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Nursing program 180 ECTS credits, Bachelor of Science in Nursing

Independent work in Nursing Science, 15 ECTS credits, VKGV51, fall 2017

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“GENDER IS NOT WHAT YOU SEE”

TRANSGENDER PEOPLE'S EXPERIENCES OF IDENTITY, HEALTH AND WELL-
BEING

AN INTERVIEW STUDY

“GENUS ÄR INTE DET DU SER”

TRANSPERSONERS UPLEVELSER AV IDENTITET, HÄLSA OCH VÄLMÅENDE
EN INTERVJUSTUDIE



Sammanfattning

Bakgrund: I Indien har transpersoner sedan tusentals år tillbaka ett stort kulturellt arv och har en lång historia av representation inom hinduismen. Dock visar forskning att transpersoner i dagens indiska samhälle saknar sociala rättigheter och diskrimineras när det kommer till anställning, boende samt hälso- och sjukvård. Att utsättas för diskriminering på grund av att en är den en är kan i sin tur skapa psykisk och fysisk ohälsa.

Hälso- och sjukvårdens möjlighet att tillgodose transpersoners behov begränsas av stigma och brist på rätt kunskaper att tillmötesgå de omvårdnadsbehov som transpersoner kan ha när de söker sjukvård.

Syfte: Syftet med studien är att undersöka transpersoners upplevelse av identitet, hälsa och välmående i Indien.

Metod: En kvalitativ semi-strukturerad intervjustudie med fem deltagande genomfördes, fyra av intervjuerna användes i resultatet. Deltagarna intervjuades om sina upplevelser av identitet, hälsa och välmående, samt tillgänglighet och bemötande av hälso- och sjukvård. Innehållet analyserades genom en innehållsanalys.

Resultat: Resultatet indelades i Identitet och Samhälle, där temat Identitet innehöll 1. Livsvärldsrelaterade reflektioner om könsidentitet. 2. Livsvärldsrelaterade reflektioner om den egna kroppen. 3. Strategier för att skydda den egna värdigheten och 4. Betydelsen av relationer och sociala nätverks för den egna identiteten. Temat Samhälle innehöll 1. Erfarenheter av bemötande från hälso- och sjukvårdspersonal. och 2. Erfarenheter av diskriminering utanför hälso- och sjukvård.

Diskussion: Diskussionen hölls utifrån ett livsvärldsperspektiv och berörde hur diskriminering och brist på kunskap inom hälso- och sjukvård orsakar att en inte blir sedd som en person. Kränkt värdighet diskuterades även och hur värdigheten är kopplad till integritet och självbild samt hur självförtroende och självkänsla är betydelsefullt för identitetsskapande.

Nyckelord: Transperson, hälsa, identitet, empati, bemötande, välmående, etiska problem.



Abstract

Background: In India transgender people have a legacy of representation and acceptance dating back thousands of years within the Hindu religion. However, studies show that transgender people in today's Indian society experience lack of social rights and are discriminated towards when it comes to employment, housing and healthcare. Being discriminated based on who you are may in turn lead to poor physical and mental health.

The healthcare services ability to promote health and give good care to transgender patients is limited due to stigma and lack of knowledge in meeting the needs that transgender people may have when seeking healthcare.

Aim: The aim of this study is to examine the experience of identity, health and well-being among transgender people in India.

Method: A qualitative semi-structured interview study with five participants was made, four of the interviews were used in the result. The participants were interviewed about their experiences of health and well-being as well as the availability and treatment from the healthcare system. The content was analyzed through a content analysis.

Results: The result was divided into Identity and Society where the theme Identity contained 1. Life-stance related reflection about gender identity. 2. Life-stance related reflections about own body. 3. Strategies to protect one's dignity and 4. The meaning of relationships and social networks for one's own identity. The theme Society dealt with the sub-themes 1. Experiences of attitudes among healthcare professionals and 2. Experiences of discrimination outside healthcare.

Discussion: The discussion was held from a life-stance point of view and touched upon how discrimination and lack of knowledge within the healthcare services can lead to not being seen as a person. Violation of dignity was also discussed and how dignity is connected to integrity and self-image as well as how confidence and self-esteem is important in forming one's identity.

Keywords: Transgender, health, identity, empathy, treatment, well-being, ethical issues

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1 Introduction

Historically there have been several known transgender communities. The south Asian “third gender”, known as *Hijra*, *Jogappas*, *Jogtas* or *Shiv-shaktis* has been around for centuries. As well as the Philippine *bakla*, the *Xaniths* in Oman and the *Serrers* in Kenya.

In April 2014 India legally recognized a third gender. This means that individuals who define themselves as neither man nor woman are now able to choose another gender identity, for example when applying for a passport or other forms of identification.

Despite being legally accepted, transgender people are still viewed as outsiders by society. Since transgender people are considered casteless in India they are only allowed basic civil rights. They are not able to get married, they are not entitled to healthcare and many have difficulties acquiring a job because of the stigma surrounding their gender identity which forces many to support themselves through sexwork or begging.

This stigma affects the acceptance of transgender people socially, not only by the community surrounding them but for many also among family members, resulting in them being disowned or voluntarily choosing to move out with some living in all-*hijra* communities due to the mistreatment they receive in their homes.

The legal acceptance of transgender people is limited while at the same time they are being shunned by society, making their right to existence paradoxical. How does this exclusion affect transgender people’s identity, health and well-being?

2 Background

The background will describe a brief historical view of the transgender people’s role in Indian society and how that role has changed through the years up until this day. The authors will be using the term *transgender people* when referring to the subject in question.

2.1 Transgender

According to Riksförbundet för sexuellt likaberättigande (RFSL) and RFSL Ungdom (2017) The word *transgender* is an umbrella term, meaning it includes several definitions about people who in different ways don’t follow society’s norms about gender and gender identity. One thing that most transgender people have in common is that they don’t define themselves with the gender assigned to them at birth. Every person has their own personal definition and it has nothing to do with sexuality. Using an umbrella term is therefore important since it

makes it possible for the participants in the study to freely define themselves as they wish. Examples of terms included in *transgender people* can be non-binary, male, female, trans-man, trans-woman, gender fluid, demigirl, demiboy and several other terms not discussed in this study.

