey (2008) warns us to understand waiting as the absence of action.

Finally, we want to emphasise how waiting positions the one waiting in a vacillation between panic and inertia (Jeffrey, 2008), or crisis and dead time (Bourdieu, 2000). Bourdieu (2000) theorises

the unpredictability and insecurity in waiting, describing waiting as ‘delaying without destroying hope’ (p. 228). We find these conceptual tools helpful both to understand and structure our findings.

Material and methods

This study is based on 16 individual semi-structured interviews with young trans people. The interviews were conducted between November 2020 and March 2021 and lasted between 35 min and 2 h (median 65 min).

The study is situated within a larger project about young trans people’s mental health and access to healthcare, which has a reference group that consists of representatives of trans organisations, healthcare professionals and experts in the field of young trans people’s health and living situation. The reference group gave input on important aspects to focus on in the interviews. For this paper, the focus is on experiences of meeting the gender-confirming healthcare and of mental health, as several participants brought up waiting in relation to a question about factors that affects their mental health in a negative way.

To recruit participants, advertisement material was sent to networks, social media groups, and associations for trans people. A targeted advertisement via social media was also used. All interviews were conducted using videophone calls (due to COVID-19), audio-recorded and transcribed verbatim. Before the interviews started, the interviewer (IL) carefully went through the informational letter and recorded oral consent from the participants.

The 16 participants are between 16 and 25 years old with three individuals being below 20 years of age. Nine individuals identify as men or trans masculine, four as non-binary, and three as women or transfeminine. They live in different parts of Sweden and are hence tied to different evaluation teams. Nine are studying (five of them at university), four are working, and three are unemployed. Fourteen had met a gender identity evaluation team, two were waiting for their first visit. Eleven had had access to some gender-confirming medical procedures, of which some had paid for it themselves. Some participants have met an evaluation team for children/youth and some a team for adults.

The transcribed interviews were analysed using thematic analysis (Braun & Clarke, 2006). First, IL carefully read and re-read the transcripts and identified parts that dealt with waiting and temporality. Next, both authors read the extracts, discussed preliminary aim, conceptual framework, and emerging themes. IL coded the parts of the transcripts that corresponded to the preliminary aim and made analytical notes that included written descriptions of revised preliminary themes. After that, both authors discussed the preliminary themes, and finalised the reporting of the findings, utilising interview extracts, and conceptual arguments. The analysis was aimed at interpretation; to identify underlying ideas in the interviews with the use of the conceptual framework (Braun & Clarke, 2006).

Confidentiality was assured by anonymising the material. The Swedish Ethical Review Authority approved the study (Dnr: 2020-00929).

Main theme: ‘It feels like it is all about waiting’

Before presenting the findings through four themes, we will illustrate the centrality of waiting in the participants’ experiences of gender-confirming healthcare. All participants talked about waiting as troublesome or problematic. P1, who at the time was in contact with an evaluation team, said:

I guess I’ve somehow accepted that I’m going to have to wait quite a long time because there’s so much waiting. There is waiting to get to [the youth evaluation team] and then there is two years of evaluation. Then there is waiting until they send you to an endocrinologist to take lots of blood tests and wait for this and wait for that and it feels like it’s all about waiting.

This type of description is common in the narratives of the other participants, it identifies a sequence of waiting, first waiting to enter the evaluation phase, then waiting during the evaluation and finally

waiting to access medical procedures. P13 also expressed how waiting was not isolated to the pre-evaluation phase:

When I was in contact with [gender-confirming] healthcare, there was so much waiting time. I met the counselor, I don't know, but a number of times. Then after her things were pretty good while I waited until I got to see the psychologist, and then I met him twice, then I waited to see the psychiatrist, I met him once. So well, most of it was just waiting. (P13)

