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## **»Doctors don't listen to us or the things we need.« Experiences of heteronormative healthcare and its aftermath for LGBATIQ patients in Germany**

### **Abstract**

This chapter investigates factors that contribute to the substandard health situation of lesbian, gay, bisexual, asexual, trans, intersex and queer (LGBATIQ) people in Germany. The focus here lies on the somatic health of LGBATIQ people facing heteronormativity within the German healthcare system as a whole. We offer three interconnected explanations: minority stress, (anticipated) discrimination leading to avoidance of the healthcare system, and lack of affirmative and empirically based healthcare. In order to analyze queer patients' experiences, we conducted qualitative interviews with trans and asexual patients. In this chapter, we analyze the findings from our interviews on three levels: the macro level, e.g. socio-political regulations concerning access to healthcare, the micro level, e.g. doctor-patient interaction, as well as the meso level, e.g. workflows in doctor's offices. In closing, we want to discuss in which way access to healthcare for LGBATIQ people can be improved.

### **1. Introduction**

It is an established fact that lesbian, gay, bisexual, asexual, trans, intersex and queer (LGBATIQ) people not only have specific healthcare needs that differ from cisgender and heterosexual patients but that their health is overall considered to be worse. What has not been established, however, is which factors contribute to that situation. This chapter, therefore, analyzes the healthcare situation of LGBATIQ people in Germany by conducting qualitative interviews with queer

patients about their experiences of healthcare. It mostly focuses on general health concerns that are not specific to LGBATIQ people like preventative medical check-ups, and not, e.g., transition-related care. We want to look specifically at the daily clinical practice by general practitioners as well as specialists etc. and discuss in what way LGBATIQ people face discrimination and other obstacles to equal access and quality of healthcare and how these experiences of discrimination shape the health of LGBATIQ people in Germany. Our sample consisted of trans patients, some of whom also identified as lesbian or bisexual, and asexual patients, a lot of whom also identified as trans and non-binary. Therefore, we analyzed patients with various sexual orientations and genders.

The focus of this chapter lies on heteronormativity<sup>1</sup> within the German healthcare system as a whole. It will analyze the macro level, e.g. socio-political regulations concerning access to healthcare, the micro level, e.g. doctor-patient interaction, as well as the meso level, e.g. workflows in doctor's offices. The chapter wants to shed light on social practices as well as regulations and laws (e.g. § 2b SGB V). Concluding, we want to discuss in which way access to healthcare for LGBATIQ people can be improved.

## 1.1. Heteronormativity as a theoretical framework

For this chapter, we work with a theoretical understanding of heteronormativity as a social power relation in which heterosexuality and the associated binary gender relation and understanding are considered the norm, and deviations are sanctioned.<sup>2</sup> In most modern

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<sup>1</sup> Judith Butler: *Gender Trouble. Feminism and the Subversion of Identity*. New York, London 2007.

<sup>2</sup> Adrienne Rich: *Compulsory Heterosexuality and Lesbian Existence*. In: *Signs. Women: Sex and Sexuality* 5 (1980), pp. 631–660; Monique Wittig: *The Straight Mind and Other Essays*. New York 1992; Michael Warner: *Introduction*. In: Michael Warner (Ed.): *Fear of a queer planet. Queer politics and social theory*. Minneapolis 2004, pp. VII–XXXI; Christine M. Klapeer: *Vielfalt ist nicht genug! Heteronormativität als herrschafts- und machtkritisches Konzept zur Intervention in gesellschaftlichen Ungleichheiten* [Diversity is not enough! Heteronormativity as a concept critical of domination and power for intervention in social inequalities]. In: Friederike Schmidt, Anne-Christin Schondelmayer, Ute B. Schröder (Eds.): *Selbstbestimmung und Anerkennung sexueller und geschlechtlicher Vielfalt. Lebenswirklichkeiten, Forschungsergebnisse und Bildungsbausteine* [Self-determination and recognition of

Western societies, it is assumed that every person with a uterus and vulva is a woman, that every woman is heterosexual who is also imposed with a certain gender role, which never changes. The lynchpin of heteronormativity is the hierarchical gender binary and the assumption that everyone is cisgender.<sup>3</sup> Judith Butler showed that all three categories, sex, gender, and desire, are social constructs and do not necessarily need to be linked.<sup>4</sup> In a heteronormative society, heterosexuality is constantly reproduced as natural and normal, while LGBTQ people face discrimination. Heteronormativity is interwoven into the fabric of society – and all of its institutions, including medicine. But it is more than a power structure that imposes pressure upon individuals to be cisgender and heterosexual – it is also upheld by individuals and institutions.<sup>5</sup>

Heteronormativity affects everyone: On the one side, LGBTQ people are marginalized by heteronormativity, including all those whose bodies, genders, sexual and romantic orientations, and/or forms of romantic relationships do not conform to dyadic, cisnormative binary, allonormative, amatonormative, and normative heterosexuality (see Table 1 – Glossary of terms), even if they do not identify as LGBTQ themselves. People who belong to these groups are often discriminated against, persecuted, or erased.<sup>6</sup> On the other

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the diversity of sexual orientation and gender. Realities of life, research results and educational modules]. Wiesbaden 2015, pp. 25–44.

<sup>3</sup> Nina Degele: Heteronormativität entselbstverständlichen. Zum verunsicherenden Potential von Queer Studies [Questioning heteronormativity. On the unsettling potential of Queer Studies]. In: Freiburger Frauenstudien 17 (2005), pp. 15–39; Bettina Kleiner: Heteronormativität (7.7.2016). <https://www.gender-glossar.de/post/heteronormativitaet> (accessed on 7.2.2023).

<sup>4</sup> Butler: Gender Trouble (Note 1).

<sup>5</sup> Nadine Rose: Subjekte der Macht bei Judith Butler und Michel Foucault. Machtvolle Diskurse, Subjektivierungen und Widerstand als Ausgangspunkt für eine rassismuskritische Perspektive in der Migrationsforschung [Subjects of power in Judith Butler's and Michel Foucault's work. Powerful discourses, subjectifications and resistance as a starting point for a racism-critical perspective in migration research]. In: Julia Reuter, Paul Mecheril (Eds.): Schlüsselwerke der Migrationsforschung. Pionierstudien und Referenztheorien [Key works of migration research. Pioneer studies and reference theories]. Wiesbaden 2015, pp. 323–342.

