

ORIGINAL ARTICLE

‘Wouldn’t it be easier if you continued to be a guy?’ – a qualitative interview study of transsexual persons’ experiences of encounters with healthcare professionals

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Aims and objectives. To describe transsexual persons’ experiences of encounters with healthcare professionals during the sex reassignment process.

Background. Transsexual persons are individuals who use varying means to alter their natal sex via hormones and/or surgery. Transsexual persons may experience stigma, which increases the risk of psychological distress. Mistreatments by healthcare professionals are common. Qualitative studies addressing transsexual persons’ experiences of healthcare are scarce.

Design. Qualitative descriptive design.

Methods. A Swedish non-clinical convenience sample was used, consisting of six persons who had been diagnosed as transsexual, gone through sex reassignment surgery or were at the time of the interview awaiting surgery. Semi-structured interviews were undertaken, and data were analysed using manifest qualitative content analysis.

Results. Three categories and 15 subcategories were identified. The encounters were perceived as good when healthcare professionals showed respect and preserved the transsexual person’s integrity, acted in a professional manner and were responsive and built trust and confidence. However, the participants experienced that healthcare professionals varied in their level of knowledge, exploited their position of power, withheld information, expressed gender stereotypical attitudes and often used the wrong name. They felt vulnerable by having a condescending view of themselves, and they could not choose not to be transsexual. They felt dependent on healthcare professionals, and that the external demands were high.

Conclusions. Transsexual persons are in a vulnerable position during the sex reassignment surgery process. The encounters in healthcare could be negatively affected if healthcare professionals show inadequate knowledge, exploit their position of power or express gender stereotypical attitudes. A good encounter is characterised by preserved integrity, respect, responsiveness and trust.

Relevance to clinical practice. Improved education on transgender issues in nursing and medical education is warranted. Healthcare professionals should be aware of how their attitudes and their level of knowledge affect the care given during the sex reassignment surgery process.

What does this paper contribute to the wider global clinical community?

- The findings in this study provide knowledge of transsexual persons’ experiences of encounters with healthcare professionals during the sex reassignment process.
- The encounters are influenced by healthcare professionals’ attitudes, level of knowledge and clinical experiences of transgender issues.
- Health professionals need access to education on issues related to transgender and sexual minorities. Educators should ensure that LGBT content is incorporated into nursing and medical curricula.

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Introduction

The internal perception of an individual's gender and how they label themselves is referred to as gender identity. The way people identify themselves may differ between cultures and may be influenced by race, ethnicity and the social roles that they have access to (Lombardi 2001, Institute of Medicine 2011). Transgender is an umbrella term that encompasses gender-variant identities, such as to not identify with the natal sex or to not fit within the binary gender categories (Alegria 2011, Institute of Medicine 2011, Merriam & Bruce 2014). Transsexuals are described as individuals using varying means to alter their natal sex via hormones and/or sex reassignment surgery (SRS) (Merriam & Bruce 2014). SRS has, in Sweden, been performed since the 1960s, and in 1972, Sweden was the first country in the world to regulate surgical and legal sex reassignment (Dhejne *et al.* 2014). Surprisingly, few Swedish studies have been published on SRS in general, and to our knowledge, none of these studies relate to patients' experiences.

Background

In Sweden, applications for SRS have increased rapidly since the year 2000; 2.5–3 times more individuals have applied between 2001–2010 compared to previous decades. The incidence of SRS per year in Sweden is about 0.42/100,000 in female-to-males (FtM), and 0.73/100,000 in male-to-females (MtF). Factors that may influence the frequency of SRS applications include social prejudice, diagnostic traditions and access to healthcare, legal possibilities for being granted a new legal gender and insurance coverage (Dhejne *et al.* 2014).

The attitudes towards transsexual persons in Sweden are internationally regarded as being tolerant; a Swedish survey showed that a majority of residents supports the possibility to undergo SRS (Landen & Innala 2000). Among 49 European countries, Sweden was during 2015 in fourth place relating to achieved human rights for lesbian, gay bisexual, transgender and intersex populations (ILGA-Europe 2015).

To be diagnosed as transsexual in Sweden, a person presenting with gender dysphoria has to be referred to one of

the six specialised gender teams, after which an evaluation period of approximately one year follows. After diagnosis, a gender confirmation treatment starts, including cross-sex hormones along with real life experience. FtM may undergo bilateral mastectomy, and MtF receive hair removal and speech therapy. After about two years, the person can apply to receive permission for SRS and change in legal sex status (Dhejne *et al.* 2014). In Sweden, all costs for pharmacological treatment and medical care are covered by the national health insurance (Dhejne *et al.* 2014), which differs from other countries where transsexuals may have difficulties in obtaining cross-sex hormones and SRS due to limited financial resources or the failure of insurance plans to cover the costs (Kenagy 2005, Rotondi *et al.* 2013, Xavier *et al.* 2013).

