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Contents

1. Preluding: Introduction

"Do you want to have children?"[1]

The question felt like it came out of nowhere. This morning I was referred to the hospital because of a stinging pain in my lower abdomen. Suspicion of acute appendicitis. But since after a few tests and several long hours of waiting my appendix turned out to be fine, I had to travel to the gynecology department two floors up.

"N-no?" I stammered after a moment of silence. Sitting in the gynecological examination chair, feeling awkward and exposed, I was confused why this question was relevant at this moment.

"Well if you don't hurry with the treatment, your wish to have children won't come true anyway." By now she probably must have noticed my bewilderment as she started to elaborate pointing at my leg hair that it seems I have an excess in male hormones. PCOS.

* * *

One time, during my overall horrible experience of taking the pill, I went to a gynecologist because I was concerned about my mid-cycle bleedings. As we were sitting at his desk after the examination, he pointed at the ultrasound image of my ovaries explaining that these cysts are disturbing my hormonal cycle, and, while at the moment this is nothing to be afraid of, one never knows if 'it' might evolve into something 'serious' in the future. Accordingly, in order to 'fix it' he suggested a three to four months 'hormone therapy', handing me a flyer and giving me five minutes in the waiting room to think about my decision. As I was studying the pink-ish colored pages, countless scary-sounding side-effects caught my eye. The benefits of this intervention, on the other hand, still did not appear to me, which is why, back in the consultation room, I declined. Upon learning about my refusal the gynecologist's expression darkened. "Well, then leave it."[2] *he muttered and, without saying goodbye, indicated that the next patient was about to come in.*

* * *

The instant feeling of relief almost brought tears to my eyes as I heard the general practitioner say the words 'insulin resistance' while pointing at a number in my blood test results labeled 'HOMA-Index'. Utterly unexpectedly, what I described as 'weird sugar problems' to my doctors

[1] "Haben Sie Kinderwunsch?"
[2] "Tja, dann halt nicht."

for all these years (without getting any conclusive answers besides shaking heads and confused looks), finally became real. And was I even happier as she proceeded telling me that a drug called 'Metformin' could easily alleviate my symptoms!

This brief moment of joy, however, instantly crumbled as, while handing me the prescription, the practitioner remarked winking at me: "Then you'll be able to shed some pounds, too!" While I have never been overweight, the reason for my extensive health check-up was my current recovery from a yearslong eating disorder.

* * *

These three narrative fragments provide a small glimpse into different moments of my life when medical consultations and exams turned the spotlight on a particular condition of my body – *polycystic ovary syndrome* (PCOS).

PCOS is classified as an endocrine disorder affecting people who are assigned female at birth[3] (afab). In addition to what is commonly considered its main characteristics, namely polycystic[4] ovaries and elevated testosterone levels, PCOS can also be accompanied by various other symptoms, like metabolic disorders, such as insulin resistance or diabetes, infertility, facial hair growth (clinically referred to as hirsutism), as well as stronger body hair growth in general, obesity, and symptoms associated with unbalanced hormone levels, such as irregular periods or acne (*Polycystic ovary syndrome - Symptoms*, 2017).

Albeit brief, the three moments present a breadth of various issues that can be encountered when dealing with PCOS within the medical context. Among others, they illustrate the entanglement of hormonal levels, their effects on the body, and gendering of appearance. They point to the framing of in/fertility as an essential aspect in a diagnosis. They offer a sense of the bewilderment, uncertainty, and overall helplessness often experienced when trying to make sense of medical interventions or potential future risks. They give an impression of the struggle to advocate one's embodiment to receive a diagnosis. And, they show how medicine's fixation on and assumption of certain bodily goals framed by societal beauty standards clash with one's own body-mind[5] states.

For me, a common way of coping with insensitive medical practitioners was to get over with the consultation as fast as possible and then never step foot into their office

[3] The terms *assigned female/male at birth* highlight "that when we come into the world, somebody else [– judging from our physical characteristics –] tells us who they think we are." (Stryker, 2017, p. 12)

[4] Exhibiting several cysts.