2.2 Cultural importance

Agoramoorthy and Hsu (2015) described *Hijra* as one of the definitions included in the term transgender and is used throughout south Asia. However the Hijra definition is limited to describing a woman or girl assigned male at birth, and therefore excludes other gender identities and definitions, even if it's frequently used in studies about transgender people in India and south Asia.

Agoramoorthy and Hsu (2015) further described that transgender people have acted out a significant role in Indian culture over thousands of years, they're portrayed in famous religious scriptures and accepted by millions of Hindu followers. According to Hindu mythology hijras were blessed with powers to bring luck, riches, rain and fertility. They were also included to perform blessings at weddings and birth of newborns according to Kalra (2011). Even today these ceremonies are performed but not as frequently due to globalization and changes in the Indian social structures. This is another reason that added to the struggles of employment among transgender people.

Agoramoorthy and Hsu (2015) described that the Hindu religion has come a long way in accepting transgender people compared to other world religions. This is exemplified by their views on god as male, female and even gender neutral. Kalra (2011) described a historical tolerance in the Hindu religion towards sexual identities. Agoramoorthy and Hsu (2015) described how this changed in the middle of the eighteenth century when the British started colonizing India. This meant that transsexuality and homosexuality was considered illegal. In 2009 India rejected this law but only five years later parts of it was reinstated.

2.3 Healthcare

The ethical code for nurses was developed by The International Council of Nurses, ICN, uniting and guiding nurses' approach. The code has a clear humanitarian focus throughout the four themes, mentioned among other things is how healthcare is to be given with respect to the human rights regardless of the patient's age, ethnicity, beliefs, disability, gender, sexuality,

political opinions or social status. The code also mentions that the nurse should practice equality and social justice in regards to resources and availability and display professional values such as respect, openness, compassion, trustworthiness and integrity, personal responsibility of continuing to maintain work-competence, helping to keep a practice culture, promoting open dialogue and ethical behavior.

A candidate essay by Casén-Nylander and Nilsson (2015) showed that transgender people had experiences of healthcare professionals exhibiting sufficient competence in terms of professionalism and an exemplary good attitude, but had also met healthcare professionals with a lack of competence manifesting itself through violating integrity, showing ignorance and a heteronormative attitude. This led to an obligation to educate the health care professionals. A good experience of healthcare professionals' attitudes correlated with the healthcare professional's competence about transgender terms and a person-centered care.

A study by Shaikh, Mburu, Arumugam, Mattipalli, Aher, Mehta, and Robertson (2016) described that anxiety and depression was frequent among transgender people due to the fact that the healthcare services lacked the ability to meet the needs that transgender people may have when seeking healthcare. These shortcomings stemmed from stigma and limited education on transgender specific issues among healthcare professionals.

Shatzel, Connelly and DeLoughery (2017) describe that the problem of education also effects transgender patients physical health. Their study on thrombotic issues in transgender medicine looked at the cardiovascular risks of hormone therapy and concluded that these risks could be minimized by educating more clinicians in transgender health along with minimizing other thrombotic risks.

Newsome, Colip, Sharon and Conklin (2017) describe an interprofessional health clinic working with transgender healthcare in New Mexico where through education pharmacists were given the opportunity to become pharmacist technicians giving them among other things prescribing authority, make medication changes and order lab tests. The role of the pharmacist technician was to assess health literacy level, discuss risks and benefits of hormone therapy, managing risk reduction strategies such as smoking and weight loss showed that the involvement of a pharmacist has improved care access and quality.

2.4 Health

RFSL and RFSL Ungdom (2017) described that you as a transgender person decide how to identify yourself and who you feel you are, which has nothing to do with how other people perceive you. Some people wish to undergo gender confirmation surgery and other people don't wish to change their body, name or legal gender. However, in Sweden it is required that you have a gender dysphoria diagnosis in order to be able to change your body and/or legal gender. In order to get such a diagnosis as a transsexual or non-binary, you need to meet certain requirements or diagnostic criteria and it is therefore necessary to conduct a gender investigation, this takes about two years. According to RFSL and RFSL Ungdom (2017) being diagnosed does not mean that you are ill. Instead, it means having needs of some type of gender confirmation treatment.

The governmental investigation *Transpersoner i Sverige* (2017) described that the transphobia that many transgender people meet in their daily life created vulnerability and mental illness. The investigation showed that four out of ten transgender people have avoided seeking healthcare due to worries of being met with a bad attitude. Only three out of ten people were satisfied with the attitudes among health care professionals when seeking referral for a gender investigation. Four out of ten transgender people between 15 and 19 years old have attempted to commit suicide due to mental illness.

Virupaksha, Muralidhar and Ramakrishna (2016) examined the topic of suicide and suicidal behavior among transgender people. Through literary research they found that suicide rates were significantly higher in transgender people compared to the general population with 31% of transgender people in India committing suicide, at least half of those people had previously attempted suicide before the age of 20. In the United states 41% of transgender people had attempted suicide at least once, in England that number was 48% and in Australia 50%.

In Japan suicide and self harm was a serious problem among sexual minorities according to Virupaksha et al. (2016). The high suicide rates were not related to openness or whether or not the person has undergone gender confirmation surgery. Out of the people questioned, 62% had problems with, or had no contact with family due to not being accepted, being treated badly or feeling embarrassed. More than half of the respondents had a habit of consuming alcohol with 15% at risk of alcohol abuse, 26% suffered from severe depression, with 14% people having consulted mental health professionals.

Virupaksha et al. (2016) further described that low socioeconomic status, high perceived stigma, poor social support and high perceived stress was prevalent among everyone questioned. Some resilience factors included help seeking, assertive communication, self-advocacy and integrity, among other things. Social and family support was a general protective factor with reduced risk of suicide attempt.