<sup>6</sup> Peter Wagenknecht: Was ist Heteronormativität? Zur Geschichte und Gehalt des Begriffs [What is heteronormativity? On the history and content of the term]. In: Jutta Hartmann, Bettina Fritzsche (Eds.): Heteronormativität. Empirische Studien zu Geschlecht, Sexualität und Macht [Heteronormativity. Empirical studies on gender, sexuality and power]. Wiesbaden 2007, pp. 17–34, here p. 17.

side, endosex, cisgender, alloromantic and -sexual, and heterosexual people are privileged by heteronormativity and remain unmarked in terms of being »natural« or »normal«. <sup>7</sup> However, heteronormativity also has a normative effect on them, for example, in the fear of being mistaken for non-heterosexual or transgender, which entails certain behaviors that emphasize the heterosexuality and cisgendering of the individuals.

## 1.2. Heteronormativity in the German healthcare system

For Germany, limited research into the health status of LGBTIQ people has been done. While some groups, like men who have sex with men, have been studied quite well, others, like intersex or asexual people, have been overlooked so far. The heterogeneity between – and within – the different subgroups of the queer community calls for an internal differentiation of healthcare needs. <sup>8</sup> Existing international studies document that LGBTIQ persons have a worse health status and enjoy poorer health and healthcare than heterosexual cis people. <sup>9</sup> Generally, health concerns for LGBTIQ people can be categorized in two ways: Firstly, they have the same health concerns as the

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<sup>7</sup> Sabine Hark: Heteronormativität revisited. Komplexitäten und Grenzen einer Kategorie [Heteronormativity revisited. Complexities and limitations of a category]. In: Barbara Paul, Lüder Tietz (Eds.): Queer as... – Kritische Heteronormativitätsforschung aus interdisziplinärer Perspektive [Queer as... – Critical heteronormativity research from an interdisciplinary perspective]. Bielefeld 2016, pp. 53–72, here p. 60.

<sup>8</sup> Kathleen Pöge, Gabriele Dennert, Uwe Koppe, Annette Güldenring, Ev B. Matthiack, Alexander Rommel: Die gesundheitliche Lage von lesbischen, schwulen, bisexuellen sowie trans- und intergeschlechtlichen Menschen [The health situation of lesbian, gay, bisexual, transgender and intersex people]. In: Journal of Health Monitoring 5 (2020), pp. 1–30.

<sup>9</sup> Gabriele Dennert, Gisela Wolf: Zugangsbarrieren im Versorgungssystem als gesundheitspolitische Herausforderung [Access barriers in the care system as a health policy challenge]. In: Femina Politica 1 (2009), pp. 47–58; Wiebke Fuchs, Dan Christian Ghattas, Deborah Reinert, Charlotte Widmann: Studie zur Lebenssituation von Transsexuellen in Nordrhein-Westfalen [Study on the living situation of transsexuals in North Rhine-Westphalia]. [https://www.lsvd.de/fileadmin/pics/Dokumente/TSG/Studie\\_NRW.pdf](https://www.lsvd.de/fileadmin/pics/Dokumente/TSG/Studie_NRW.pdf) (accessed on 7.2.2023); BVT\* – Bundesvereinigung Trans\*: Policy Paper des Bundesverbandes Trans\*: Trans\*-Gesundheitsversorgung. Forderungen an die medizinischen Instanzen und an die Politik [Policy Paper of the Trans\* Federal Association: Trans\* Health Care. Demands on the medical authorities and on politics] (2017). <https://www.bmfsfj.de/resource/blob/120620/0c5e19af792f13569e13407bf0bbf825/trans-gesundheitsversorgung-bv-trans-data.pdf>

rest of the population: They too have toothaches, need vaccinations, and need to have their check-ups for cancer prevention. In regular healthcare, LGBATIQ people are often subjected to discrimination and sometimes violence. Secondly, they have specific healthcare concerns, for example, Hormone Replacement Therapy (HRT) for trans people or HIV prevention for men who have sex with other men (MSM).

We propose that the worse health status of LGBATIQ people has three reasons. Firstly, they experience discrimination, causing minority stress additionally to daily life stressors.<sup>10</sup> Minority stress affects the physical and mental health of minority groups.<sup>11</sup> People who experience minority stress often use coping mechanisms that affect their (somatic) health, like smoking, self-harm, risky sexual behavior and not taking care of their health. It is important to note, however, that it is not being queer that leads to depression, self-loathing, and suicidality but the discrimination and stigma LGBATIQ people face.<sup>12</sup>

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(accessed on 7.2.2023); Pöge, Dennert, Koppe, Gildenring, Matthigack, Rommel: Die gesundheitliche Lage (Note 8).

<sup>10</sup> Ilan H. Meyer: Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations. Conceptual issues and research evidence. In: *Psychological Bulletin* 129 (2003), pp. 674–697.

<sup>11</sup> Tina Dürbaum, Frank A. Sattler: Minority Stress and Mental Health in Lesbian, Gay Male, and Bisexual Youths: A Meta-Analysis. In: *Journal of LGBT Youth* 17 (2010), pp. 298–314.

<sup>12</sup> David Deschamps, Bennett Singer: LGBTQ stats. Lesbian, gay, bisexual, transgender and queer people by the numbers. New York 2017; Niels Graf: Substanzkonsum unter LSBT\*: Zwischen erhöhter Prävalenz und Defizitorientierung [Substance use among LGBT\*: Between increased prevalence and deficit orientation]. In: Stefan Timmermanns, Maika Böhm (Eds.): *Sexuelle und geschlechtliche Vielfalt. Interdisziplinäre Perspektiven aus Wissenschaft und Praxis* [Diversity of Sexual Orientation and Gender. Interdisciplinary perspectives from science and practice]. Weinheim 2020, pp. 274–290; National LGB&T Partnership: #LBTWomensHealth18 Facts and Figures. <https://nationalelgbtpartnership.org/lbtwh/lbtwh18-facts-and-figures/> (accessed on 7.2.2023); Martin Plöderl: Suizidrisiko bei LSBTI\* [LGBTI\* suicide risk]. In: Stefan Timmermanns, Maika Böhm (Eds.): *Sexuelle und geschlechtliche Vielfalt. Interdisziplinäre Perspektiven aus Wissenschaft und Praxis* [Diversity of Sexual Orientation and Gender. Interdisciplinary perspectives from science and practice]. Weinheim 2020, pp. 291–306; Pöge, Dennert, Koppe, Gildenring, Matthigack, Rommel: Die gesundheitliche Lage (Note 8); Laetitia Zeemann, Nigel Sherrieff, Kath Browne, Nick McGlynn, Massimo Mirandola, Lorenzo Gios, Ruth Davis, Juliette Sanchez-Lambert, Sophie Aujean, Nuno Pinto, Francesco Farinella, Valeria Donisi, Marta Niedźwiedzka-Stadnik, Magdalena Rosińska, Anne Pierson, Francesco Amadeo, Health4LGBTI Network: A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. In: *European Journal of Public Health* 29 (2019), pp. 974–980.