[5] Eli Clare (2017) uses this term to resist the dualism of White Western culture that regards the body and mind as two separate entities, and instead, by following the lead of the many communities and spiritual traditions that have done so before, reflect their inextricable linkage. As such thought neatly resonates with my theoretical sensitivities I am, too, using this term when referring to the corporeal and the psychic.

again. However, trying to make sense of this ambivalent syndrome on my own turned out to be equally unsuccessful. As I soon noticed, not only medical papers and guidelines, but also informational material, self-help books, and even medication packaging solely speak of and address cis[6] women and exclusively suggest solutions and management approaches in line with ideals of normative femininity. As a non-binary[7] person, who has always been content about how the higher testosterone levels affect my body, while having experienced the changes induces by the oral contraceptive pill as seriously distressing, I do not recognize myself in these ressources. And I am not alone.

In an online article presenting trans[8] people's accounts on their experiences with PCOS, Esco, a trans masculine, non-binary person, states, "my 'in the middle' body makes a whole lot more sense to me" (Bell, 2018, para. 8). The same article also contains numerous encounters with cisnormative assumptions, and doctors who do not appear to be eager to offer alternative treatment options. Generally, the framing of PCOS as a 'women's health issue', its description in normative gendered terms, and the objective of its treatment shaped by standards of normative femininity, including the pathologization of 'excessive' body hair and weight, infertility, and menstrual irregularity, renders trans and gender-diverse people with this diagnosis invisible (Fisanick, 2009; Vleming, 2018). "So in case you want to feel emasculated, get your birth control in this packaging", Elliott James remarks holding a plastic packaging covered in pastel-colored flowers into the camera in a *Youtube* video documenting his experiences with PCOS care as a trans man (James, 2017a).

What additionally complicates this case, is the uncertain and contested nature of the syndrome. From its first cohesive formulation by Stein and Leventhal in 1935 (Azziz & Adashi, 2016), PCOS to this day is subject to controversy and debate. With the introduction of the *NIH*[9] criteria in 1990, its reform to the Rotterdam criteria in 2003

[6] Also refered to as cisgender, describes those who identify with the gender they were assigned at birth. The terms are used as adjectives.

[7] *Non-binary*, also occurring as *nonbinary*, describes people whose gender does not exclusively fit into the binary model of female/male. It is both used as a label to refer to one's gender identity, and as an umbrella term for genders falling into the above-given definition, such as agender, genderfluid, genderqueer, etc. Notably, not everyone who identifies as non-binary considers themselves trans. While in my thesis I use *trans* in the broadest sense, I try to take this into account by referring to my participants by their self-chosen labels.

[8] The term *trans* – also occurring as *trans**, *trans-*, or *transgender* – describes everyone who does not identify with their gender assigned at birth. In this thesis the descriptor is kept as open as possible and used as an umbrella term involving those who identify within the spectrum of both binary and non-binary gender, or something completely beyond these spheres (Stryker, 2017; Stryker, Currah, & Moore, 2008). In my usage the term is deliberately held open so it can be combined with other terms indicating individual labels (e.g. transgender, trans non-binary, transfluid etc.) (Appenroth & Castro Varela, 2019). The respective terms are used as adjectives

[9] National Institute of Child Development and Health

(Azziz, 2004), to the proposal of the *AES*[10] criteria in 2006 (Ning et al., 2013), the medical research community remains far from having a 'gold standard' for its diagnosis (Dewailly, 2016). Consulting research articles on the syndrome offers an insight into several points of dispute in regard to these different classifications: Are they able to fully grasp the heterogeneity of PCOS (Azziz, 2004)? Should the polycystic ovaries, the syndrome's eponym, even be included into the definition, or should ovarian dysfunction in general rather be moved to the fore (Azziz et al., 2009)? Are classificatory criteria too broad (Azziz, 2004) turning people with a problem into patients (Copp, McCaffery, Doust, Hersch, & Jansen, 2017; Wilcock & Taylor, 2018)? Or is such broadness necessary in order to acknowledge the wide spectrum of symptoms and phenotypes the syndrome comes in (Franks, 2006)? What complicates the classifications of PCOS even further, is that even the criteria these classifications are based on are, themselves, full of uncertainty – be it in terms of their definitions, thresholds, measuring techniques, or diagnostic tools (Azziz, 2004; Dewailly, 2016).