A study by Meyer, Brown, Herman, Reisner and Bockting (2016) showed a higher prevalence of poor general health, more days of poor physical and mental health as well as higher prevalence of myocardial infarction among transgender individuals compared to cisgender individuals (a person whose gender identity matches the sex they were assigned at birth). The study also showed that transgender individuals to a greater extent lacked healthcare coverage and a healthcare provider compared to cisgender individuals. However there was no significant differences between cisgender and transgender people regarding chronic disease, cancer or depressive disorders as well as health behaviors such as smoking. The authors conclude that there are unmet needs within the transgender population.

Shaikh et al. (2016) described in a quantitative study that transgender people faced inequalities at individual, communal and structural levels. The study showed that transgender people were at a higher risk of being exposed to HIV due to the fact that 20-30 % of transgender people in India are forced into sex work as their primary source of income. Unprotected sex, multiple sex partners and hormone injections in combination with lack of availability to healthcare were described as contributory factors for an increased risk of HIV.

Shaikh et al. (2016) found that the extreme social exclusion and deficiency of acceptance of transgender people are structural problems in the society and lead transgender people to social isolation, discrimination and victimization. This negatively affected transgender people's self-esteem and ability to participate in social events.

De Pedro, Gilreath, Jackson and Esqueda (2016) found a need for community and school intervention to tackle the issue of substance use in transgender students. Their study found that transgender students were more likely than cisgender students to use cocaine or meth, more likely to smoke cigarettes and showed a higher likelihood of using inhalants or prescription pain medications past 30 days.

The existing knowledge is focused on transgender people's sexual health, and while this is relevant for physical health, the experience of health is multidimensional in the salutogenic perspective. Quantitative studies have described the existence of mental illness among

transgender people and qualitative studies made on the subject have generally failed to mention a psychological aspect of identity and well-being and only mentioned the need of further studies in this field. The authors therefore think that more research and understanding on the relationship between identity, health and well-being is needed. There is an evident connection between these topics and further research could prove helpful in giving the healthcare services and other societal functions the right tools to be able to understand and meet transgender people's needs when it comes to mental health.

3 Problems

The authors consciously chose not to focus on transgender people's health in a sexual context, since existing studies have already thoroughly examined this aspect. Further, the authors find it problematic that previous research has focused on aspects that might have more to do with pre-understanding and prejudice of transgender people's sexuality rather than including all aspects of health and well-being upon which the healthcare sciences are based. On the one hand, research regarding sexual health is necessary for HIV prevention, but on the other hand an ethical dilemma occurs when all funding goes towards this cause and all other dimensions of health are missing. Ignorance leads to stigma and as long as the stigma still exists in society and continues to permeate the healthcare services, healthcare isn't as available for transgender people as it is to the general public.

4 Aim

The aim of this study was to examine the experience of identity, health and well-being among transgender people in India.

4.1 Questions

1. How do transgender people experience their identity, health and well-being?
2. How are transgender people's identity, health and well-being affected by the attitudes of others?

5 Theoretical framework

The theoretical framework chosen in this study is the lifeworld perspective. *Lifeworld* refers to the relationship between object and subject, between human beings and their surroundings according to Dahlberg, Segesten, Nyström, Suserud and Fagerberg (2003). The focus is however always on the person's experiences and interpretations. The lifeworld is at the centre of phenomenology and hermeneutics, moving away from the presumed, un-reflected and expected, the way most people generally experience the world. In the context of this study the lifeworld perspective can be applied on the participants experience of identity and self-esteem, as a view of themselves of who and what kind of person they are, as well a view of the body as a lived body.

Dahlberg and Segesten (2010) describe the lifeworld in an experience of identity and self-esteem as how a person moves and reacts in different situations, how the body acts and reacts, both affects and has been affected by who the person is, as well as by how the person experience themselves. The experience of gender is an example of how existential aspects are included in the view of the body as lived. The gender identity is more than just an experience of the body. The body is just a part of the unit as a whole. In the lifeworld perspective the human is seen as a unity consisting of both mind and body; both psychological, physical, existential and spiritual components.

Lifeworld is also applied on the way the participants are approached when seeking healthcare according to Dahlberg, Segesten, Nyström, Suserud and Fagerberg (2003) even though there are articles and books to read, the story as told by the patient will give the best insight as to how they experience their situation. Experiences, memories and emotions make up the way a person experience the world around them. This is true for both nurses and their patients.

Dahlberg et al. (2003) mean that in the context of healthcare and nursing the lifeworld is an integral part, allowing for the caretaker to focus on the way the patient describes how they are feeling, their perception of pain or how they experience a situation. Due to this people are paradoxically both alike and different, meaning that they share similar experiences but interpret them in a unique way. It is therefore of utmost importance to utilize the patient as the primary source of information about the patient in question, to regard the importance of curiosity and to have the ability to let the unexpected take you by surprise.

6 Method

6.1 Study design

The study is based on qualitative semi-structured interviews. Danielson (2012) describes that semi-structured interviews help authors to gain understanding of the participants' experiences. The interviews were conducted through a phenomenological approach, due to this the participants were able to give their own view of identity, health and well-being. Therefore the authors believed this approach suited the the aim of the study.

6.2 Participants

The project was conducted by carrying out five individual in-depth interviews with people who define themselves as transgender. Participants were informed about the study through organizations for people who identify as lesbian, gay, bisexual, transgender, queer or other (LGBTQ+) and via social media in Bangalore. Contact information was made available for those interested in participating so they in turn could reach out to the authors. The purpose of letting the participants contact the authors was to make sure that participation was voluntary. This approach minimized the risk of putting participants in harm's way. If the participants were approached in a public setting, there would have been a greater risk of them feeling forced to partake.