Secondly, LGBATIQ people do not necessarily need to experience discrimination from doctors and other health professionals<sup>13</sup> – anticipating discrimination is enough to diminish trust in the medical system<sup>14</sup>. Often, trans people anticipate misgendering and deadnaming at the doctor's office.<sup>15</sup> This leads to LGBATIQ people not or seldom seeking medical help, especially for preventive medical examinations like dental check-ups or gynecological care. In the case of acute symptoms, getting late or no medical attention can lead to worse health outcomes. Thirdly, doctors and other medical professionals are not equipped to deal with the healthcare of LGBATIQ people in an affirmative way.<sup>16</sup>

Although not perceived as a crisis by many societal groups beyond those concerned, such inadequate treatment constitutes a critical dimension of virtually untackled inequality – not only – in the German healthcare system, leading to tangible and/or unresolved – albeit treatable – health problems for those affected by it. From this perspective, LGBATIQ healthcare is an overall ethical issue that warrants a discussion about social inequality.

Heteronormativity in medicine includes violence against LGBATIQ people by doctors and medical staff, as well as objectification, traumatization, and humiliation in medical contexts. On a structural level heteronormativity in medicine can look like the pathologization of queer sexualities, relationships, genders, and bodies and resulting efforts to change these, e.g., conversion therapy, and epistemic

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<sup>13</sup> FRA – European Union Agency for Fundamental Rights: Being Trans in the European Union. Comparative analysis of EU LGBT survey data. [https://fra.europa.eu/sites/default/files/fra-2014-being-trans-eu-comparative-0\\_en.pdf](https://fra.europa.eu/sites/default/files/fra-2014-being-trans-eu-comparative-0_en.pdf) (accessed on 7.2.2023), here p. 41.

<sup>14</sup> Stephen Whittle, Lewis Turner, Ryan Combs, Stephenne Rhodes: Transgender EuroStudy. Legal Survey and Focus on the Transgender Experience of Health Care. [https://www.ilga-europe.org/sites/default/files/Attachments/transgender\\_eurostudy.pdf](https://www.ilga-europe.org/sites/default/files/Attachments/transgender_eurostudy.pdf) (accessed on 7.2.2023), here p. 60.

<sup>15</sup> Luisa Kcomt, Kevin M. Gorey, Betty J. Barrett, Sean E. McCabe: Healthcare avoidance due to anticipated discrimination among transgender people. A call to create trans-affirmative environments. In: SSM – Population Health 11 (2020), pp. 1–8.

<sup>16</sup> Malin Houben, Gabriele Dennert, Muriel González Athenas, Constance Ohms: Gesundheit »jenseits der Mann/Frau-Binarismen«. Bedarfe an eine nicht-normative Versorgung in Bezug auf Körper, Geschlecht und sexuelle Orientierung [Health »beyond male/female binarisms«. Needs for non-normative care related to body, gender, and sexual orientation]. In: Max Nicolai Appenroth, María do Mar Castro Varela (Eds.): Trans & Care. Trans Personen zwischen Selbstsorge, Fürsorge und Versorgung [Trans & Care. Trans people between self-care, care and provision]. Bielefeld 2019, pp. 103–123; Whittle, Turner, Combs, Rhodes: Transgender EuroStudy (Note 14).

violence – meaning that queer people are not seen as experts for themselves. More subtle forms of heteronormativity can include taking a patient's medical history and only asking questions that assume the patient is cisgender and heterosexual, e.g., »Do you have a boyfriend?«.

## 2. Methods and Materials

In order to analyze the reasons for LGBATIQ patients' deficient physical and mental health we decided to conduct different forms of qualitative interviews with queer people, whose names we have pseudonymized for this publication to preserve their anonymity. The aim is to let queer patients speak about their experiences in and expectations of healthcare. Hence, this is a sociological study and as such, there is no obligation for an ethics statement or evaluation. Qualitative interviews are particularly suitable for openly inquiring about situational interpretations or motives for action, and for collecting everyday theories and self-interpretations in a differentiated and open manner.<sup>17</sup> Immersion in the lifeworld of those affected makes it possible to capture the subjective views of marginalized groups.<sup>18</sup> Furthermore, another advantage of qualitative interviews is that one gets a holistic picture<sup>19</sup> of the reality of the interviewees' lives: Even if the interviewees and the associated results can only be compared to a limited extent, it is still possible to obtain a comprehensive portrait of the interviewees, which can also be of social significance beyond the individual case.<sup>20</sup>

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<sup>17</sup> Christel Hopf: Qualitative Interviews [Qualitative interviews]. In: Uwe Flick, Ernst von Kardorff, Ines Steinke (Eds.): Qualitative Forschung [Qualitative research]. Reinbek bei Hamburg 2008, pp. 349–360, here p. 350.

<sup>18</sup> Arnulf Deppermann: Interview als Text vs. Interview als Interaktion [Interview as text vs. interview as interaction]. In: FQS – Forum Qualitative Sozialforschung / Forum: Qualitative Social Research 14 (2013), Art. 14, here para. 5.

<sup>19</sup> Siegfried Lamnek, Claudia Krell: Qualitative Sozialforschung [Qualitative social research]. Weinheim 2016, here p. 323.

<sup>20</sup> Lamnek, Krell: Qualitative Sozialforschung (Note 19), p. 323.