Consequently, questions regarding PCOS' susceptibility to different kinds of treatment remain unsettled. The only approach towards treatment is managing its symptoms. But because bodies are different, this is not a straightforward approach. Relying on the Rotterdam diagnostic criteria, the guideline by the German, Austrian and Swiss society for gynecology and obstetrics, for example, suggests (depending on the problem) hormonal therapies (e.g. in form of the oral contraceptive pill), insulin sensitizers (like *Metformin*), and lifestyle changes (DGGG, OEGGG, & SGGG, 2019). However, medical practitioners' lack – and sometimes even nonexistence – of knowledge on PCOS, as well as the insufficiency of alternative options in the case of unpalatability of the above mentioned ones (Gibson-Helm, Lucas, Boyle, & Teede, 2014; Sterling, Vincent, DeZarn, & Perloe, 2010; Tomlinson et al., 2017), further get in the way to obtaining feasible and adequate care for the individual.

For some trans people living with PCOS, such ambiguity can create further complications, namely when they wish to undergo hormone replacement therapy (HRT) as a part of their transition[11]. As Redditor dragonmyst94 starts off their question on PCOS and HRT posted in the support-based subreddit *ftm*, "I love the fact that I have extra testosterone in my system, that I kinda got a jump start when it came to it (Male body

[10] Androgen Excess Society

[11] Transition describes the process one goes through in order to reach their desired social role, and/or physicality ("Transition", n.d.). As this process is based on unique requirements of each individual, there is no single definition for it (ibid). To name a few examples, it might entail legal name and gender entry change, but might also be done by means of medical procedures, such as genital, or top surgery, and/or hormone replacement therapy (HRT). Whether or not, and in what ways a person wishes to transition also highly varies from individual to individual

odor, hairier skin, less sensitive skin, etc. All the not really noticeable but there effects)" (dragonmyst96, 2017). While being content about the extra testosterone, the Redditor's concern whether it would get in the way of gaining access to HRT as well as their doctor's confusing remarks in regard to their questions, points out the ambiguity of trans PCOS embodiment: "It just figures that my stupid body had to be a special cupcake and make my life even harder" (ibid.). In another part of his video documentation, Elliott James, too, speaks about the uncertain effects additional testosterone could have on his body, as well as the lack of knowledge his medical practitioners apparently have on this matter (James, 2017b).

Concerns like these need to be taken seriously, particularly considering how (as will be illustrated in **chapter 2**), medicine's close association of certain body parts, functions, and characteristics with norms on sex-gender[12], its embeddedness within structures of power and inequality, and its co-constructuve relation with political debates, to this day, contributes to strict regulation, pathologization, and neglect of trans people's body-minds.

In Germany, where my case study is located, the legal requirements for change of name and sex entry are ruled by the *Transsexuellengesetz* ('transsexual[13] law'), obliging people, at their own expenses, to give testimony in court to a range of intimate, invasive and pathologizing questions (Darida, 2021) in order to 'adequately assess' their gender identity (Garcia Nuñez, Meier, & Schaefer, 2019). While with the release of the *ICD[14]-11*, the classification of trans identity has underwent a depathologization (Sauer & Nieder, 2019), German health insurances still refer to the outdated entry classifying it as a mental illness, thus, compelling people to be pathologized in order to receive financial coverage of transition-related medical services (Neander, 2019). Such conditions make the process of social and medical transitioning arbitrary, inconclusive, intransparent, and violent, and any further uncertainty can become a potential barrier along the way to the desired medical services.

But even beyond trans-specific medical care, as will be elaborated in **subsection 2.7.2**,

[12] In consideration of the culturally varying and not clearly definable conceptions of what excatly counts as 'sex' (Stryker, 2017), as well as the scholarly work my thesis is built upon which approaches the 'social' and the 'biological' as entangled, I intend to avoid creating a clear-cut dichotomy between sex and gender. Instead, I utilize Latham's (2016; 2017b) approach of viewing *sex-gender* as an assemblage which gets enacted and materializes in different situated ways.

[13] Coined within the medical sciences, *transsexual*, while being ambigious in usage, is commonly refered to those trans people who seek medical interventions in order to physically change their bodies, usually within a gender binary (Stryker, 2017). Nowadays, particularly because of its medicalizing and binary subtext, the term is considered old-fashioned, and not everyone who identifies as trans wishes to be referred to as transsexual (ibid.). However, it is important to note that some people use the term as a self-chosen label

[14] International Classification of Diseases

medical practitioners' unwillingness to acknowledge their patients' needs and identities, or the blatant transmisia[15] our society is entrenched in, can make PCOS care an uncomfortable, even hurtful experience, or impede its process altogether.