6.3 Data collection

Data was collected from September through November of 2017. Interviews were conducted at a time and place chosen by the participants. Two interviews were conducted at an office for a LGBTQ+ organization, two at a restaurant and one at the participant's place of work. All interviews were done in English. The data was collected with a semi-structured interview guide (see Appendix 1) with open-ended questions to encourage the participants to speak freely about their experiences. Follow-up question were used to ensure that all the topics of interest were covered. Two recording devices were used to capture the conversation including affective communication, meaning how participants express themselves, and details such as tone of voice and pauses. Both authors were present during the interviews. One of the authors was in charge of the interview and the other focused on the recording equipment and other practical matters such as keeping track of the time and taking notes if needed. Participants

were informed that the interviews would take about 30-60 minutes, but were free to speak beyond the time frame if they wanted to.

6.4 Data analysis

The recorded data was transcribed verbatim, expressed feelings and pauses were also noted. The findings were processed with a content analysis according to Danielson (2012), the knowledge will therefore never be absolute but will instead consist of a deeper understanding of the experience of identity, health and well-being based on the dialectical process of understanding a unity, explaining parts and then understanding another unity.

The transcribed interviews were read through multiple times to obtain a sense of the whole according to Graneheim and Lundman (2003). The data was divided into meaning units that were condensed. The condensed meaning were abstracted and labelled with a code based on differences and similarities, which led to a first understanding of common units.

This first analysis was further processed to a fewer number of units, where some of the themes that emerged in the first analysis could be included in the same unit. This process amounted in two main themes and six sub-themes. An example of codes, subcategories, categories and a theme from the content analysis is shown in Table 1.

6.5 Table 1

Meaning unit	Condensed meaning unit: Description close to the text	Condensed meaning unit: Interpretation of the underlying meaning	Sub-theme	Theme
<i>"I need to find someone who's like me, because I just thought that in the whole world I'm the single person who are like this."</i>	Need to find someone who's like me, thought that in the whole world I'm the single one who are like this.	Longing to have relationships and networks with people in the same situation in order to not feel alone.	The meaning of relationships and networks for one's identity	Identity

6.6 Ethical considerations

When conducting qualitative interviews with a potentially sensitive and private topic it is of the utmost importance to clarify the aim and intentions of the study. A contact form containing information about the study and the participants' rights was sent out (see Appendix 2). Before every interview the participants were again informed that they may opt out at any time without further explanation. They were also informed that their answers and personal information would be handled confidentially. No names or other personal information that could be used to identify the participants was included. The participants were also given the opportunity to choose the time and place for the interview to make sure that the interviews would be conducted where they would feel safe. They were then again informed that the interview would be recorded and asked about their consent. All material of the study and the result was stored in a safety locker with regards to the participants' safety. No names or places were documented. If information about a person who has been interviewed would have leaked out it could have put them at risk of harm, which is in violation of the nursing profession.

Kjellström and Sandman (2013) stresses the importance of regarding the risk of letting the data collection get in the way of the participant's well-being. For the study to be justified, the benefits that the study will yield must always outweigh the risks according to Danielson (2012).

This study was approved by the Research Ethical Committee at Department of Healthcare Sciences, Ersta Sköndal Bräcke University College in Stockholm, Sweden.

7 Results

The results of the study were presented in two main-themes *Identity* and *Society*, which included a number of sub-themes (see Table 2). The sub-themes were discussed below and exemplified with quotes from the participants. The participants were between 20-40 years old and were all born and resided in India. In the result the participants were assigned letter instead of a fictive name. To distinguish quotes from each individual the participants were named as: Participant A, Participant B, Participant C and Participant D. In second person pronoun the participants A, B and D were called "he" and "she" according to the pronouns

chosen by the participants. Participant C wanted to be referred to as a female male or just a person, due to this the authors avoided using other terms.

7.1 Table 2

Main themes	Sub-themes
Identity	<ul style="list-style-type: none"> ● Life-stance related reflections about gender identity ● Life-stance related reflections about own body ● Strategies to protect one's dignity ● The meaning of relationships and networks for one's identity
Society	<ul style="list-style-type: none"> ● Experiences of attitudes among healthcare professionals ● Experiences of discrimination outside healthcare

7.2 Identity

7.2.1 Life stance-related reflection about gender identity

The participants in the study all had individual reflections and experiences about themselves as a person in their life. What all participants had in common was that the reflections and experiences about their gender identity and their relationship towards their own body had an important role in the participants' view of themselves and experience of their own body. Some of the participants described that they knew at an early age that they didn't fit in with the society's normative perspective on gender. Something that was prevalent with most of the participants was a feeling of otherness and not having an accepted role within the society.

Participants also reflected on how feeling left out of society or being treated badly because of their non-conforming gender identity for some had affected their mental health and well-being with some participants describing self-destructive behavior and even attempts at ending their own life.

Participant A talked about being different

I kind of always knew that I'm different from the beginning (...) Then you're thrown into this very heteronormative system that your conditioned to think so and so (...) And that make me "okay, I'm thinking wrong" (...)

Participant C described struggles with society's norms

Because due to the society look at only "female" and "male" There is not other chance to live. (...) I'm born as a male, but I'm not fitting in to the

male-box. I'm something else. (...) But people not accepting (...) At that time I wanted to take my life so many times.

7.2.2 Life stance-related reflection about the own body

Participants shared thoughts and feelings of their relationship to their own body. Several participants described feelings of not identifying with their physical body, some described it as difficult and how they would feel trapped in a body they didn't belong to. This led some participants to either have gender confirming surgery or want to go through gender confirming surgery in the future. One participant however described feeling content with their body and saw themselves as a non-binary feminine man. One participant described how behaving and dressing more like the opposite sex was socially accepted and never questioned when he was young, but that at a certain age society starts having higher demands on what you're supposed to be like as a man or woman, meaning you are not as able to diverge from the expectation other people have of you. Another participant shared what it was like to go through the same physical struggles as a woman does while he himself did not identify as a woman.

Participant B described an early memory

I identified at the age of 6 that I'm trapped in the wrong body (...) So my change is feminine, because I was born genetically male (...) gender is not what you see, gender is what your psychological speaks.