## 2.1 Types of interviews and their analysis

For our diverging Ph.D. projects, we chose different kinds of interview methods: To analyze asexual patients' experiences with healthcare, Annika conducted one group discussion with asexual activists. Questions in the group discussion included if the participants had come out to their doctors, which experiences they had had in healthcare, and if they were ever offered conversion therapy. Kristin conducted individual interviews with trans people in Germany regarding their experiences with regular, i.e. non-transition-specific healthcare. She asked the interviewees about »good« and »bad« examples of interactions with medical staff due to gender presentation and perception, problems they encountered within the German healthcare system, and what improvements they would like or need to see.

Group discussions, as used by Annika, are not a standardized or rigidly defined method. They are qualitative procedures in which a group of about 5–15 people discusses a stimulus or question given by the researchers.<sup>21</sup> The focus of the research also lies on the group dynamics and interactions during the discussion to analyze the constitution of opinions and orientational patterns of the group.<sup>22</sup>

Annika analyzed the conducted group discussion on asexual patients' experiences in healthcare with Jan Kruse's so-called integrative basic procedure (in German: *Integratives Basisverfahren*), which is a form of reconstructive research. The *Integratives Basisverfahren* is, in essence, a (micro-)linguistic approach to analysis, in which one does not approach a text with a singular method of analysis, but the other way around: during the open, (micro-)linguistic analysis of a text, one arrives at the integrative application of specific analytic heuristics, like metaphor analysis, positioning analysis or an analysis of arguments, which fit the research objective and methodology in order to analyze the central structures of meaning in a process of progressive abstraction.<sup>23</sup>

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<sup>21</sup> Philipp Mayring: Einführung in die qualitative Sozialforschung [Introduction to qualitative research]. Weinheim, Basel 2002.

<sup>22</sup> Ralf Bohnsack: Rekonstruktive Sozialforschung. Einführung in qualitative Methoden [Reconstructive social research. Introduction to qualitative methods]. Opladen, Farmington Hills 2014.

<sup>23</sup> Jan Kruse: Qualitative Interviewforschung. Ein integrativer Ansatz [Qualitative interview research. An integrative approach]. Weinheim, Basel 2015, here p. 463.



To investigate trans people's experiences within the German healthcare system, Kristin conducted problem-centered interviews.<sup>24</sup> The problem-centered interview is a survey method that focuses on the interviewee's experiences, perceptions, and reflections on a very specific problem. Based on a guideline, open questions are asked, thus no fixed dimensions or categories – in the form of so-called items – are queried in the problem-centered interview. Hence, this interview type differs from quantitative methods but has a higher degree of structuring than narrative interviews. The leading questions of the problem-centered interview have on the one hand the function to give impulses for a free narration – narratives – of the interviewee, but should on the other hand also enable the interviewer to link to the narratives of the interviewee and to relate the interview to the problem. Accordingly, they are divided into narrative-generating and understanding-generating communication strategies. In this respect, the problem-centered interview also differs from the narrative interview, in which the narrative and inquiry phases are strictly separated. Andreas Witzel<sup>25</sup> suggests that the analysis of the problem-centered interviews should be based on the principles of Grounded Theory<sup>26</sup>. The theoretical presuppositions, which have already been incorporated into the interview guide, now need to be explicated and specified. This is done during open, selective, and axial coding.<sup>27</sup> Grounded Theory aims to capture and explain an as-yet-unknown phenomenon. This makes it clear that an evaluation is particularly suitable if the research question is very open and explorative. Grounded Theory is a research paradigm, which pursues the goal of developing an object-anchored theory from the collected

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<sup>24</sup> Andreas Witzel: Das problemzentrierte Interview [The problem-centered interview]. In: Gerd Jüttemann (Ed.): *Qualitative Forschung in der Psychologie. Grundlagen, Verfahrensweisen, Anwendungsfelder* [Qualitative research in psychology. Basics, procedures, fields of application]. Weinheim 1985, pp. 227–255.

<sup>25</sup> Andreas Witzel: *Auswertung problemzentrierter Interviews. Grundlagen und Erfahrungen* [Evaluation of problem-centered interviews. Basics and Experiences]. In: Rainer Strobl, Andreas Böttger (Eds.): *Wahre Geschichten? Zur Theorie und Praxis qualitativer Interviews* [True stories? On the theory and practice of qualitative interviews]. Baden-Baden 1996, pp. 49–76, here p. 65.

<sup>26</sup> Kathy Charmaz: *Constructing Grounded Theory*. Los Angeles, London, New Delhi, Singapore, Washington DC 2014.

<sup>27</sup> Charmaz: *Constructing* (Note 26).

data. The research process is not linear: the different phases of data collection and evaluation take place in parallel or alternate.<sup>28</sup>

## 2.2. Sample

The group discussion Annika conducted took place during a larger meeting of asexual people and activists in Germany in 2019. The participants did know each other from this meeting, but many of them had not met before the previous day. The group consisted of 12 participants, who were female, nonbinary, genderfluid, genderqueer, or gender questioning. Most of the participants were students or in their professional training. All but one participant self-identified as asexual or on the asexual spectrum.

The problem-centered Interviews Kristin conducted took place between 2019 and 2021 in different cities in Germany. The part of the sample we are taking a closer look at for this article consists of five trans people, who are (trans) feminine, (trans) masculine, or genderqueer. The youngest participant was 28 years old, and the oldest was 40 years of age. The interviews and the group discussion were conducted in German; we translated the quoted bits for this article and edited them for clarity. All names are of course pseudonymized.

## 3. Preliminary Results and Findings

Our data shall exemplify and illustrate the perception of discrimination queer people face within the German healthcare system and how these – potential – patients deal with it. We analyze asexual patients as an example of the diversity of sexual orientation and trans people's experiences as an example of gender variance.

### 3.1. Asexual people's experiences in healthcare

The participants in the group discussion express similar critiques of medicine as the general public. They want doctors to listen to them and their needs:

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<sup>28</sup> Charmaz: Constructing (Note 26).

Sasha (25): »A big problem, I would say, is that therapists and doctors don't listen to us or the things we need. They just do what they think is best.«

The participants recounted multiple situations when they were not taken seriously by doctors and therapists. As cis women, trans men, and non-binary individuals they not only experience allonormativity but also sexism and transphobia. We want to argue that their marginalized position means they are affected more by medical discrimination and that it has specific effects on their health and healthcare in comparison to heterosexual and cisgender patients.