Conjointly, these challenges point to several overarching tensions within the case of medical trans PCOS care. What does it mean to carry out standardized protocols to tackle a syndrome that is so difficult to standardize? What implications arise when seeking care within a system prevailed by cis-normative and binary assumptions on the body, whilst not aligning with these norms in term of one's own body and identity? And what remains invisible when trans people's needs and perspectives are neglected within a discussion on PCOS care?

Tensions, that bear significant ramifications if viewed through Annemarie Mol's (1999; 2002) lens of *ontological politics* which conceives (medical) practices – be it describing, classifying, diagnosing, managing, or treating – as inevitably enacting the reality of the concerning object. Hence, this thesis examines the multiple ways, PCOS is enacted in different situations and medical encounters, while delving into their implications for notions of health, illness, sex-gender, identity, and or body. Taking on Donna Haraway's (2001 [1988]) *partial perspective of feminist objectivity*, I specifically tend to trans people's stories, perspectices, experiences, and enactments of the matter. Thus, sensitized by María Puig de la Bellacasa's (2017) theoretical framework of care, my aim is to give trans people a voice within the discussion on PCOS to not only shed light on what has been neglected by its absence, but also explore what it requires for an attentive and inclusive PCOS care. Conducting qualitative narrative interviews with six trans and gender-diverse people based in Germany, I explore the research question: *How do trans people enact PCOS, and what does that tell about care for their bodies within the framework of standardized medical practices?*

Backed by my theoretical sensitivities and strands of (queer-)feminist intellectual thought, I argue that, while medical practices produce a *singularizing* PCOS that, like a monolithic dome is pulled over all patients exhibiting a certain set of symptoms disregarding of their needs, concerns, and identities, medicine should tend to the multiplicity exhibited in trans people's enactments of the syndrome, and thus provide care that is embodied, situational, non-linear, and hence, tangible for the individual living with PCOS.

After setting the scene for this project by outlining the different strands of research informing my inquiry in **chapter 2**, a detailed elaboration of the research question including

[15] '-misia' is a word in Ancient Greek meaning 'hatred' or 'disgust'. Hence, transmisia means disgust or hatred towards trans people. It is chosen as an alternative to '-phobia' which describes irrational fear (Troop, 2013)

the corresponding sub-questions by which I approached the field is provided in **chapter 3**. Thereupon, **chapter 4** presents my theoretical lens through which I glance at this case, including a critical reflection of my own positionality and assumptions. A documentation of getting involved in the empirical field including corresponding methodological considerations is given in **chapter 5**. In **chapter 6**, then, the results of my empirical inquiries are unfolded along different lines traced throughout my interlocutors' narratives. Lastly, the thesis will be concluded with a discussion embedding my observations into a broader discourse on the infrastructural dimensions of PCOS care in **chapter 7**.

2. Setting the scene: State of the art

Unpacking the intellectual strands that my research case is intertwined with is not a straightforward endeavor. Indeed, there are multiple angles to telling this story. On the one hand, it is dear to my heart to explore the manifold experiences and realities that trans people make and encounter when engaging with the medical system. On the other hand, I am deeply concerned with the uncertain and controversial nature of PCOS and the research thereof. Thus, in order to make both lines of inquiry (Ingold, 2016) commensurable, I would like to discuss the particular elements that they have in common; that is, both of them being shaped and confined by a system consolidated by norms on sex, gender, bodies, health, and dis/order. Therefore, in order to approach this case study from a Science and technology studies (STS) angle, it is crucial to tend to the ambivalent role of (scientific) knowledge production, its situatedness, and embeddedness within structures of power, and the political implications knowledge practices within this context bring about. In doing so, I am going to put different strands from STS, social sciences, and transgender studies in conversation with each other by highlighting their intersections and relevance for this case.