Participant D talked about physical differences

The kind of difficulties that a woman's body (...) goes through. Which I go through too, even though I'm not a woman. (..) I have to go through that, as well as a lot of additional things.

7.2.3 Strategies to protect one's dignity

Several participants described strategies to deal with situations in their daily life where they felt the need to protect and defend themselves and their dignity. Situations like these arose for example when having their gender questioned or revealed, as well as being at work or meeting family members. Ways in which the participants described dealing with these issues included amongst other things having to always explain their pronouns in order to protect their dignity, or choosing to dress as their assigned gender when visiting family to avoid

conflict. Some opted to not be open about themselves and their gender identity in order to protect their dignity.

The different ways of dealing with protecting one's dignity seemed to correlate with whether the participant had been subjected to generally positive experiences or generally negative ones. Participants who had been harassed or had met with a lot of negative experiences generally tended to avoid situations where conflict could arise and also described being troubled with depression. Participants who had generally more positive experiences or had a support system described being happy in themselves and/or having the strength to stand up to society.

Participant A talked about compromising

So, when I go home I dress androgynous, I don't really dress completely as a woman. (...) It took a long time for me to be comfortable with myself, because every time (I dress like a woman) people are gonna stare at me, or people are gonna talk a lot (...) it will disturb me a lot. But then I decided it's very important that I have to be comfortable with my body and with what I am, and then I don't really care much about them.

Participant B described how she dealt with society

I'm mentally strong women, so I fight with the society every day. So I'm happy! (...) I'm happy who I am. I'm proud of my gender, I'm proud to be a women.

7.2.4 The meaning of relationships and networks for one's identity

This sub-theme included the participants' descriptions of loneliness and alienation as well as how feeling connected with people facing similar situations was meaningful and also helped strengthening the participant's identity. Several people described meeting with people similar to themselves and how that helped them accept themselves and got them through hard times.

The participants that had struggled with finding social support in the form of friends and accepting family also mentioned feelings of depression and alienation while the participants who had found people similar to themselves described feeling like they were part of something and being able to talk to people with similar experiences as themselves.

Several people described being from rural parts of India and having trouble being themselves and therefore moving to a bigger city. After moving some described finally finding others like them which in turn helped them find peace with their own identity.

Participant A talked about the importance of having a support system

*I have great friends here. I have a lot of support system in Bangalore (...)
And also we have a lot of LGBT organization events where we meet up and
we share a lot of things, there's a connectivity.*

Participant C described struggles with acceptance

*My family is not accepting, friends aren't accepting (...) Why am I like this?
All the confusion came up and I wanted to die (...) Two times I attempt
suicide. And finally (...) they admitted to hospital and I saved. (...) I wanted
to go back to my village (...) and suddenly I saw one guy like me. He was
also feeling feminine (...) I talked to him and finally I'm really happy
because (...) I'm not the only one in the society. We have so many people.
Then I got friendship with him. And I met a lot of friends.*

7.3 Society

7.3.1 Experiences of discrimination from healthcare professionals

Participants experienced a lack of knowledge among healthcare professionals regarding basic terminology, some not even being aware of what the term transgender means or confusing it with intersex. Some participants thought this had to do with healthcare professionals receiving insufficient education in these matters. Ways in which the participants noticed these issues included having to explain themselves and their identity when meeting a doctor, having to explain what it means to suffer from dysphoria, what treatments are available or even why someone would want to receive gender confirming surgery to begin with. The participants also received questions which stemmed from the healthcare professionals' own personal curiosity and values, which was unrelated to why the person was seeking healthcare in the first place.

Another issue that surfaced was that while private healthcare alternatives were often considered to be better in terms of knowledgeable staff and the patient being met with understanding and respect, it is also more expensive and thus not as widely available. Only one person interviewed said not to have had any negative experiences with healthcare, although they thought this would not have been the case had they not been able to visit a reputable clinic. Due to their socioeconomic situation and being met with poor attitude when seeking healthcare, some participants therefore took their medical needs to regular pharmacies instead of going to the hospital or their general physician.

Participant D described the lack of acceptance and knowledge about gender dysphoria.

Most places transgender people are not treated well. They're treated as this is not normal for you to do. And they don't understand the concept of this... this gender dysphoria. They don't understand how painful it is for us.(...) Everywhere you have to (...) undergo this stress of explaining it to them.

Participant C shared how the doctor didn't want to perform physical examinations.

If I got fever, I don't like to go to doctor (...) You talking about fever, first you go HIV-test, then let see we will treat. (...) doctor he don't like to touch. (...) the don't like to do the test properly. He just will ask and writing the prescription and send back.

Participant D described an interaction with a gynecologist.

She's looking at my face, she's looking at my hands, she's looking to see if I have all the things in my body that a regular human being does. (...) I was lying on the bed and she was rubbing my belly: "Don't you want a baby here! huh?". "She's trying to make me think how wonderful it would be to give birth to a child, how beautiful womanhood is. I was frozen by that time. My jaws were locked. I was not able to speak.

7.3.2 Experiences of discrimination in situations outside healthcare

Not only did the participants share experiences of discrimination when seeking healthcare but from the rest of society as well. Areas in which the participants had experienced discrimination included employment, housing and education. Some felt that they had to perform extraordinarily well compared to others in order to be treated as equals, otherwise they would suffer discriminatory treatment at their place of work or school. Sometimes the difficulty of finding a job could be the result of a lifelong struggle with discrimination, being denied education with some never learning to read or write which leads to not being seen as educated enough to get a job.

The issue of employment was regarded by some as the reason why some transgender people in India make a living as sexworkers, there is simply no other jobs available if you want to be open with your gender identity at work. Several participants talked about the dangers of being openly transgender, with some having experiences of harassment, violence and even rape and threats of being killed.

Participant D described how transgender people are discriminated against

(...) so they suddenly hold back on giving you the place, or allowing you to sit somewhere. I've experienced that people did not allow their kid to talk to

me because they felt as if it's a disease I'll transmit, or I'll be a very bad influence on the child.