Sex reassignment surgery in MtF aims to create a natural-appearing and functioning female genitalia, with a short urethra and a neovagina lined with moist, elastic and hairless epithelium that enables effortless intercourse and full orgasm, without donor-site morbidity (Amend *et al.* 2013, Wroblewski *et al.* 2013). SRS in FtM includes hysterectomy, ovariectomy and genital transformation consisting of vaginectomy, reconstruction of urethra, scrotoplasty and phalloplasty. At a later stage, testicular prostheses and/or erection prosthesis can be inserted. The aim is to create a cosmetically satisfactory penis that is sensate and allows for penetration during sexual intercourse, without functional loss in the donor area and minimal scarring or disfigurement (Monstrey *et al.* 2011, Wroblewski *et al.* 2013).

Transsexual individuals may experience stigma and isolation, which increases the risk of depression, anxiety and somatisation (Bockting *et al.* 2013). Some transsexual individuals hesitate to seek care due to fear of being mistreated by healthcare professionals (Rachlin *et al.* 2008). Several studies reveal that mistreatments of transsexual individuals are common in the healthcare context, despite the mandate that all healthcare professionals have ethical obligations. The international code of ethics for nurses specifically states that nursing care must be respectful of and unrestricted by considerations of age, colour, creed, culture, disability or illness, gender, sexual orientation, nationality, politics, race or social status (ICN 2012).

The mistreatments of transsexuals in healthcare context described in the literature include gender insensitivity (for example using incorrect pronouns) (Kosenko *et al.* 2013, Xavier *et al.* 2013), display of discomfort (such as staring or fidgeting) (Dewey 2008, Kosenko *et al.* 2013), denial of services or substandard care (such as denial of referral for gender reassignment or not being given quality care) (Kenagy 2005, Dewey 2008, Lambda Legal 2010, Kosenko *et al.* 2013), verbal abuse (Lambda Legal 2010, Kosenko *et al.* 2013), hostility and ignorance (Xavier *et al.* 2013) and forced care (to be forced to undergo unnecessary examinations) (Kosenko *et al.* 2013). In the survey by Lambda Legal (2010), transgender respondents also experienced that healthcare professionals were physically rough or abusive, and that the respondents were blamed for their own health problems. Dewey (2008) describes that although not all transsexuals experience outright refusal of treatment, many sense a discomfort with their medical encounter due to healthcare professionals distancing themselves. Poteat *et al.* (2013) explored stigma in healthcare interactions between transgender patients and healthcare providers, and describe that transgender patients experienced limited knowledge among the providers and that they anticipated the providers to be unprepared to meet their needs.

Worldwide, there are few qualitative studies addressing transsexual persons' experiences of healthcare; existing studies have been conducted in the USA, and may not be transferable to the European healthcare context. It is therefore relevant to study transsexual persons' experiences of healthcare encounters in another context, differing in the insurance system and healthcare culture, albeit obliged to follow the same international ethical codes.

The aim of this study was to describe transsexual persons' experiences of encounters with healthcare professionals during the sex reassignment process.

Methods

Design

In this study, a qualitative descriptive design was used, with open-ended interviews. This method was chosen because qualitative research methods are particularly well suited to describe experiences, and the Institute of Medicine (2011) advocates that qualitative methods can bring unique strength in the efforts to understand LGBT health. Qualitative descriptions are not committed *a priori* to any theoretical or philosophical view of the target phenomenon. The method is instead directed towards discovering the basic nature and shape of experiences, and offers a comprehen-

sive summary of an event or experience. Qualitative description is less interpretive (producing more data-near findings, from readings of lines contrary to *between* or *beyond* lines) than, for example, phenomenological descriptions, and the data are less transformed than, for example, grounded theory studies (Sandelowski 2000, 2010).

Participants

A Swedish convenience nonclinical sample was used, consisting of six persons who had been diagnosed as transsexual, gone through the evaluation period, had had gender confirmation treatment and finally, SRS, or were at the time of the interview awaiting surgery.

Two participants were recruited via one of the authors' own social networks and four participants were found through their blogs on the Internet. The keywords 'transsexual' and 'blog' were used in a Google search. A portal entitled 'Transformation' was found with links to transgender/transsexual persons' blogs. Eleven Swedish bloggers were contacted by e-mail with information and a request for their participation in the study. Four of these bloggers accepted participation.

Data collection

The interviews were performed during two weeks in spring 2014. Semi-structured interviews were performed, and a brief interview guide with two focus areas was created with two overarching questions: 'Please describe a positive encounter with the healthcare, if any, during your sex reassignment process,' and respectively: 'Please describe a negative encounter, if any, during your sex reassignment process.' Follow-up questions, such as 'Can you elaborate on that?' were also used. The participants had the possibility to choose the place for the interview: one interview was conducted in the participant's home; two interviews were conducted in a secluded location chosen by the participants; and three participants were interviewed by telephone. The interviews lasted between 20–60 minutes. The interviews were recorded and transcribed verbatim.