In **section 2.1**, my point of departure will be a general molding of STS insights into knowledge production as a socio-culturally situated practice with a particular spotlight on standards and classifications. Subsequently, **section 2.2** I will expand these rather constructivist conceptions towards a focus on ontology and its praxeological multiplicity. In challenging the notion of objectivity and impartiality of scientific knowledge through these lines of scholarly work, I will further emphasize the embeddedness of this mystified framework within prevailing power relations and inequalities through a focus on feminist technoscience in **section 2.3**. These insights invite a reflection on forms of knowledge that diverge from what is traditionally considered as science, i.e. situated and lay knowledges, which I will include in **section 2.4**. This will, then, be followed by an interlude on the role that non-knowledge and ignorance plays with regard to power in **section 2.5**. Having outlined these different strands of literature, I will build a bridge between the current state of social science and STS research on PCOS in **section 2.6**. In **section 2.7**, I will move the discussion towards an elaboration on, first, the ways medicine conceptualizes,

marginalizes, and regulates trans bodies and identities in **subsection 2.7.1**, and, second, the erasure of trans people's own lived experiences in **subsection 2.7.2**. Subsequently, in **subsection 2.7.3** I will reflect on my search for research specifically focusing on trans people and PCOS. Linking to the previous arguments, **section 2.8** features speculation on the ways transgender studies and its de-subjugated knowledge can be a vital angle in studying this case. To finish off this conversation, I introduce the sensibility of care in STS in **section 2.9**. Last but not least, in **section 2.10**, I will devise an outlook for this research.

2.1. Departing: Shaping scientific knowledge – classifying reality

Pioneering groundwork in studying science as a social endeavor has been laid out by Ludwik Fleck (1979 [1935]), particularly through his framework of *thought collectives*, which characterizes communities of researchers maintaining intellectual interactions and active exchange of ideas. Shaped not only by researchers' personal and scientific experiences, but also societal status quo, this exchange gives birth to a particular thought style, which, in turn, guides and shapes a thought collective's thinking, perception and understanding of the world. This framework, consequently, challenges the idea of an objective and pure scientific truth. According to Fleck, facts can only be accepted as such if they coherently align with a conventionally held thought style, while in turn alternative modes of thought are excluded. And even when examining things utterly unfamiliar, they are still approached through the lens and set of practices specific to a particular thought style (Fleck, 1986 [1947]).

Fleck's work on medicine and public health was also significantly influenced by this framework. Disease, in his understanding, is not simply 'out there', but instead, shaped by and produced through different medical specialities and classifications (Löwy, 2016). Thus, "[m]edical knowledge is partial, fragmented, [...] incomplete" and always situated (ibid., p. 514). Consequently, one has to be attentive to the power dynamics at play and the possibilities of serious error. While there is no such thing as objectivity, facts have practical consequences, and thus researchers, according to Fleck, bear significant responsibility (ibid.).

Within this rather general framework for studying the social dimensions of research, the focus of my inquiry is turned towards a particular set of scientific practices as a subject matter within STS scholarship, namely standardizing and classifying.

Being a significant compound of societies' - unsuccessful (Latour, 1993) - project of modernity, classifications and standards are ubiquitous and unavoidable (Busch, 2011). "To classify is human", as in every step of our lives, be it professional decisions or merely mundane routines, our thinking is guided by classifications (Bowker & Star, 1999; Busch, 2011). Here, however, lies the power and danger of classificatory practices. Classifications and standards guide our perceptions and expectations of the world, they tacitly shape our decisions and actions, and they weave objects and people into a set of practices, narratives, and beliefs (ibid.). Classifications and "standards shape not only the physical world around us but our social lives and even our very selves. Indeed, standards are the recipes by which we create realities." (Busch, 2011, p. 2). Their danger is also tied to the fact that, while appearing seamless and objective, classifications and standards are never consistent or clearly delineated, but rather constantly mixed together, enrolled in controversies, and never able to exhaustively cover the world they describe (Bowker & Star, 1999).