Participant C described how they wanted to stop doing sex work but was abused and harassed at their new job.

Then I wanted to work...mainstream. And I started work in a factory ... that time I thought I wanted to behave like a male, because if people they know my identity then they will start stigma, discrimination. But I can not. Some of... is natural, no? Some of it came out in the factory, so I got sexually abused, raped, and all these things. And then I thought I want to do suicide myself.

8 Discussion

8.1 Discussion of method

This section will deal with discussing the method through which the data was collected and analyzed. This section will include how the participants were selected, how the interview process was done and finally a reflection on analyzing the data collected.

Information about the study was sent out via email to various LGBTQ+ organizations in Bangalore requesting their help to reach potential participants through their contacts and/or members. Since this method didn't yield many replies, an attempt at calling the different LGBTQ+ organizations was made. Several organizations responded with positivity and offered to help with contacts to other organizations and people who might be interested, but ultimately only a few of them resulted in actual interviews. One person replied directly and wanted to participate.

It was of great importance to the method that the participants had the opportunity to think about the participation first and then make contact with the authors as an active choice to avoid feeling forced to participate. This method resulted in more time for data collection being needed. On the other hand, it resulted in that the participants who actually were interviewed took part of their own free will and ensured that they felt comfortable enough to share their personal experiences on the subject.

The authors also visited different locations where LGBTQ+ organizations were supposed to be, but came to find that the organizations had either relocated or closed down. Fortunately one organization got in touch and had both the time and will to offer their help to the study. E-mails, phone calls and one meeting at the organization's head office resulted in two interviews. Two people called back to the authors and wanted to participate after being given

information over the phone about the study. In total five interviews were conducted, out of these four interviews were used in the actual study, this was due to the audio quality being sub-par in one interview due to a noisy environment.

The complications with finding participants were affected by the ethical considerations and also challenges related to differences in culture. On top of that the topic can be encountered by much stigmatization. Talking about being a transgender person in India may come with risks of threats, violence and/or discrimination. Due to this however, the sample of the study turned out to be very varied in the participants' age and background.

The interviews were conducted using qualitative semi-structured interviews, the method proved well-suited for the aim of getting personal perspectives and answers based on the participant's understanding of the question. One downside of keeping the questions open was that some of the answers given were presented in the general "we"-form, instead of the participant sharing personal thoughts and experiences.

Using a phenomenological approach during the interviews meant that the participants were able to take the interview in the direction they preferred and give answers at a level they felt comfortable with. Had more direct questions been asked the interviews might have resulted in more direct answers, but at the risk of not getting the depth and width of the answers as achieved with the phenomenological approach. The authors occasionally asked the participants to expand their answers in order to assure that the questions presented in the interview guided were covered.

In one interview with an activist and teacher working with LGBTQ+ issues requested that further clarification of the author's terminology was made. This was important to ensure that everyone present shared the same definition when using the term *gender*. As soon as the authors made a clarification of the term the interview could continue.

The data from the interviews were then transcribed and analyzed through content analysis and the interviews were made into common themes and sub-themes. In these common themes and sub-themes the authors also found differences which were included in the study.

In hindsight the interview process would have gone a lot smoother if a gatekeeper had been used, preferably a person working for an organization who in turn could make contact with possible participants.

8.2 Discussion of results

8.2.1 Being who you are

The aim of this study was to examine the experience of identity, health and well-being among transgender people in India. The theoretical framework was a lifeworld perspective and in the context of this study the lifeworld was applied on the participants experience of identity, health and well-being and came out in two main themes. The two main-themes “Identity” and “society” illustrated that the transgender people who participated in the study met ongoing challenges due to their own view of themselves, their body and identity when going outside the normative gender roles. Some participants described that they have met with stigma and discrimination from both healthcare professionals and also experienced of discrimination, threat or violence in situations outside healthcare due to simply being yourself. This result contributes to the current literature by shedding light on the participants lifeworld as a challenge of both being aware and taking care of one’s own dignity and autonomy to be yourself. It also shows a need for developing strategies to be able to encounter reactions from other people in the society to protects one's dignity and well-being. This result is not something specific phenomena for India, the Swedish report Hälsa och hälsans bestämningsfaktorer för transpersoner by Folkhälsomyndigheten (2015) showed that the three main reasons why transgender people in Sweden did not live in accordance with their gender identity were: 1. General reaction from the society (81%) 2. Fear of being discriminated (78%) and 3. Reaction of the parents (51%)

8.2.2 Not being seen as a person

To understand the result in a health science perspective Nordenfelt (2010) described the concept of dignity and how a person can experience having their dignity violated. Nordenfelt means that since the feelings of confidence and self-esteem are pivotal in the forming of one’s identity, having them threatened could in turn lead to feelings of a threatened identity. This view of dignity can be applied on the participants in the study in situations where they had experienced a lack of respect among healthcare professionals and where their integrity was threatened. The sense of dignity shows a connection to physical and emotional integrity according to Nordenfelt (2010) which is often linked to the image one holds of themselves. Participants in the study describe feelings of being questioned as an individual in situations

when health professionals and others acted with disrespect towards their integrity by asking irrelevant questions or giving unwanted advice during examinations.

In a study of Hague and Waytz (2012) the authors described the problem in which healthcare professionals dehumanize their patients. The dehumanization was encountered in situations where the healthcare professionals had difficulty relating to the patient because of difference in health, especially when the patient is labelled as their illness such as being a diabetic instead of a person with diabetes. The dissimilarity in power could also affect the doctor to dehumanize the patient, this is in line with the result of the study in that experiences of discrimination were related to situations when the participant had been seen as a “transgender” and not as a person in the first place. This can be understood as dehumanization and not feeling met with respect, which was a recurring topic during the interviews and a cause for avoiding to seek medical attention. Engdahl (2010) describe the importance of recognition when you are a transgender person. Engdahl divides the recognition in two dimensional categories: 1. Recognition as a human being (a citizen) and 2. Recognition as a unique and specific person (a subject). The recognition as a human related to being included in the society, being perceived as a human being among other people as well being understood as a human being.