P13's description of single meetings with different evaluators and then 'just' waiting in between testifies to how he experienced that waiting dominated, in quantitative terms, the contact with the gender-confirming healthcare. P6 said that his 'strongest memory from the trans-care' was that 'it was a lot of "twiddling one's thumbs"'. These experiences resonate with P1's statement that 'it feels like it's all about waiting', and P15's conclusion: 'It feels like this whole contact with healthcare has just been marked by waiting, really, at every step I would say'. All in all, waiting was a very central aspect in the participants' descriptions of their experiences of trying to get access to gender-confirming medical procedures. Jeffrey (2008) argues that waiting can have the effect that the objects of longing, in this case, gender-confirming medical procedures, 'dominate their thought and actions' (p. 956). In our study, it however seems that waiting in itself can also dominate the experiences of gender-confirming healthcare, and contribute to action, which we will come back to. In the following themes, we will look closer at different aspects of the experience of waiting for and in gender-confirming healthcare. The first two themes focus on how the young participants narrated the reasons for waiting. The second and third themes discuss psychosocial consequences of the waiting in a system where access to care is restricted (Bremer, 2011; Linander, 2018).

Waiting due to lack of priority

Participants mentioned waiting when asked how the gender-confirming healthcare could be improved, in the words of P10: 'More resources. I think it is very inhumane to force especially young people to in effect spend their entire youth waiting to feel good'. When identifying lack of resources as a cause for waiting, participants talked about both pre-evaluation waiting and waiting that prolonged the evaluation phase. P13 said: 'It felt like it [the evaluation] was drawn-out for unclear reasons, probably due to lack of resources but, yes, the current arrangement doesn't warrant itself'. Some participants argued that this lack of resources was connected to the rising number of care-seekers but P4 also argued that waiting was a matter of priority:

I've personally assumed that if my thing takes time, it is because I don't have a life-threatening problem. I'm not as important. According to this logic, I have to be at the end of the line. / ... / But if you look at it afterwards, you might think that's probably because I have a problem with a very low priority. Maybe it is not a small problem. But it has very low priority. (P4)

P8 echoes this: 'I feel deprioritized by the system'. In a system with limited resources, as healthcare systems always are, waiting times have to do with how different medical issues are ranked and understood in relation to one another. As P4 and P8 say, the effect is that some patient groups are prioritised over others. P4 describes this as having a subjectifying effect: 'I'm not as important'.

As Jeffrey (2008) argues, chronic waiting can be an effect of neoliberal economic reforms and the disinvestment in the welfare state. Neoliberal changes and a decentralisation of parts of the Swedish healthcare system have contributed to a relocation of resources (Burstrom, 2009), a shift that might have contributed to a situation in which parts of healthcare, that deal with less prioritised patient groups, suffer from a lack of resources.

Waiting as evaluation

Waiting was also talked about as an integral part of evaluation. For some participants, this waiting started before the gender identity evaluation:

Quite a few of the referrals were not accepted, it was like this: "Yes, but we also need a referral from ...", because I had quite a lot of psychiatric history, so when they saw that, they didn't accept a simple referral from the general practitioner, nor from the psychologist at the healthcare centre, nor from my psychologist contact at the psych clinic, but they wanted a medical opinion [from a psychiatrist] before they could accept a referral. (P16)

Here waiting was understood as a biproduct of being assessed by medical expertise, and the ranking between different types of medical knowledge as more or less legitimate in the matters at hand. Like P16, that highlighted the issue of 'psychiatric history', P3 connected the waiting to the fact that he has autism:

My first evaluator has even admitted that it was because I have autism. / ... /

I: And what do you think, or have they told you why it ought to take longer time if you have autism?

P3: The only explanation was "because you have autism" / ... / according to BUP at the time, gender dysphoria could be a symptom of autism. / ... / I didn't get a referral until I was 15, because they insisted on "you're just an autistic girl, it's normal to have gender dysphoria when you have autism". So, I didn't get a referral to the evaluation team for a long time because of that, and like, they tried a lot of different things to get rid of the "symptom", as they called it, first, before they finally gave in and sent [the referral].