Data analysis

Manifest qualitative content analysis, as described by Graneheim and Lundman (2004), was used to analyse the interview material. All authors read the transcribed text repeatedly to obtain a sense of the whole. The text about the participants' experiences of the encounter with healthcare professionals during the sex reassignment process was

extracted and brought together into one text that constituted the unit of analysis. The text was thereafter divided into meaning units. The meaning units were condensed to shorten the text and to preserve the central core. The condensed meaning units were labelled with a code to enable abstraction. The codes were compared for similarities and differences, and sorted into subcategories. Finally, categories were formed by related subcategories. The analysis was completed in a back-and-forth movement between the whole and the parts of the text. The authors discussed the categorisation until consensus was reached: to what extent the data belonged to a certain subcategory and category, and how subcategories and categories were internally homogenous and externally heterogeneous (Patton 1990). The analysis process is exemplified in Table 1.

Ethical considerations

According to Swedish law, recruiting a nonclinical sample from the Internet, and interviewing outside the healthcare sector, does not require permission from a regional ethics board (Ethical Review Act 2003). In order to protect the participants, the Declaration of Helsinki (World Medical Association 2008) was followed: the participants were informed about voluntariness and the possibility of terminating participation at any time, and that the data would be treated confidentially. The transcribed interviews were

coded, and only two of the authors (IE, CM) had access to the coding list for the possible identification of participants. The coding list was kept secure and separated from the interview material. In order to further protect confidentiality and make identification of the participants impossible, the background data for the participants in this study are not presented on an individual level.

Results

The participants were aged 20–36 years, three were FtM transsexuals and three were MtF. Five participants had at the time of interview gone through the SRS process, the duration of the processes ranged three to eight years and were concluded between 2010–2013. The sixth participant was awaiting SRS at the time of interview. Two participants spontaneously described having a homosexual sexual orientation in relation to their corrected sex, and one participant described a heterosexual sex orientation. Three participants did not mention their sexual orientation, as this issue was not included in the interview guide. Three participants resided in Stockholm County, whereas the remaining three were residents of other Swedish counties.

Three categories and 15 subcategories of transsexuals' experiences of encounters with healthcare professionals were identified from the interviews, which are presented in Table 2.

Table 1 Examples of meaning units, condensed meaning units, subcategories and categories

Meaning unit	Condensed meaning unit	Code	Subcategory	Category
I explained I am transsexual. After she had understood, she said, 'So you identify yourself as a guy, but sleep with guys. Isn't that kind of double?' The next time we met she said, 'Ah, last time you were a bit uncertain about your sexual orientation.'	Double identity as a man and sleep with men. Uncertainty of sexual orientation	Lack of knowledge about sexual orientation/gender identity	Level of knowledge	
No, I wasn't, YOU were! [During psychological evaluation] they had no idea what they were doing. She didn't know what to do, so she more or less asked me what she should do. I said, I have no idea. I'm not the psychiatrist. It is up to you	Psychiatrist didn't know what to do, she asked what to do	Psychiatrist didn't know what to do		Healthcare professionals' attitudes and caregiving
When I have been on emergency visits it has been 'he, her, it, that, the patient over there.' It was easier to say 'the patient' than to call me by name	He, she, it, that, the patient instead of real name	He, she, it, that, the patient	How they speak to and about you	
In the waiting room, in the surgical department, they usually call you by your family name. He said they do that on purpose to not become insecure when persons are in transition	Use family name on purpose to not be insecure when persons are in transition	Purposeful use of family name		
At the [plastic surgery] clinic, they called me by my male name. It was terrifying. I almost left	Terrifying to be called wrong male name	Used wrong male name		

Table 2 Categories and subcategories

Category	The good encounter	Healthcare professionals' attitudes and caregiving	Perceptions of vulnerability
Subcategory	Professionalism Integrity and respect Responsiveness Trust and confidence The transsexual person's own part in the encounter	Level of knowledge How they speak to and about you Exploiting position of power Withholding information Gender stereotypes	Condescending view of oneself In dependence Cannot choose not being transsexual Not being taken seriously External high demands

Each subcategory is described below with quotations from the transcribed text.

The good encounter

This category includes descriptions of circumstances that constitute a good encounter with healthcare professionals from the participants' point of view, and encompass positive experiences. In this category, five subcategories were identified: *Professionalism*, *Integrity and Respect*, *Responsiveness*, *Trust and Confidence*, and *The transsexual person's own part in the encounter*.