So what kind of experiences do asexual patients have in medicine? One big aspect of being an asexual patient is being confronted with normative assumptions by medical staff. The participants recounted two key questions to illustrate that problem. One question almost every participant said they had been asked by medical staff was »Could you be pregnant?«:

Gabrielle (25): »Well, I think especially those of us who are femme presenting have all been asked ›Are you pregnant?‹ – ›No‹ – ›Are you sure?‹ – ›Yes‹. Everyone has had this experience where they weren't believed. ›Are you really sure? Do you use protection?‹ – ›No, but I'm really sure I'm not pregnant.‹«

The problem here is not the question itself. It's that the participants anticipate they were not believed their answer, because doctors assumed that every patient is sexually active and did not understand why someone would not want or use protection and still could not be pregnant. For medical staff, the possibility of being pregnant seems to be tied to a patient's physical ability rather than their actual sexual practices. The second question is usually posed during gynecological check-up examinations:

Bastian (26): »A lot of gynecologists don't ask whether you have penetrative sex, but they use a different question like ›Do you have a boyfriend?‹. This question has a lot of normative assumptions: one, that you're in a heterosexual relationship, two, that you and your partner are both cisgender, three, that you are only sexually active when you are in a romantic relationship, four, that when you are in a relationship you have to be sexually active. These are a lot of misconceptions in one sentence.«

The »Do you have a boyfriend« question is, as Bastian analyzes, a proxy for a lot of different information the doctor is trying to get from

their patient. Being asexual means not fitting into the human norm in doctors' minds. It also means not fitting into standard forms, like the depression questionnaire, which includes a question on libido. Maxi (30) recounts instead of checking one of the given answers writing in her own answer »I have never had an interest in sexuality and I don't want to change that« because that is the only way she could make herself visible.

Charlie (28) remembered one exchange with his doctor who assumed that everyone was – or wants to be – sexually active, which is why she pitied Charlie for not needing protection. Rami told the group how once her doctor almost did not prescribe her antidepressants because they would lower her libido even more – something that she did not mind. It was much more important to her to get the medication. When doctors accepted that some patients have not been sexually active yet, they still assumed that they would be in the future. Like Jagoda's (34) doctor who could not examine her internally because of Jagoda's vaginismus and then told her to come back once she had sex – which she never did. The normative assumption around being sexually active and other norms around romantic relationships even lead some doctors to pressure their asexual patients, as another participant mentions:

Ola (33): »I had this gynecologist once who told me that if I was in a relationship I would have to have sex.«

The last section showed the implication of normative assumptions by healthcare staff. Now on to the question if the participants come out to their medical providers and what experiences they have with that. Rami told the group she tried to come out to her gynecologist, who did not believe her:

Rami (24): »My gynecologist still doesn't believe me to this day that I'm asexual and that I'm not sexually active. Every time I see her she asks the same questions – and I have just given up. So I'm like ›yes sure, protection, works perfectly‹.«

Because her gynecologist does not believe her, Rami states that she has given up on explaining herself and pretends to be using protection – implying she is sexually active. Rami also thought about coming out to her therapist but described being afraid of his reaction to the

term »asexual«. As a consequence, Rami decided not to come out to doctors anymore:

Rami: »My maxim now is: no coming out to doctors, period.«

Sasha tells the group they were currently looking for a new therapist but were afraid that they would not find an appropriate one because their identity would be questioned and problematized. This refers to another problem asexual people face at the doctor's office. Oftentimes, asexuality is still understood as a medical or psychological problem. For example, Maxi talks about when she was a patient at a psychiatric hospital, she told her therapist that she was asexual but that the asexuality was not a problem. However, the therapist posed further questions, which Maxi felt as violating her boundaries. She felt as though the therapist was pushing asexuality as a topic of therapy and as something possibly treatable onto her. Maxi also recounted that asexuality was part of the therapist's report after the stay in the psychiatric hospital ended and remarked that a patient's heterosexuality would not be part of such a report. Rami is afraid that something similar would happen to her:

Rami: »For me, the biggest problem would be if you said, my asexuality is not a problem – and then you were ignored or asked about it relentlessly – that would be very bad.«

Nina (26) also recalls experiences with doctors where her asexuality was framed as a phase, something she would grow out of to become sexually active and heterosexual. In the accounts of the participants, their marginalized gender and their asexuality intersect to make their accounts of themselves seem unreliable to doctors. Some of the participants had doctors or therapists suggest or hint at conversion therapies. All of the participants who experienced this, strongly and aggressively made clear that they were not interested in such treatment.

Bastian: »My therapist asked me once if I wanted help with my asexuality. She hinted that I could be asexual because of past trauma or something like that. I stated clearly that I didn't want or need that. With that, the topic was dropped.«

Bastian also talks about experiencing a doctor looking for a medical explanation of their sexual orientation, suggesting Bastian should have their hormone status looked at. For doctors, asexuality seems to

be a symptom of an underlying condition and/or something treatable, not a sexual orientation in its own right.

How do these experiences shape asexual patients' relationship with medicine and healthcare? They develop coping mechanisms, the first of which is humor. So when Rami was asked about a possible pregnancy, she answered that the only possibility would be if she was pregnant with Jesus' sibling. Jagoda had a similar strategy, joking that she had been pollinated by wind.

Nina has a different coping strategy. She is asexual and in a relationship with an allosexual partner and they are sexually active with each other. Even though they do not have penetrative sex, she still sometimes needs gynecological care.

Nina: »Before visiting a gynecologist, I always think beforehand about how and what I will tell them. With my relationship situation, I have to explain a lot in order to get a diagnosis that actually fits. It's quite complicated and pretty embarrassing for me.«

Bastian told the group that they did not have the patience or strength to explain asexuality to doctors or speak up if they feel mistreated. So they chose to change doctors if they acted negatively. That means that Bastian has often changed doctors. They also expressed having difficulties making appointments and consequently often delaying necessary doctor's visits by weeks or months. One of their coping mechanisms with this stress is that they already know that they need a period of rest after any doctor's appointments and plan accordingly. Bastian is also in psychological therapy and reports having great difficulties finding a good therapist. The one they found rarely has open appointments for them:

Bastian: »I only have one therapy appointment a month at the moment. That's not enough but it's better than nothing. It is a compromise I have to make to be at least treated by a trustworthy therapist.«

For Bastian, to receive good quality healthcare means to find a therapist who accepts Bastian's trans identity. To receive this Bastian had to compromise and got fewer appointments as would be necessary. For Bastian, this also means putting up with discrimination in order to receive medical care at all:

Bastian: »I sometimes have the feeling that I had to put up with discriminatory behavior.«

For asexual people, doctor's visits are stressful, complicated, and embarrassing which is why they prepare well beforehand. Many also experience anxiety, not knowing how their doctor will react when they come out. Some participants report having trust issues with medicine and, as a consequence, some of them, like Kay (32), have not seen a doctor in years:

Kay: »I haven't been to a gynecologist for around four years, since I self-identify as asexual. I just didn't see the need and couldn't bring myself to go to a check-up appointment. This is also because I have difficulties finding doctors who take me seriously and who are patient and gentle.«

Nina also stresses how she is disillusioned by the medical system and does not believe doctors want to help her.