In medical practice, as Berg and Timmermans (2000) demonstrate, this modernist myth of universality by standardization, too, is upheld. Universalities, being clearly defined and singular, follow the linear temporal pattern in which order is preceded by, and, through classificatory, diagnostic, and technological practices, "is said to arise as a phoenix out of the ashes of disorder" (p. 58). However, this oppositional conceptualization of dis/order is itself a fallacy, since, as will be elaborated in the subsequent section focusing on ontological multiplicity, classifications are never singular, and attempting to create order, thus, always produces disorder. Instead of holding on to this myth of universality, medicine should rather tend to the inherent disorder that lies within its standardized categories and routines. Singularity in regard to the biomedical is particularly hard to achieve, since living things, be it tuberculosis or DNA sequences, do not come in a fixed or static form, but rather are in a constant process of change and deformation (Bowker & Star, 1999; Mackenzie et al., 2013). Trying to standardize life forms is also always entangled with forms of lives, be it publics, infrastructures, and forms of disciplinary practice and compromise (Mackenzie et al., 2013). When it comes to standards targeting the human body, such as in the case of organ donation, the identity of a person is also simultaneously shaped, negotiated, and co-constructed by "scientific knowledge, technologies, tools, theories, moral beliefs, and other cultural elements" (Hogle, 1995, p. 496). Diagnostic labels in particular play an ambivalent role in this. For instance, Giles's (2014) examination of online reactions to the removal of the classification *Asperger disorder* in the *DSM-V*, illustrate how, on the one hand, their imposition can be confining, exclusive, and pathologizing, while on the other hand, their abolition can be perceived

as a threat to provision of medical services, or sense of community. Likewise, quality standards for medical consultations can be used and interpreted in different ways by medical practitioners, and, in the case of a too strict adherence to those standards, can even interfere with drawing attention to patients' personal needs and concerns during clinical encounters (Lippert, Reventlow, & Kousgaard, 2017).

2.2. Expanding: Turning to ontology of medicine, bodies, and self

In view of universality's shaky foundation, STS has the ambition to 'open up' and contest the putatively 'objective' medical knowledge (Casper & Berg, 1995), and thus, shed light on the chaos within (Berg & Timmermans, 2000). Looking closely at this notion from a social constructivist perspective reveals how medicine is a continuous aggregation of heterogeneous elements, objects, and entities. Thus, similarly to the laboratory (Knorr-Cetina, 1981, 1983; Latour & Woolgar, 1979), a great amount of medical practice is about 'making things work', i.e. coordinating, shaping, and transforming objects within this aggregation in order to handle them by standardized practices and established work routines (Casper & Berg, 1995). In doing so, medicine is involved in the continuous (re)construction of human bodies, and transformation of patients' meanings of health, illness, and, consequently, their identities, which grants medical practices the ability to exert power and control (ibid.).

This seemingly natural state of medical science and practice is further challenged by Annemarie Mol's (1999) framework of ontological politics, in which "reality does not precede the mundane practices in which we interact with it, but is rather shaped within these practices" (p. 75). However, she goes as step beyond social constructivism arguing that contemplating alternative realities merely retrospectively reflects an otherwise static reality. Similarly, it is insufficient to only speak of different perspectives on a certain reality, because it solely "multiplie[s] the eyes of the beholders" (ibid., p. 76). Rather than understanding reality as plural while accepting its already "made-ness" (Fraser, 2010, p. 233), and thus regarding objects and phenomena as complete and immutable, reality should be considered as multiple and actively done by the different ways an object is approached by, handled, interacted with, spoken about, etc. In other words, reality is enacted through practices (Mol, 1999).

As will be elaborated on in more detail in the chapter on the sensitizing concepts used for this study, Mol's (2002) framework is illustratively exemplified in her ethnographic work

studying doctors and patients working with lower-limb atherosclerosis in a Dutch hospital, where she observes how atherosclerosis is enacted differently in different sites of the hospital through the application of different medical tools, treatment methods, or forms of diagnosis, and how these different enactments influence each other, are coordinated or kept apart in order to make diagnostic decisions, and, sometimes, even inevitably clash.

That even medical guidelines cannot be perceived as universal matters of fact is demonstrated in Mol's (2013) observation of different traditions, practices and doctor-patient consultations within nutritional medicine. Such variety of practices and situations results in different *ontonorms* with regard to food, eating, 'good' and 'bad' dietary choices, or even the goals and purposes of dieting, which sometimes can get in conflict with each other. Similarly, Stronge (2013) challenges the assumption that medical screening, in this particular case for type 2 diabetes, can either be perceived as a momentary 'cut' within a longer process or a singular event with its own durational integrity. Instead, medical screening encompasses a rich heterogeneity of temporalities held together by a constellation of tenses. Further, albeit without specifically using Mol's framework, Baszanger (1992) examines the ways medical practitioners 'decipher' chronic pain, a condition that cannot be easily apprehended as a solid, unquestionable fact. In the process, she demonstrates how different deciphering practices yield not only different notions of pain, but also different notions of the body, which, in turn, influences the doctor-patient relation, and determines the applied medical interventions.