The subcategory *Professionalism* consists of participants' descriptions of how healthcare personnel act in a professional manner in the encounter, such as describing why psychological tests need to be conducted, normalising the transsexual condition, not enlarging the transsexual background, seeing people for what they are and focusing on what is relevant for the time being. They were well read on the subject and made an effort not to delay the SRS process more than necessary. They also made an effort to have good communication with the transsexual persons. Some participants expressed that demonstrations of professionalism occurred when they were treated the same as all other patients to be one of the crowd and not stand out:

My psychologist said that there is nothing to be ashamed of, it is not your fault, it is a medical condition. (Participant 2)

They did not make a fuss of the transsexual background. If it's not relevant, they don't discuss it, and see persons for what they appear to be. (Participant 6)

The *Integrity and Respect* subcategory contains descriptions of how healthcare personnel preserve the transsexual person's privacy and integrity, such as 'using a special screen in front of the examination room door during consultation to shield me from unintentional door openings.' The category also includes descriptions of how healthcare professionals show respect, by not questioning the transsexual person's choice of life or reducing the transsexual person's

feelings or experiences and involving the patient in their care. One participant described the first meeting with a general practitioner:

I was present when he dictated the referral [for psychological evaluation] and he asked, "does this sound ok?" And I said yes. He was just positive. Even though it was a difficult situation he did the best out of it. (Participant 2)

The subcategory *Responsiveness* includes descriptions of healthcare personnel listening, showing empathy and compassion, and being considerate and understanding when caring for the transsexual person. The participants described that these healthcare professionals, for example, identified mental illness and offered care or that they in various situations did more than they needed to on the basis of their professional liability. One of the participants described healthcare professionals being extra committed and acting according to the person's needs:

They were very friendly. They did not come telling me, "Now we shall do this or that." They really listened. They were compassionate and cared about me. I was lying there in real pain and could barely push the button to make them come. [...] To do the little extra: "Do you want me to raise the bed for you? Another blanket?" They asked me instead of letting me having to ask. (Participant 3)

The subcategory *Trust and Confidence* contains descriptions of how participants felt confident and secure in relation to some healthcare professionals. These healthcare professionals brought tranquillity and gave the impression of safety and security, that 'everything will be alright, we will take care of you'. A good encounter generates trust and makes it possible to re-evaluate a previous opinion of mistrust:

It was the encounter [with a transgender specialised physician] that made me trust him. (Participant 1)

I had been scared stiff of hospitals and hated doctors. Doctors are not humans one can trust [...]. But they were real nice and took really good care of me. [...]. This was not the scary doctors I've always happened to meet before. (Participant 3)

Some of the participants pointed out that the transsexual person has their own responsibility to create a good encounter; it is not only the responsibility of the healthcare professionals. They described it to be, to some extent, dependent on the self of the individual transsexual person; how sensitive you are and what you find difficult asking people about. These descriptions are included in the subcategory *The transsexual person's own part in the encounter*:

Some [transsexual persons] cannot agree with anyone, and believe that the whole world is against them. (Participant 2)

I think it is the personal chemistry that does not quite match. I think much lies in that, if you meet a doctor you don't feel confident with for some reason; that you don't agree due to other social structures. Maybe it [the encounter] fails just there. (Participant 4)

Healthcare professionals' attitudes and caregiving

This category encompasses descriptions of areas that influence transsexuals' experiences of encounters with healthcare professionals, areas that could be influenced positively or negatively. The category contains five subcategories: *Level of knowledge*, *How they speak to and about you*, *Exploiting position of power*, *Withholding information* and *Gender stereotypes*.

The participants described a varying level of knowledge amongst healthcare professionals in the areas of gender identity verses sexual identity, SRS and related treatments. Sometimes, the healthcare personnel admitted that they lacked knowledge, were curious and wanted to know more. But sometimes they were just ignorant:

The woman I met [during psychological evaluation] was a bit older, and she started saying, "I don't know anything about transsexuals." Somewhat surprising for a person working in the field of psychology. I was in the beginning of my transition. She asked, since I see myself as a homosexual woman and am interested in women, she said, "Wouldn't it be easier if you continued to be a guy?" (Participant 2)

Some participants described that they had informed or to some extent educated healthcare professionals, which could be perceived as positive, that the healthcare professionals had a genuine interest and searched for information. But some participants expressed that this could also be tiring, to be perceived as a primary source of information, that the healthcare professionals had not tried to find information elsewhere. The participants described that the healthcare professionals also lacked knowledge of other treatments and surgeries related to SRS. One participant describes the

reaction from healthcare professionals at a specialised reassignment ward at a university hospital after undergoing feminising face surgery abroad:

In Sweden, they didn't even know at the reassignment ward that this existed, and to me that is stupendous. Face reconstruction, feminising surgery. They were very interested after my operation and wanted to take photos. I said yes. They wanted to know how it was done. I was really surprised, not of the encounter, but of their lack of knowledge. (Participant 2)

The subcategory *How they speak to and about you* consisted of descriptions of healthcare professionals using the wrong name or pronoun. Almost all participants had had those experiences. Some described that they were most sensitive in the beginning of the sex reassignment process. As the transformation continued, the wrong name or pronoun was used more infrequently. Some of the participants realised that they, in the beginning of the SRS process, looked androgynous, and were somewhat more understanding that healthcare professionals sometimes had difficulties using the correct pronouns. But most descriptions related to how healthcare professionals were unthinking and did not endeavour to find out the transsexual person's preferences.