Lastly, we want to draw attention to how asexual patients conceptualize good medical care. The participants do not only talk about negative experiences but, as activists, analyze them as normative and discriminatory practices. In the same vein, they express requirements for good and affirming medical care. For example, Jagoda had an appointment with a gynecologist which she describes as good:

Jagoda: »He said, he had heard of asexuality before, but he didn't know exactly what it was. I brought a leaflet which he took to read and learn more. I was delighted.«

Bastian counts themselves lucky for having a therapist who only tried to problematize asexuality once and not again after Bastian asked her to. When Gabrielle found a new therapist, she decided to have her coming out as asexual at the start of the therapeutic relationship.

Gabrielle: »So I thought I will let her know from the start to see how she reacts. She said ›Ok, I have heard of that, but I would need to inform myself further‹. I believe that this is the best possible answer by a healthcare provider.«

The therapist also agreed to hand out leaflets to other potentially asexual patients to help them. This means: It is vital for asexual patients to be taken seriously by their medical providers. Affirmative medical care for asexual people is not a difficult new approach but means that doctors should be willing to learn more about asexuality and question their assumptions about sexuality. These measures alone would build trust in asexual patients.

### 3.2. Trans people's experiences in healthcare

The problems trans people face – and the interviewees describe – within the German healthcare system are somewhat similar to the issues described by the asexual patients. Yet, not coming out to doctors or medical staff is often not an option. A certain degree of congruency between the photo and the gender designation stored on the health insurance card, and therefore within the patients' file, and the appearance of a patient is generally assumed. »Mismatches« lead to confusion among medical staff:

Lena (30, genderqueer): »I was sitting in the waiting room, being called by the receptionist who just entered the room: »Mrs. Galanti?«. I stood up and answered, »That's me.« The receptionist looked at me questioningly and repeated, »Mrs. Galanti?« I answered again, standing right in front of the doctor's receptionist, »That's me.« This exchange was repeated one more time. Then I entered the treatment room and the doctor asked, »Mrs. Galanti?«, looking surprised. And yet again I answered – slightly annoyed at this point –, »That's me!.««

Lena, assigned female at birth, asserts that they are often »read as male«. They called the described situation exemplary: medical staff questioning Lena's identity, which is why they have to claim it insistently. Lena detailed that they feel being held responsible for irritating the staff – and sometimes other patients. Thus, it is not the practice's internal processes that are questioned, but the fitting of Lena's name – meaning gender designation – to Lena's appearance. Lena and Emil (33, trans man) formulate the wish that patients should be called by their first and last names only – without a gendered title.

Robyn (28, trans woman) also recounted being misgendered while being called into the treatment room – from the waiting area – because her health insurance card was taken as a starting point for the gendered salutation.

Robyn: »I haven't changed my health insurance card yet. Then it's just always Mr. and then I just get in there and then everyone is like »Huh?««

She stated that she is usually gendered – hence addressed – correctly in face-to-face interactions with medical personnel. Before an x-ray was performed, Robyn was asked »Could you be pregnant?«, which was, in this case, a »validation« of Robyn's passing, but also a possible invisibilization of her medical history. Chris (32, genderqueer) recalled mixed experiences with medical staff and doctors: In the



community practice that they usually visit for primary care, the physicians tend to have limited information regarding transitions and trans-specific healthcare and/or needs. However, most of them are described to make up for it by listening carefully and taking thorough notes, without asking superfluous or intrusive questions. And the employees are noticed to behave in an extremely professional manner, too:

Chris: »I had an ECG. And then she said, »Please uncover your upper body. Also your bra.« And when she turned around to me and there were only the scars [from mastectomy], she didn't make a face. She didn't let on anything.«

Still, one of the doctors of that joint practice Chris came into contact with due to an emergency consultation confronted Chris with her psychopathological views. Chris recalled that she tried to explain their stomach issues with their – voluntary and self-determined – mastectomy holding it responsible for gender identity problems and the stomach issues deriving from those.

Unsurprisingly, avoidance is also an issue within the trans community when it comes to healthcare. Sophie (40, trans woman), whose partner is an MD, has stopped seeing doctors who are not involved in her transition process since starting HRT. She omits preventive examinations to avoid reliving her coming out again. Robyn also shuns »uninvolved« doctors unless it is absolutely necessary. Emil tries to refrain from outing situations like these by limiting his »medical contacts«:

Emil: »I have two or three doctors with whom I must have regular contact. Actually only two, namely the gynecologist and the endocrinologist. I actually avoid everything else.«

He elaborated that this is not due to bad experiences, but the reluctance to explain himself time and again.

Emil: »Because the explanation usually already starts in the initial situation, not in the treatment room.«

He highlighted another factor why doctor's offices are not considered particularly welcoming for most trans people during the interview: open waiting areas. Emil blames a specific kind of architecture, the open design of some practices, which results in a lack of privacy, for the fact that there all other patients directly know your »diagnosis« if you have to come out at the front desk to explain why your appearance, the

so-called »Passing«, and the picture on your health insurance card or the gender in your file seem incongruent.

Uninformed/not sufficiently informed physicians as well as medical staff are also an issue for trans people. Robyn researches doctor's offices in a Facebook group for trans people, trying to find sensitized physicians and minimizing bad experiences. And Emil reported that his gynecologist was unfamiliar with hormones that are supposedly atypical in gynecological practice, namely testosterone.

Emil: »She was insecure about certain interactions between HRT and vaginal suppositories containing estrogen, which is why she had to consult Dr. Google.«

These findings suggest that education and awareness might be the key to improving healthcare for trans people.