P16 also identified waiting as an intentional use of delay in the process of diagnosis and treatment, as in the following description of how the psychiatrist questioned them ...

... a lot because of like comorbidity, so like "Okay, but if you've been having an eating disorder 7 years, how can you be convinced that it's dysphoria and not eating disorders?" And since I'd had an addiction and self-harm and then it was like "maybe you should get better from that before you start an evaluation". And so on. Which, of course, you can understand, well it's a problem if you were to start overtreating people for dysphoria that do not have dysphoria, but it was hard for me because I was so convinced that I knew best and so on.

P16 had not gotten access to gender-confirming medical procedures through the tax-financed gender-confirming healthcare and ended up paying for a mastectomy themselves. A practice where care-seekers must wait until they have recovered from an eating disorder to be deemed eligible for gender-confirming care risks ignoring how eating disorders and other mental health problems, can be connected to gender dysphoria rather than separate from it (Hartman-Munick et al., 2021). It also risks establishing a catch 22 for care-seekers, in which they must address one factor affecting their well-being in order to be able to address another. The guidelines for care for gender dysphoria explicitly state that psychiatric 'comorbidity' can affect the length of the evaluation, and autism spectrum conditions are mentioned as conditions that might merit that the diagnostic evaluation needs to take longer or decisions on 'somatic treatment' have to be 'slower' (The National Board of Health and Welfare, 2021, p. 21). However, it is also important to note that other participants with psychiatric diagnoses had not experienced this to be an obstacle in the evaluation.

In the above quote, P16 also touches upon being 'convinced' of their own need of care, similarly, P4 said: 'At the same time, I understand this thing that one wants it to take its time because you want to be sure that it is correct. That it's an accurate diagnosis'. Other participants criticised this aspect of the evaluation process:

Generally, I don't feel like I need to be evaluated. Now I understand it's not that easy, but I feel it's already such a big process and so much to go through to find out that "okay, now let's check if you're trans". (P8)

Some participants expressed that they did not need to be evaluated, that their process of exploring their gender identity and care need was done before they had sought care:

I had waited to apply until I was absolutely sure that I wanted to go through it all. And now in hindsight I know that it of course takes a long time if you get there and are unsure, but they help you in the process of exploring your own gender identity and exploring whether you want treatment or not. When I applied, I felt like okay, I'm ready to start treatments tomorrow. (P12)

The participants often talk about uncertainty – not being sure about one's needs – as an issue that might be common among other care-seekers (and not relevant for themselves), but two participants described having time to think things through as beneficial for them. In the words of P2:

I was actually quite happy that it took such a long time because they assumed their responsibility, to take it slow and really understand me and [make sure] that I would understand myself. That's where I found out who I was. In the last few times, I was dead sure; this is me. (P2)

P15 experienced, 'in retrospect' that it was good to have some time to think things through, 'it made me feel very safe', but that the very extended waiting had negative effects. These aforementioned experiences relate to how the guidelines for care for gender dysphoria for youth emphasise 'the stability of the gender identity' and that '[t]he evaluation needs to last as long as necessary to meet the purpose of the evaluation and, in extension, to minimize the risk of the wrong treatment' (The National Board for Health and Welfare, 2021, p. 15), as well as that '[t]ime is an important factor in the certainty of the assessments' (p. 8). In other words, both the participants and the guidelines refer to time and waiting as a diagnostic tool. Although these discourses on temporality also appear in guidelines for, and experiences of, care for older trans people (Alm, 2018; Linander et al., 2020), they are closely tied to dominant ideas about youth not being certain of what they want (Threadgold, 2020). On the international arena, a scientific controversy about the difference between so-called persisters and desisters – youth who persist in their need of gender-confirming care and those who seek care, but desist later on in adolescence – has played out for the past two decades (Steensma & Cohen-Kettenis, 2018; Temple Newhook et al., 2018). This controversy is part of the context of the medical practices and in which the Swedish guidelines for care for gender dysphoria have been formulated. In the international debate, emphasis has been put on the uncertain future of young care seekers and the lack of studies on long-term effects of treatment, both these concerns are referenced in the recent local decisions, by Swedish teams, to pause hormonal treatment for trans people below 18 years. In other words, the participants' narratives of reasons for waiting can be tied directly to guidelines for care, but also to current debates in academia and healthcare.