It felt bad [when they used wrong pronoun], like they are normative in their way of looking at gender. [...] I feel as if they doubt which sex I am. Like they didn't quite believe me. (Participant 5)

On the contrary, participants also described that some healthcare professionals were respectful and asked which name they preferred or used their family name when this was unclear.

In the subcategory *Exploiting position of power*, participants described how healthcare personnel used their position to deprecate the transsexual person. For example, they deliberately adopted a distanced attitude, used one-way communication or an arcane academic language. One participant described how a healthcare professional used a domination technique to mark her ascendancy:

It was a funny little woman, a senior physician, who held the whole [transsexual] investigation by herself. She is somewhat short, but raises her chair so that she sits looking down at you. And then she went on, continuously trying to persuade. (Participant 1)

Healthcare professionals also used their position of power to make the participants reveal private matters:

My social evaluation, or the counsellor, did not feel very good, because she discussed matters that weren't relevant. She was supposed to evaluate my social situation, whether I had the social

support I needed among friends and family. Sometimes she asked very private questions, like what kind of sex I prefer, if I prefer anal or vaginal intercourse. It has not felt relevant, and very uncomfortable that she has asked that. She is in some kind of position of power towards me. It has felt very uncomfortable. [...] When I hesitated to tell her, she told me, “Just as well tell me now, so that we get this over.” I felt forced to answer her to get what I wanted, to get my correction. (Participant 5)

The subcategory *Withholding information* consists of descriptions of how healthcare professionals insufficiently inform or deliberately withhold information. The insufficient information could concern examinations such as tests for osteoporosis due to hormone therapy, or the transgender investigation process and its purpose along with the tests the transsexual persons have to undergo during this process:

It was very fuzzy. I expected questions concerning how I feel and so on, but it was nothing about that, it was more like looking at pictures and say what you see in it. [...] I got worried afterwards. Will she [a psychologist] assess me from what I see in a picture? I cannot see how that defines who I am? I have no clue how, and have no idea why these tests were conducted. (Participant 3)

The participants perceived being subjected to *Gender stereotypes* from the healthcare personnel: they were expected to dress, appear and act according to their preferred gender identity. They felt that their clothes were assessed, and they felt questioned and criticised. If you want to correct your natal female sex and become a man, you are not supposed to wear a skirt at any time. Both FtM and MtF participants described perceptions of the reinforcement of gender stereotypes by healthcare professionals:

If you as a male-to female transsexual and not quite fulfil, or want to fulfil a typical female stereotype, they are questioning you continually. (Participant 6)

The psychologist also said, “I actually know a transsexual person, and she had very broad shoulders and played ice hockey, and when she did, it wasn’t odd.” (Participant 1)

Some participants also expressed preconceptions of what gender stereotypes health professionals make:

The Rorschach pictures with inkblots you should look at and interpret, many people warned me that you absolutely not should say that it looks like a vagina or a butterfly. You could say neutral things, but not feminine things if you’re a transsexual guy. (Participant 1)

Perceptions of vulnerability

The participants described having varying perceptions of vulnerability during the sex reassignment process, whereof some were influenced by healthcare professionals. The participants described several situations where healthcare professionals conducting nonreflective care enhanced their sense of vulnerability. Alternatively, there were healthcare professionals who were able to diminish the perception of vulnerability. Five subcategories were identified in this category: *Condescending view of oneself*, *In dependence*, *Cannot choose not being transsexual*, *Not being taken seriously* and *External high demands*.