#### 4. Discussion

It is well documented that LGBTAIQ people have worse mental and physical health in comparison to heterosexual and cisgender people. We put forward three interlocking causes, that are all rooted in heteronormativity. (1) Stigma and discrimination lead to minority stress and unhealthy coping mechanisms, which in turn impacts health.<sup>29</sup> (2) Actual or anticipated discrimination in the medical system leads to avoidance. In both our samples participants described delaying or not seeking necessary medical help because of the – anticipated – reaction of medical staff to their queer way of being. (3) Healthcare professionals lack knowledge about LGBTAIQ people's specific healthcare needs. Deficient awareness can lead to physicians asking encroaching and inappropriate questions, not knowing how to properly deal with their queer patients.<sup>30</sup> And/or – this would be the worst-case scenario – to treatment errors. Even though some physicians seek to inform themselves: In one example, the doctor seems genuinely interested and wants to read up; in the other, the doctor has to google to be able to help her patient acutely.

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<sup>29</sup> Meyer: Prejudice (Note 10); Dürrbaum, Sattler: Minority Stress (Note 11).

<sup>30</sup> Makini Chisolm-Straker, Logan Jardine, Cyril Bennouna, Nina Morency-Brassard, Lauren Coy, Maria Olivia Egemba, Peter L. Shearer: Transgender and Gender Nonconforming in Emergency Departments. A Qualitative Report of Patient Experiences. In: *Transgender Health* 2 (2017), pp. 8–16.

Heteronormativity is fundamentally ingrained in medicine. With our data, we can show that heteronormative assumptions play a weighty role in doctor-patient interactions, thus on a micro-level. These can look like normative assumptions about gender identity or sexual activity, or epistemic violence<sup>31</sup> when queer people are not believed when talking about their experiences and identities. On the meso level, we found examples of architecture and questionnaires which embarrass LGBATIQ people and make them invisible or – equally crucial – overly visible. On the macro level, one big issue is the continued medicalization of queer identities, bodies, genders, sexualities and lives<sup>32</sup> and attempts at conversion therapies. All in all, queer lives still seem to be unintelligible<sup>33</sup> and unreadable to the medical system. It is still necessary to come out to a medical provider because overall, all patients are assumed to be heterosexual and cisgender<sup>34</sup>. At the same time, it is not guaranteed for LGBATIQ people to have accepting doctors and therapists, causing anxiety and stress in queer patients. Some patients even opt not to come out at all to medical staff, but not all queer people are able to do that.

Structural stigma can manifest in organizational policies that are not affirming of queer identities and/or providers' knowledge deficits about queer people's health needs.<sup>35</sup> Queer bodies and experiences are not normal within medicine.<sup>36</sup> They irritate routines and presumptions about norms and standards. At the same time, the idea of gender-specific medical measures and/or prevention (§ 2b SGB V) suits only particular gender identities and – up to a certain point – people who engage in particular sexual practices: In the German healthcare

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<sup>31</sup> Miranda Fricker: *Epistemic Injustice. Power and the ethics of knowing*. Oxford 2010.

<sup>32</sup> Annika Spahn: *Frigidität 2.0. Aktuelle Medikalisierungen von A\_sexualität* [Frigidity 2.0. Current medicalizations of a\_sexuality]. <https://www.gender-blog.de/beitrag/medikalisierungen-von-asexualitaet> (accessed on 7.2.2023).

<sup>33</sup> Butler: *Gender Trouble* (Note 1).

<sup>34</sup> Markus P. Bidell, Lara M. Stepleman: *An Interdisciplinary Approach to Lesbian, Gay, Bisexual, and Transgender Clinical Competence, Professional Training, and Ethical Care. Introduction to the Special Issue*. In: *Journal of Homosexuality* 64 (2017), pp. 1305–1329, here p. 1314.

<sup>35</sup> Chisolm-Straker, Jardine, Bennouna, Morency-Brassard, Coy, Egemba, Shearer: *Transgender* (Note 30); Kcomt, Gorey, Barrett, McCabe: *Healthcare avoidance* (Note 15).

<sup>36</sup> Jamie L. Feldman, Joshua M. Goldberg: *Transgender Primary Health Care*. In: *International Journal of Transgenderism* 9 (2006), pp. 3–34, here p. 6.

system, special gender-specific preventive examinations are covered by the statutory health insurance with reference to the gender entry. For example, statutory health insurance only pays for prostate cancer screenings for people who are registered as male. All others with a prostate must pay for this service themselves, if it is made available to them at all. That is, the health insurance card is elementary in many cases as the key to these services. Therefore, it poses a problem for some queer patients.<sup>37</sup> Heteronormative perspectives also come into play when it comes to sexual health: The costs for a chlamydia test are only covered by the statutory health insurance up to the age of 25 and only once a year. This does not only affect queer people, but people who engage in certain sexual practices and/or queer living situations (Table 1) might be more dependent on regular control of sexually transmitted infections (STIs).

There are tangible consequences for LGBATIQ people and their health from experiencing heteronormativity in medicine. While some may find numerous ways to cope with difficult situations, others need to change doctors frequently, plan rest periods to recover from discriminatory doctor's visits, or plan if, what, and how they will tell their healthcare providers about their identity. Our research suggests that some have to make compromises to receive the treatment they need, e.g. getting too few therapy sessions with a competent therapist or putting up with discrimination in order to get healthcare at all. And at last, some queer people either delay important doctor's visits for weeks or months or even do not seek medical help at all.

## 5. Conclusion

Queer people represent an underserved group in need of comprehensive healthcare. Our preliminary results have shown multiple explanations for the worse mental and physical health of queer people. We have also shown that the general criticized position of the patient as inferior is even more so for marginalized people. Therefore, which measures can be taken in order to improve queer people's healthcare? First, medical staff needs to question their normative assumptions:

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<sup>37</sup> Tiffany K. Roberts, Corinne R. Fantz: Barriers to health care for the transgender population. In: *Clinical Biochemistry* 47 (2014), pp. 983–987.

Not every person is cisgender, and not every person is heterosexual. Consequently, questions about sexuality and gender need to be posed openly, directly, and without embarrassing the patient. Assumptions about sexual orientation, gender identity, behavior, or anatomy should be avoided<sup>38</sup> and sensitive questions should be asked in private spaces only<sup>39</sup>.