Waiting as panic and inertia – and the need for psychosocial support

Participants mentioned waiting when asked about factors that contributed to worsening their mental health. P10 described going through puberty and waiting for gender-confirming healthcare as 'Extremely anxiety-inducing because I couldn't do anything about it'. Or in the words of P7:

It's like pure anxiety. It's just pure anxiety. I'm like, well, okay, I probably won't get to start testosterone until I'm like 40. Which isn't realistic, but it's a little bit of panic thinking.

P10 also mentioned panic: 'Like shit. Well, it was, I had panic attacks almost daily and was self-harming'. P13 elaborated on aspects that she felt had affected her mental health:

One thing that affects my mental health was kind of the powerlessness when it comes to health care. It took three years from when I first applied until I was given hormones. The whole time I was, like, I was very apathetic in the meantime, so that probably helped a little bit to endure in a way, but otherwise it was a little bit like this, okay, I'm just going to sit and wait, who knows for how long and, in the meantime, my body will masculinize, and if I don't start self-medication then there's nothing I can do.

P13's quote shows how waiting was associated with experiences of powerlessness, a body developing in an unwanted direction, and apathy and to 'just sit and wait'. These feelings of not getting anywhere were recurrent in the interviews; being asked about what they needed to feel better, P8 said: 'Well, first of all, I'd like my trans care to get somewhere. It's extremely slow and I've basically just been waiting for it to start'. Similarly, P2 said:

Then to get the diagnose was quite, there I felt stuck, that it got nowhere. I was almost like this, I'm not going to get this diagnosis because, I don't know. I'm just standing there and stomping [metaphor close to "treading water"]. (P2)

Feeling stuck and treading water were strong narratives connected to waiting and the participants' narratives show how exhausting it is to wait; it requires effort to stomp and tread water. Based on these different experiences, waiting can be described as oscillating between panic, or acute crisis, and inertia (Jeffrey, 2008). What the participants experience as panic and acute crisis seems to be turned into inertia *in* the encounter with the healthcare system. The discrepancy between the participants' feelings of acuteness, the slowness of the evaluation, and the use of time as an instrument to assess suffering and the need of treatment within the healthcare system, might contribute to the frustration among the participants.

P13 talks about how she did not know for how long she would have to wait, a situation several participants brought up as especially difficult to endure. P1 elaborated: 'It's not just a long wait, but a lot of uncertainty that I think has affected me a lot, that you kind of don't know'. P1 states that not knowing when the waiting will end contributed to his feelings of uncertainty and an inability to prepare emotionally. Similar P15 said:

Well, no one knows how long it's going to take, because no one can answer that. / ... / Because I know that, for example, when I saw the doctor at the last step, in trans care, he said that "well you should expect a year, at least". That was the first person to say something like that to me, and it made a huge difference to me, because I felt like I could live my life then.

These experiences of uncertainty, and of not being able to live one's life, need to be understood as a result of waiting: waiting means that you are not really in, and, at the same time, you are not really out (Bourdieu, 2000). As P6 said: 'But now it's really just been having to wait to even try, to have to wait to even get started [with the evaluation]'. Pitts-Taylor (2020) shows that waiting for hormones and surgery among transgender people manage at the same time to keep one *out* and also keep one invested *in*. The unpredictable waiting encompasses that least two different aspects of temporal uncertainty: not knowing *if* you will get access to gender-confirming medical procedures and if you do, *when*.