The subcategory *Condescending view of oneself* describes that it is common that transsexual persons at some point in time feel odd, wrong or weird. The participants expressed that they have experienced the real life test as being long and wearing, trying to fit into their opposite natal sex, without the typical attributes. For example, ‘it is difficult to impersonate a woman if you have been bodybuilding for eight years and have a big beard’. During this period, the participants perceived that they were seen as eerie by others, not fitting into any of the binary gender categories, contributing to the condescending view of themselves:

I used to say I don’t need help to dislike myself, I have already done that for a long time. (Participant 2)

I was malformed, misshaped, not a real human being. I was some kind of weird thing my parents got. Something went wrong there. (Participant 3)

The subcategory *In dependence* contained descriptions of how the transsexual person is dependent on healthcare professionals during the sex reassignment process. They decide whether they will get the diagnosis or not. This dependence on healthcare professionals was particularly strenuous when the healthcare professionals showed limited transgender knowledge, which was described as “to be in the hands of ignorant people”. In Sweden there are few sex reassignment investigation teams, and the queues are long:

It is not possible to change doctors and there are long queues everywhere, so if you want to change investigation team it will not work. There are queues everywhere. So it is just to say “thanks” to what you get. (Participant 4)

I need their help, and they are deciding if I can go through with my correction or not. (Participant 5)

The *Not being taken seriously* subcategory included descriptions of ignorance from healthcare professionals due

to transsexual persons' young age. One participant describes a visit at the child and adolescent psychiatry department, where they refused further referral to a transgender investigation:

And they are extremely negative to everything. And they [said], "We cannot do that, we cannot send a referral if we are not sure you really are transsexual" [...] And there were many of them who said, "You are only 16, you don't know what you're talking about." (Participant 1)

In the subcategory *Cannot chose not being transsexual*, the participants described vulnerability and insecurity during the SRS process. They described being questioned and having to explain to healthcare professionals that they already had tried not to be transsexual, and they would not expose themselves to the transgender investigation process unless it was necessary that they needed to correct their biological sex to feel as a whole person. One participant described the emotional turbulence and doubts they experienced during this period:

It is like an emotional roller-coaster up and down with hormones and transformative operations, questioning how it will go. Will it work, will I pass? Because there is no plan B. You cannot say, no I think I'll skip this. It has to work, if it doesn't, I'm screwed. (Participant 2)

The participants described that they felt vulnerable due to *External high demands*, mainly from the healthcare professionals. They felt that they didn't receive sufficient support during the reassignment process, having to push the process forward all by themselves and be the driving factor even when feeling ill. Most of the descriptions concerned lack of psychological support:

I felt I had to mature more than I was able to. (Participant 1)

It is formed so that I'm supposed to be the driving factor in the reassignment process, and that is pretty hard when you feel really ill. Naturally this is also reflected in the psychological support that you receive or not. If I phone and cancel a visit because I feel ill, so sure I get a new visit [...], but nobody calls and asks how you feel. (Participant 2)

Moreover, the participants describe other areas when they lacked support, such as the need early on in the process to discuss possibilities for having biological children at a later stage (such as freezing eggs or sperm). Also, when the SRS was completed, the participants expressed a general lack of support from healthcare regarding the 'legal sex reassignment,' meaning 'where to apply, who will grant, and how does it work?'

Discussion

This study was taken on as very few studies had been executed on SRS-matters in Sweden, and, to our knowledge, no effort has been given to explore the patients' experiences, although SRS has been legal in Sweden since 1972 and is performed at several centres. Although the participants gave a most appreciative picture of the surgical care at the centres, their descriptions of the struggle leading up to the final surgery correspond with results from previous studies; a study from the USA revealed disproportionately high rates of depression, anxiety and overall psychological distress among transgendered persons, when compared to community norms (Bockting *et al.* 2013). Other studies show that experiences of vulnerability in transgender persons involve harassment and violence (Lombardi *et al.* 2002), exposure to risks, discrimination and marginalisation (Grossman & D'Augelli 2006), serious thoughts about taking their lives or a history of suicide attempts (Grossman & D'Augelli 2007).

Part of the perceptions of vulnerability of the participants in this study is that they have a condescending view of themselves, and that they cannot choose to not be transsexual. They have to go through with the process to become a whole person. Bess and Stabb (2009) have described this seeking of wholeness: transsexual people do not want to be fixed, they want to be whole and are risking a tremendous amount to confront the pain and are undergoing life-changing transformative treatments and surgeries so that they can be perceived by others as the sex they consider themselves to be.

In the vulnerable period of the sex reassignment process, some participants described being dependent on healthcare professionals to receive the transsexual diagnosis or treatments they wanted, there is no possibility to change doctor or sex reassignment team. This finding is consistent with findings by Mayer *et al.* (2008), who identify that insufficient numbers of healthcare providers are competent in dealing with transsexual care as one of the main barriers to optimal healthcare for sexual and gender minority patients.

Some participants described that the external demands were high, that they didn't receive sufficient support. The lack of resources for mental health concerns available for transgendered persons has previously been identified by Grossman and D'Augelli (2006) as one of the major issues related to vulnerability in health-related areas among young transgendered persons. To reduce vulnerability, steps need to be undertaken by providing transgendered persons access to resources that meet their specific needs.