Some participants in the study described that the attitudes of other people had a negative impact on their own health and well-being. In a current Swedish governmental investigation *Transpersoner i Sverige* (SOU 2017:92), 85 % of participants described that they had experiences of being addressed with the wrong pronouns. The authors further mean that being assumed for another gender identity than your own also had effects on experience of health. In the group who experience that they always or often are addressed as the wrong pronouns, 46% also experienced their health as bad. In the corresponding group of participants who did not have experiences of being addressed as the wrong pronouns, 21 % experienced their health as bad. In line with the study result, the participants who had experiences of passing as their gender identity and who never or very rarely were addressed with the wrong pronouns experienced their health as good.

8.2.3 Discrimination because of gender identity

Some participants in the study described that they had been discriminated against when seeking healthcare because of their gender identity. In a survey performed by the National

Center for Transgender equality and the National Gay and Lesbian Task Force (Grant, Mottet, Tanis, Herman, Harrison & Kiesling, 2010) the topic of transgender discrimination was examined. The findings showed that 28% of the participants postponed medical care due to discrimination and 48% postponed due to inability to afford healthcare. 28% reported being the subject of harassment within a medical setting, and 2% of participants reported suffering violence at the hands of a healthcare worker. Half of the participants shared having to educate healthcare professionals on transgender care. 19% of respondents had been denied treatment because of their gender identity.

In line with the results from the study by Grant et al. (2010) a majority of the participants had experiences of having to educate health professionals on transgender care, as well as several had difficulties to afford good health care and also met harassment from healthcare professionals when seeking health care.

Finally, the authors conclude that ignorant attitudes among health care professionals in the meeting with transgender patients leads to stigma and discrimination, and as long as the stigma still exist in society and continues to permeate the health care services, health care isn't available for transgender people as it is to the general public. This is in conflict with the United Nations (1948) universal declaration of human rights, specifically article 25 which focuses on the right to medical care and necessary social services without distinction of any kind.

8.2.4 Gender Identity and own body

In the life-stance related reflections about identity that came out in the study, the reflections of gender identity and own body can be considered to be interconnected.

Merleau-Ponty (1945/1997) described the lived body as a constant presence where all perspectives come from the body itself. There is a lived unity between mind and body, the awareness of the body manifests inside and the soul is present and going through all parts of the body. However the body is present in thoughts, experiences and dreams. In line with this, the interviews revealed reflections about how participants experienced their own identity in relationship to their body, possessing a physical body that doesn't correspond to one's gender identity and at the same time having a physical body that doesn't correspond to heteronormative expectations that others may have. In situations where participants were questioned about their gender by healthcare professionals several participants experienced

that their identity or existence was questioned, which in line with the theoretical framework that lifeworld has an influence on one's identity.

8.3 Clinical implications

The findings of this study implies a need for increased knowledge and awareness among healthcare professionals. This has the potential to increase the health care professionals' trustworthiness as well as to minimize discomfort among patients. These factors could in turn create opportunities to better meet the needs that transgender people may have when seeking healthcare. It could also encourage patients to seek healthcare in the first place. Increased knowledge and awareness could lead to healthcare wherein the patient can feel safe and respected.

8.4 Further research

The result of the study suggests a need for further research on multiple dimensions of health and well-being among transgender people. Further research is also needed in the protecting factors which help to promote a sense of identity, health and well-being among transgender people. It would also be interesting to look into if experiences of quality of life among transgender people has a correlation with the availability to healthcare. The authors also see a need of examining how healthcare staff is currently educated in LGBTQ+ issues and how education can be improved to provide caregivers with the tools they need when meeting this group of patients. Finally, a need for further research on the subject of identity is also prominent, especially in the realms of how identity is created and how it can be maintained as well as what the patient's role is in this, and how the nurse can work with promotion.

9 Conclusion

Experiences of identity and own body is personal and highly complex. Being questioned and being discriminated towards due to gender identity has negative effects on well-being and health. Experiences of bad attitudes among health care professionals led to transgender people avoiding to seek health care when needed, the bad attitudes were interpreted as a result of stigma and ignorance. Thus, transgender people should be seen as people just like everyone else, even when seeking health care.

10 References

- Agoramoorthy, G., & Hsu, M. (2015). Living on the Societal Edge: India's Transgender Realities. *Journal of religion and health* 54(4), 1451-1459. doi:10.1007/s10943-014-9987-z
- Casén-Nylander, T., & Nilsson, S. (2015). Transpersoners upplevelse av bemötande från vårdpersonal. En innehållsanalys av bloggar (Kandidat Uppsats, Göteborgs universitet, Institutionen för vårdvetenskap och hälsa). Från https://gupea.ub.gu.se/bitstream/2077/41756/1/gupea_2077_41756_1.pdf
- Engdahl, U. (2010). Att vara som/den 'en' är: En etisk diskussion om begreppen rättvisa, erkännande och identitet i en trans*kontext
- Dahlberg, K., & Segesten, K. (2010) *Hälsa och vårdande: I teori och praxis*. Stockholm: Natur & Kultur
- Dahlberg, K., Segesten, K., Nyström, M., Suserud, B-O., & Fagerberg, I. (2003). *Att förstå vårdvetenskap*. Lund: Studentlitteratur AB
- Danielson, E. (2012) Kvalitativ forskningsintervju. I M. Henricson (Red.) *Vetenskaplig teori och metod*. (s. 163-173) Lund: Studentlitteratur AB
- Danielson, E. (2012) Kvalitativ innehållsanalys. I M. Henricson (Red.) *Vetenskaplig teori och metod*. (s. 285-301) Lund: Studentlitteratur AB.
- De Pedro, K., Gilreath, T., Jackson, C., & Esqueda, M. (2017). Substance use among transgender students in California public middle and high schools. *Journal of School Health*, 87(5), 303-309. doi:10.1111/josh.12499
- Folkhälsomyndigheten. (2015). Hälsa och hälsans bestämningsfaktorer för transpersoner: en rapport om hälsoläget bland transpersoner i Sverige. Stockholm: Folkhälsomyndigheten. Från: <https://www.folkhalsomyndigheten.se/contentassets/a55cb89cab14498caf47f2798e8da7af/halsan-halsans-bestamningsfaktorer-transpersoner-15038-webb.pdf>
- Graneheim, U. H., & Lundman, B. (2003) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24, 105-112. doi: 10.1016/j.nedt.2003.10.001
- Grant, J. M., Mottet, L. A., Tanis, J., Herman, J. L., Harrison, J., & Keisling, M. (2010). National transgender discrimination survey report on health and health care. National Center for Transgender Equality and National Gay and Lesbian Task Force. 1-23. http://www.thetaskforce.org/static_html/downloads/resources_and_tools/ntds_report_on_health.pdf