In our data, it was shown that especially trans, intersex, and non-binary persons would prefer to be invoked or approached by their first and last names only, without any gendered form of address involved.<sup>40</sup> Using their preferred names and/or pronouns that might differ from their legal documents hits the same notch. Another step should be incorporating queer-inclusive language on intake forms and assessment tools as well as promoting a welcoming environment within the doctor's office.<sup>41</sup> This includes adding »queer imagery«, e.g. pictures of a pregnant trans man<sup>42</sup> or a lesbian couple, and content on patient education and marketing materials as well as providing education to staff to promote medical competence in serving queer patients.<sup>43</sup> Queer-friendly treatment regimens and protocols must be implemented to sensitize all healthcare practitioners. »Physical exams should be structured based on the organs present rather than the perceived gender of the patient.«<sup>44</sup> Queermed Deutschland for

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<sup>38</sup> Alison B. Alpert, Eileen M. Chichoskikelly, Aaron D. Fox: What Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Patients Say Doctors Should Know and Do. A Qualitative Study. In: *Journal of Homosexuality* 64 (2017), pp. 1368–1389, here p. 1377.

<sup>39</sup> Chisolm-Straker, Jardine, Bennouna, Morency-Brassard, Coy, Egemba, Shearer: *Transgender* (Note 30), here p. 14.

<sup>40</sup> D. Brienne Hagen, M. Paz Galupo: Trans\* Individuals' Experiences of Gendered Language with Health Care Providers. Recommendations for Practitioners. In: *International Journal of Transgenderism*, 15 (2014), pp. 16–34.

<sup>41</sup> Annika Spahn, Lena Ellenberger: Sexuelle und geschlechtliche Vielfalt in der Gynäkologie [Diversity of sexual orientation and gender in gynaecology]. In: Marcel Hackbart (Ed.): *Gesunde Vielfalt pflegen* [Maintaining healthy diversity]. Vol. 2. Göttingen Waldschlösschen 2021, pp. 79–95.

<sup>42</sup> Ann Kristin Augst: Quo vadis, (Gender) Medizin? Denkanstöße zur (Regel-) Gesundheitsversorgung von trans Personen [Quo vadis, (gender) medicine? Thought-provoking impulses on (regular) health care for trans people]. In: *amatom. ein Magazin von kritischen, jungen Mediziner\*innen* 31 (2018), pp. 11–12.

<sup>43</sup> Augst: Quo vadis (Note 42); Kcomt, Gorey, Barrett, McCabe: *Healthcare avoidance* (Note 15), here p. 6.

<sup>44</sup> Feldman, Goldberg: *Transgender* (Note 36), here p. 8.

example offers a checklist to examine whether a doctor's office is queer-friendly or not.<sup>45</sup>

Heteronormativity, as discussed earlier, does not only impact queer people's lives. The proposed measures would also benefit cis-gender and heterosexual patients. For example, not every person who is not sexually active is asexual – and vice versa. By just asking if someone is sexually active and accepting the answer as valid without pressuring patients, a lot of pressure is taken from sexually inactive patients. Inferring sexual practices from relationship status can also lead to a bias in the case history of non-queer people. And assuming that certain organs are present because a person has a certain gender entry, like assuming a person who is listed as a woman always has ovaries and a uterus, instead of eliciting the *status quo*, like questioning if a patient of any gender marker could be pregnant, could also lead to poorer care for cis persons. Still, queer people are a minority, facing discrimination inside and outside the healthcare system. They are a vulnerable group that must be given the attention they need to adapt and improve their healthcare. Social disadvantage often leads to health inequalities, so action is urgently needed. The optimal provision of healthcare and prevention services to sexual and gender minorities requires providers to be educated, reflected and attentive – as every healthcare professional should be.

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<sup>45</sup> Queermed Deutschland: Ein Leitfaden für den Umgang mit Patient\*innen [A guide to dealing with patients]. <https://queermed-deutschland.de/leitfaden-fuer-den-sensibilisierten-umgang-mit-patientinnen/> (accessed on 7.2.2023).

<b>Allo-normativity</b>	Allonormativity is a social norm that assumes that every person wants to have sex or feels sexual attraction toward others. Sexuality is therefore seen as normal and necessary. Allonormativity is part of heteronormativity and leads to discrimination against asexual people.
<b>Amato-normativity</b>	Amatonormativity is a social norm that assumes that every person wants to have a romantic relationship or falls in love with other people. Romantic love is therefore seen as normal and necessary. Amatonormativity is part of heteronormativity and leads to discrimination against aromantic people.
<b>Asexual</b>	An asexual person does not experience sexual attraction.
<b>Aromantic</b>	An aromantic person does not experience romantic attraction.
<b>Bisexual</b>	A bisexual person is attracted to more than one gender.
<b>Cis</b>	»Cis« is the opposite of »trans«. The adjective is used to express that a person identifies with the gender they were assigned to at birth based on genitalia.
<b>Endosex/ Dyadic</b>	Dyadic or endosex refers to a person who is not intersex, that is, whose body fits into the medical norm of male or female bodies.
<b>Gender-queer</b>	Genderqueer is an umbrella term for a person who does not fit into the gender binary norm. It can also describe the gender identity of a person who identifies as both female and male (simultaneously or alternately) or neither female nor male. Thus, genderqueer cannot be clearly distinguished from the term »non-binary«.
<b>Intersex</b>	An inter(sex) is a person whose physical sex (for example the genitals or the chromosomes) cannot be assigned to the medical norm of »unambiguously« male or female bodies, but lies in a spectrum in between.

<b>Non-binary</b>	Non-binary refers to a person who does not (or not to 100 %) identify as male or female, but rather, for example, as both at the same time, between male and female, or as neither male nor female.
<b>Queer</b>	Queer is an umbrella term that refers to anyone who does not fit into society's norms around gender and sexual orientation, including lesbian, gay, bisexual, asexual, and aromantic, as well as trans, non-binary, and intersex people and anyone who is questioning their identity.
<b>Trans</b>	A trans person is someone who identifies with a different gender and/or expresses gender identity differently from the gender that they were assigned at birth. The term »trans« can cover many gender identities, e.g. transsexual, transgender, gender variant, non-binary or genderqueer, only to name a few.

Table 1: Glossary of terms