Several participants also described a lack of psychosocial support when discussing the effects of waiting:

It became so clear to me that throughout this process they have been nothing more than "a gate I need to get through", "gatekeeping", because there was no psychosocial support whatsoever. I talked several times about this wait, that it was so annoying: "Is there nothing you can do about the wait?" There was nothing they could offer me that eased this pressure of waiting. (P14)

For P14 the lack of psychosocial support reinforced his feeling that the function of the evaluation was gate-keeping the access to medical procedures. P15 also emphasised the importance of psychosocial support in dealing with waiting:

To give clear information about where to turn for ... like help, or some counselling ... something like that ... that might help you stay well while you wait, I would say that is very important. You understand what I mean, don't you?

I: Absolutely, [you mean] that one ought to get psychosocial support during the waiting period?

P15: Exactly! And to be very clear about where to turn to get it. I'd say that is really important. Because it feels like you're just walking around in circles, waiting for something that might not happen, because you don't get any information at all ...

The gender-confirming healthcare has a dual responsibility, to support and to evaluate care-seekers (The National Board for Health and Welfare, 2021). Some of the participants point out that this double bind might be hard to reconcile since they feel that their future is dependent on the outcome of the evaluation and the evaluators' assessments have precedence over their own descriptions of their life situations. Previous research shows that it is hard to both provide psychosocial support and at the same time evaluate the care seeker's need of care (Linander et al., 2017). Here, social workers in other parts of the healthcare system can have important roles to fill, providing, or pointing out routes to, psychosocial support.

Lost youth and stratified active waiting

As discussed in the previous theme the participants' experiences of waiting can be understood as inertia. This 'loss of motion' was also constructed as having specific meaning for youth, P4 said:

You walk around in circles all the time. / ... / When I was 13, I was sitting with my friends and I said that, "I won't be able to have a real [romantic] relationship until I'm done with this". When I was 23, I still wasn't done. I'm almost 26 and I'm still not done.

Waiting for gender-confirming medical procedures was experienced as having consequences for the possibility to initiate romantic relationships. Similarly, P7 states:

But to move, to start a new education, there is something that hinders me a little bit because I don't want people to see me the way I am now, but like once I feel like myself, I want to meet new people and experience new things. Right now, because I'm waiting for this, I feel like I'm just splashing in the same puddle. / ... / I mean, I want to go forward in my life, but now I'm just standing here. I'm like getting older and older and nothing happens.

For P7 waiting for gender-confirming medical procedures restricts him from moving forward in life. P6 described a similar feeling of putting his life on hold:

So a bit like, life has somehow ended up on hold. These are parts of my life where I've almost tread water and that I've lost. It has been varying degrees of not feeling well, but above all things have been very slow and sluggish. And I feel like I've lost one, two years of my life – during which I could have felt a lot better. And I could have come much further, and I could have built a much more stable foundation to stand on for the future.

P6 not only experienced waiting as putting life on hold, but also as lost time. All in all, these participants describe waiting as a liminal period. P4 is explicit about the liminality:

But it's like you're standing there stomping. Especially when it's like I've been, in this transition period. / ... / during which life stands still. It does. You can't, you don't want to do certain things because of obstacles.

These experiences of putting life on hold can be understood in relation to previous research which argues that waiting within the evaluating process could be connected to medical discourses on a stable gender identity, clinical certainty and issues of regret (Linander, 2018; Roen, 2011). The participants also talk about being left behind, P4 said: 'I don't have the right education and stuff like that. I generally feel behind and have felt behind for a very long time'. The feeling of being left behind seems related to a feeling of being out of sync with time, not on the same timeline as other youth. The aspects of life that the participants emphasised – relationships, work, education, hobbies, moving from the hometown – are fundamental in what constitutes a successful migration from adolescence to adulthood (Threadgold, 2020). The participants' experiences of being stuck and lagging behind, can be understood through the frame of youth as liminal in and of itself, as a transition period from childhood to adulthood that is highly focused on the end goal: becoming an adult (Threadgold, 2020).