- Hague, O. S., & Waytz, A. (2012). Dehumanization in Medicine: Causes, Solutions, and Functions. *Perspectives On Psychological Science*, 7(2), 176-186.
doi:10.1177/1745691611429706
- Kalra, G. (2011). Hijras: the Unique Transgender Culture of India. *International Journal of Culture and Mental Health* (5), 121-126 doi:10.1080/17542863.2011.5709115
- Kjellström, S., & Sandman, L. (2013). *Etikboken: etik för vårdande yrken*. Lund: Studentlitteratur AB.
- Merleau-Ponty, M. (1997) *Kroppens fenomenologi*. (William Fovet, övers). Göteborg: Daidalos (Originalarbete publicerat 1945)
- Meyer, I. H., Brown, T. N., Herman, J. L., Reisner, S. L., and Bockting, W. O. (2017). Demographic Characteristics and Health Status of Transgender Adults in Select Us Regions: Behavioral Risk Factor Surveillance System, 2014. *American Journal of Public Health* 107(4):582–89.
- Newsome, C., Colip, L., Sharon, N., & Conklin, J. (2017). Incorporating a pharmacist into an interprofessional team providing transgender care under a medical home model. *American Journal of Health-System Pharmacy*, 74(3).
- Nordenfelt, L. (2010). Begreppet värdighet. I: Nordenfelt, L. (Red.). *Värdighet i vården av äldre personer*. (s. 63-94) Lund: Studentlitteratur
- RFSL & RFSL Ungdom (2017) *Vad är trans?* Hämtad 16 januari, 2017, från RFSL Ungdom, <http://www.transformering.se/vad-ar-trans>
- Shaikh, S., Mburu, G., Arumugam, V., Mattipalli, N., Aher, A., Mehta, S., & Robertson, J. (2016). Empowering communities and strengthening systems to improve transgender health: outcomes from the Pehchan programme in India. *Journal of the International AIDS Society*, 19(3Suppl 2), 20809.
<http://doi.org.esh.idm.oclc.org/10.7448/IAS.19.3.20809>
- Shatzel, J., Connelly, K., & DeLoughery, T. (2017). Thrombotic issues in transgender medicine: A review. *American Journal of Hematology*, 92(2), 204-208.
doi:10.1002/ajh.24593
- Statens offentliga utredningar. (2017). Transpersoner i Sverige: förslag för stärkt ställning och bättre levnadsvillkor. Stockholm: Statens offentliga utredningar. Från: <https://www.regeringen.se/4adda9/contentassets/3e2e892900fc4034a9d822413fdaefe7/transpersoner-i-sverige---forslag-for-starkt-stallning-och-battre-levnadsvillkor>
- Svensk sjuksköterskeförening [SSF]. (2007). ICN:s etiska kod för sjuksköterskor. Stockholm: Svensk sjuksköterskeförening.



UN General Assembly. "Universal Declaration of Human Rights." 217 (III) A. Paris, 1948. <http://www.un.org/en/universal-declaration-human-rights/> (accessed November 6, 2017).

Virupaksha, H. G., Mualdhar, D., & Ramakrishna, J. (2016). Suicide and Suicidal Behavior among Transgender Persons. *Indian Journal Of Psychological Medicine*, 38(6), 505-509. doi:10.4103/0253-7176.194906

11 Appendix 1

Interview guide

Study: being transgender in a stigmatizing society: experiences of health.

1. What is your experience of being a transgender person?

The time before your transition

How did you realize that you didn't identify with your biological gender?

The time after your transition?

What impact has that had on...

- your relationships (family, friends, love)
- your self-esteem
- your well-being
- your identity

2. How does society's views of transgender people affect you?

What impact has that had on your...

- daily life
- employment
- availability of healthcare
- opportunities to get married or have romantic relationships

Other aspects

- have you ever felt that you had been sexualized because of your gender? If yes: in what way?

Follow up questions

- could you expand on that
- in what way
- how did that make you feel
- what do you mean

12 Appendix 2

Do you define yourself as a transgender person?

We are two Swedish nursing students doing an interview study about transgender people's experiences of health and well-being in India. We're also want to describe how transgender people are treated by healthcare professionals and how accessible healthcare is for you. Current studies have mainly examined transgender peoples' health in a sexual context. We want to listen to all your stories about being a transgender person in a stigmatizing society, and how that affects your well-being in your daily life. We hope that this research will shine some light on the situation and hopefully benefit the community.

We know that there have been several studies that inadvertently caused many problems for those interviewed, so safety is a high priority for us and all information will be handled with confidentiality. Our study has been ethically approved and the result will be presented to our peers (teachers, students and healthcare professionals) in Sweden, but you and/or your organization can also take part of the outcome if you wish.

We're looking for about 3 people willing to participate. The interviews will be conducted separately and at a time and place of your choosing. They will take about 30-60 minutes. You can choose to opt out at any time.

**If you're interested in partaking or know someone who might be,
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