The results in this study reveal that some healthcare professionals lack knowledge relating to how gender identity is a separate phenomenon to sexual orientation. Like all individuals, transsexual people's sexual orientation could be heterosexual, homosexual or bisexual relative to their desired sex, independently of having modified their gender identities and presentation or not (Diamond *et al.* 2011). Johansson *et al.* (2010) conducted a long-term follow-up of Swedish adults with gender identity disorder and showed that a fairly large proportion (31%) have a nonheterosexual sexual orientation in relation to their gender identity. Furthermore, the participants also described a lack of knowledge among healthcare professionals in other areas, such as the sex reassignment process, operations and related treatments. This finding is not surprising. Mayer *et al.* (2008) argue that neither medical and nursing schools nor continuing education programmes provide the sufficient training needed to improve attitudes, knowledge and skills of healthcare professionals in caring for transsexual people. Rondahl (2009) found that only 17.7% of nursing and medical students had a basic level of knowledge concerning the care of lesbian, gay, bisexual and transgender persons. Furthermore, results from a recent study showed that registered nurses to a large extent also lack understanding about gender identity and sexual orientation terminology (Carabez *et al.* 2015). Without more knowledge, sexual and gender minorities will continue to encounter healthcare professionals who are unaware and unprepared to meet their needs (Mayer *et al.* 2008).

Some participants had experienced that the personnel exploited their position of power to make them reveal private matters or to deprecate them. Peate (2008) points out that the attitudes of healthcare professionals' caring for transsexual people can adversely affect transsexual persons' well-being and make them feel uncomfortable. It is vital that transsexual people do not experience discrimination or failure to provide dignity in any setting, which is tantamount to professional misconduct. Along with the ICN code of ethics for nurses, Swedish nurses have other supportive documents; the Swedish Society of Nursing have formulated a foundation of nursing care values, aiming to create a common stance and approach, as well as a universal ethical platform for everyday work (Swedish Society of Nursing 2011). In these care values, the importance that care providers reflect on power-related aspects in the encounter with patients is emphasised. The care relationship is asymmetrical; the patient is often in a situation of dependence and the carer has an influence of not merely the physical care but also over the patient's situation and understanding of themselves (Swedish Society of Nursing 2011).

Almost all participants had experienced that healthcare professionals used the wrong name or pronoun. Peate (2008) emphasises the importance of using the name the transsexual person prefers, and if this is ambiguous they should discuss the person's preferences in private and these should be honoured.

The results show that participants felt that they were expected to present and behave according to sex stereotypes. Lombardi (2001) suggests that healthcare professionals should allow people some flexibility and not question their gender identity, have a respectful manner and not expect that all people fall into neat categories. Moreover, if transsexual persons meet gender stereotypical attitudes they may alter their behaviour and prepare how they will approach health professionals to gain credibility and avoid stigmas to improve their likelihood of receiving the desired treatments (Dewey 2008).

The findings in this study also show that some participants were not fully informed about the transsexual investigation and the SRS process, and that health professionals withheld information, which could result in worries. Alternatively, when they were thoroughly informed and were involved in decisions relating to their own care they described the encounter as good, and perceived the healthcare personnel as being professional. This finding is confirmed by Lombardi (2001), who argues that giving transgendered persons greater influence on their own care would improve their health. One participant described the relief when the healthcare professionals were extra committed and acted according to the participant's needs; they did the 'little extra.' Arman and Rehnsfeldt (2007) have previously showed that 'little things' have the power to preserve dignity, make patients feel they are valued and alleviate their suffering.

A great part of the good encounters described by the participants in this study had taken place in departments employing healthcare professionals with extensive experience on caring for transsexual individuals. Sex reassignment surgery has been performed in Sweden for more than 50 years (Dhejne *et al.* 2014). Few specialised surgical departments at a few regional hospitals are involved. It is obvious that a nonjudgemental culture may have developed within these departments, which makes it possible to believe that the findings in this study regarding transsexual persons' positive experiences of encounters with staff in the specialised surgical departments may well be transferable within the Swedish setting. Unfortunately, this transferability may also be the case regarding the less positive experiences described during the diagnosis process in the primary care system.

Methodological considerations

In qualitative research, the aim is to explore experiences and generalisable results cannot be retrieved. Instead, the trustworthiness of the findings is evaluated in terms of credibility, confirmability, transferability and dependability. Credibility refers to the selection of participants and the approach used for data collection (Graneheim & Lundman 2004), and could, in this study, be assessed by the varied experiences of the included participants; they lived in different parts of Sweden, and their diagnosis process, gender confirmation treatment and SRS were performed in different healthcare settings and hospitals in Sweden. The participants were of various ages and the time since the sex reassignment process also varied. Participants were both MtF and FtM, and both heterosexually and homosexually orientated relative to their desired gender identity. Thus, the research question was elucidated from a variety of aspects, which may also make the results transferrable to the care of transsexual persons as a whole in Sweden.