In relation to losing time, the participants also described waiting as active or mobilising. After waiting more than 1.5 years for a first meeting with the gender-identity evaluation team, P5 had had enough:

And it got to a point where I was like, I can't, I literally can't. I ended up self-medicating, I've ended up subsequently switching from that [self-medication] to GenderGP, so an informed consent-based thing online, and then now I'm also out to my parents since December, and then I am weening by paying for a private diagnosis and laser.

I Do you feel like the waiting for the public trans care becomes a bit easier as you have access to hormones in another way?

P5: It does in a sense, it certainly alleviates it to a degree. However, the figures, it's a fact that it is financially draining. Now, thankfully I do get additional financial support from my parents.

After waiting 3.5 years to getting a referral to the gender-confirming healthcare and then the evaluation, P16 said: 'I was just like, "I'm kind of giving up". I am just going to eat oatmeal and save money to pay for it myself.' Several participants described self-medication with hormones to try to endure the waiting and to make up for lost time – making sure that the body developed in 'the right direction'. There are those who have accessed hormones from a friend or bought it online, from international suppliers, who have paid for mastectomy themselves and sought online doctors for a gender identity evaluation. Jeffrey (2008) argues that while waiting compels people to engage in different strategies, where consumption of privatised care is one such strategy, such active strategies often make 'inequalities manifest themselves in new ways' (p. 957). This study shows that the possibility to pay for expensive medications and surgeries is unequally distributed, which creates stratified opportunities to endure the waiting and to make up for 'lost time'. The stratification of who is able to employ active strategies for navigating the tax-paid Swedish healthcare system, and who is not, is an explicit theme in the participants' narratives:

I found out now in hindsight, because I was talking to a couple of other transgender people, that there are ways to make this waiting time shorter. You first have to check what the waiting time is in all places and then send your own referral to the places that is functional, and I didn't even know that was a thing ... (P8)

In other words, the possibility to negotiate the waiting by obtaining information about how the healthcare system works is not a given ability, but rather an acquired one. Together with the stratified possibilities to acquire gender-confirming medical procedures in private healthcare, this might contribute to a situation in which some are given faster access to gender-confirming medical procedures, both within and outside the public system.

Concluding remarks

We have in our analysis shown how waiting is a very central issue in the participants' encounters with the gender-confirming healthcare, narrated as one of the most challenging aspects of trying to get access to gender-confirming medical procedures. We have shown how waiting contains active aspects, how waiting can be understood as a time for reflection, a time to become 'sure' as some participants call it, which is in line with the intention of using time and waiting as an evaluating or diagnostic tool described in the guidelines for care. Waiting as an evaluation or a diagnostic tool can in this sense be seen as a discouraging governing technique, which affects the participants both because their non-normative gender position is the object of evaluation rather than self-definition, but also, as we have shown, because they are young and constructed as not knowing their own best interest. Inherent in the idea of using waiting as a diagnostic tool is the belief that those who are not sure enough will drop off, i.e. the emphasis on certainty and motivation among care-seekers (see also Bertilsdotter Rosqvist et al., 2014; Roen, 2011). However, the idea that persistence per se ensures that the 'right treatment' is reserved for the 'right care-seekers' could be problematised in relation to our findings of how being an 'active care-seeker' might facilitate access to care.

The analysis shows that waiting has dire consequences for young trans people's mental health and social life. Social workers, both within gender-confirming care and in other areas, can have important roles in providing psychosocial support in times of waiting, to help care-seekers cope with the strain that waiting entails. Social workers can also have important roles in helping the care-seekers to navigate in the chain of care, to help them reach appropriate care levels and competent care without extra delay.

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