In this study, a manifest content analysis method was used, describing the visible and obvious content of the transcribed interviews. Manifest analysis has less depth and abstraction than a latent analysis, but some degree of interpretation always occurs (Graneheim & Lundman 2004). Texts have no 'objective truth,' meanings are always brought to it by the analyst, and it is important to confirm and acknowledge whether interpretations and inferences make sense to someone else and that another researcher could confirm the findings (Krippendorff 2004, Marshall & Rossman 2006). To achieve confirmability, the authors discussed until agreement on how the data were coded, how the data were covered in subcategories and categories. The subcategories are presented with representative quotations to enable the assessment of categorisation.

Data were gathered over a period of a couple of weeks; the brief interview guide was followed in all six interviews and no new topics were introduced; thus, this strategy strengthened the study's dependability. However, the time that had passed since the participants had experienced the investigated phenomena varied from still being in the process to several years. For one participant, memories faded over the years, but more important, the experience, knowledge and attitude within the healthcare organisation have developed over that time, which may explain differing recollections of encounters.

This study has some limitations that need to be mentioned. A convenience sample was used; four out of six participants were recruited from a blog portal on the Internet. Recruitment and data collection from the Internet have

predominantly been used in quantitative studies and the method has both strengths and limitations. In qualitative studies, with stigmatised populations such as transgender people, the strengths are that the Internet enables the researcher to quickly reach geographically dispersed non-clinical members of the population for little cost. Moreover, it is an environment that is sufficiently anonymous so as to also allow the possibility to reach still closeted people (Shapiro 2004, Miner *et al.* 2012). However, Miner *et al.* (2012) found that qualitative online data collection, such as online chat interviews, resulted in shorter and more parsimonious material than material usually gained in qualitative face-to-face interviews or telephone interviews. Thus, in this study, the Internet was only used for recruitment, and data were collected face-to-face and by telephone.

Another limitation is that the sample size was small; it would have been desirable to include more participants. Another seven transgender/transsexual persons were approached during the recruitment period, but declined participation. The small sample size may be explained by the fact that the transgender population is small by total in Sweden; from 1960–2011, a total of 681 individuals were granted a new legal sex (Dhejne *et al.* 2014). The recruitment of participants from a blog portal on the Internet provided a very limited possibility to approach more potential participants.

Some of the interviews were short and did not give the same richness of data as the longer interviews, but contributed to variation in descriptions and thus a sufficient richness of data was retrieved to describe the domain of interest: experiences of encounters with healthcare professionals in the SRS process. Saturation (in this study defined as multiple descriptions from more than one participant) was achieved in all categories, and all subcategories but one (*Not being taken seriously*), which was only described by one participant.

The interview guide did not include any questions relating to sexual orientation due to ethical considerations regarding respect for the participants' dignity and choices in life (ICN 2012). However, sexual orientation was spontaneously mentioned by some of the participants, describing how healthcare professionals confuse sexual orientation with gender identity. It is a limitation in this study that this issue was not further explored.

Conclusion

Transsexual persons are a vulnerable group; vulnerable when growing up – thinking they are freaks, self-loathing, being alone with all kinds of thoughts and feelings. They

are vulnerable during the year-long evaluation period; SRS is not a choice – one cannot decide not to be transsexual. They must argue their case in all encounters with healthcare professionals, often who adopts gender stereotypical attitudes and who have insufficient knowledge of transsexual issues. They feel as though they are not being taken seriously, humiliated by neglect and ignorance by the professionals, whose decisions they depend on, and who sometimes even exploit their position of power to extract very personal information from the patient. They describe vulnerability during the gender confirmation treatment period which is several years long, while not looking as they are supposed to, being on a hormonal roller coaster ride, never feeling well and, despite doubt, anxiety and depression, still having to lead and push the process forward unassisted. The agony is prolonged over years.

But there were also descriptions of good encounters, characterised by preserved integrity, respect, responsiveness and trust. Healthcare professionals being committed, showing compassion and acting in accordance with the transsexual person's needs, can make them feel valuable and alleviate some of their suffering. For example, when, after years of humiliation and constant struggle, reaching the final stage, during the actual sex reassignment procedure, the participants in the study unanimously described a period of ease, trust and professional caring.

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Relevance to clinical practice

Improved education on transgender issues in basic medical and nursing education is warranted, as well as clinical training to make doctors and nurses more prepared for meetings with transgender persons. Healthcare professionals should be aware of how their attitudes, behaviour and level of knowledge affect the care given from the first appointment to providing a further referral to a transgender investigation, and throughout the SRS process.

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Contributions

Study design: A-CvV, IE, CM, LS; data collection: IE, CM; data analysis and manuscript preparation: A-CvV, IE, CM, LS.

Conflict of interest

None declared.

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