Particularly the latter study points to the ways STS's turn to ontology and the materiality of scientific practices is an important lens for thinking about the body (Berg & Akrich, 2004; Michael & Rosengarten, 2012). In this line of thinking, the body is neither a pre-given biological fact (Berg & Akrich, 2004), nor a coherent and confined whole that medicine generates knowledge about, or that patients develop self-awareness for (Mol & Law, 2004). Instead, embodiment is a process which yields a specific (concept of) the body – it gives shape to the *emergent body* (Berg & Akrich, 2004; Michael & Rosengarten, 2012), the *lived body* (Latimer, 2009). Through this continuous interplay between the discursive and the material, bodies, from moment to moment, are performed differently, consecutively becoming known, knowing, and unknowing, thus bringing different worlds into being, and vice versa (Latimer, 2009). Contouring the sociology of the body, Latimer (2009) traces four different perspectives on this *world-forming* effect. The first, *embodiment*, points to the body as *world-reflecting*, i.e. shaped by a combination of culture and practices. Attention towards *groups* extends this view by understanding bodies as enacted through interaction with each other, rather than merely shaped by habit. Such re-interpretation of social practices has *world-making* effects. This relationality is further reflected in the

conceptualization of the body as an *assemblage*, or *actor-network* in which the *world-building* effects of the flesh are seen as symmetrical to other material forms. Being part of an assemblage of various human and non-human actors, the body is involved in a series of trials, and confrontations with these different elements (Berg & Akrich, 2004). In opposition of death, having a body, or living a 'good' bodily life in this context, means to learn to affect and be affected, it means to learn *having* a body (Latour, 2004a). Likewise, while with less insistence on symmetry, the concept of *relational extension* frames bodies as part of a constant process of *world-shifting*, i.e. being retheorized in terms of the ever-changing relationalities they are involved in (Latimer, 2009).

Among the strands of literature on the multiple ontology of bodies, various shapes of this world-forming theme can be identified. Following, for instance, Mol and Law's (2004) case of hypoglycemia, it becomes clear that the enactment of this condition involves the entire body with its senses, its hands, its mouth, its digestive system, or its metabolism. By engaging in practices such as measuring blood sugar levels, interfering with an upcoming hypo, or avoiding it through precautionary measures, patients also always *do* their bodies, while at the same time the body itself is also actively engaged in enacting hypoglycemia. Further, since such practices also involve elements like measuring technology, insuline, food, carbohydrate tables, or friends and family members, there is no clear-cut distinction between a bodily in- or outside. Instead the body has leaky and fluid boundaries. Such interminglings of bodies with the objects around them is further corroborated by Akrich and Pasveer's (2004) study of women's childbirth narratives, showing how bodies, perceptions of selves, and one's environment are performed and mediated by a variety of elements, for example through the technical devices used in the delivery room.

What is more, as Mol and Law (2004) argue, people's lives are not solely determined by their health conditions, as they also engage in a range of other things, such as doing sports, working at a construction site, or falling in love. All these things can interfere and create tensions with the management of their disease, and, thus, require continuous engagement and coordination by both doctors and patients. This is further reflected in the studies by Thille, Abrams, and Gibson (2020), focusing on children with muscular dystrophy in a rehabilitation clinic, as well as Setchell, Nicholls, and Gibson (2018) examining physiotherapeutic practices. Both studies show how, from moment to moment through shift of repertoires, the introduction of new treatment methods, or simply the patient's prompts and their practitioner's reply, a different body with different needs, concerns, and pleasures comes to the arena. Some of them are familiar within the day-to-day routine of the practitioners, while others are unexpected, contested, or perceived as

disruptive. Especially in the latter cases, these multiple bodies need to be negotiated, and are sometimes disregarded, while other bodies are prioritised. Each moment is a coordination between different bodies – what is more important, the *playing-child*, who wants to jump on a trampoline or the *at-risk-body*, who should avoid activities causing fractures (Thille et al., 2020), the *fat body* that needs to lose weight, or the *emotional body* whose comfort should be cherished (Setchell et al., 2018)? Sometimes, as Moser (2006) illustrates, different enactments of bodies create alternative realities. Practices of enacting differences, such as in terms of class, gender, and dis_ability[1], can clash and compete with each other, certain dis_abling conditions invoked by institutional practices or bureaucratic choices can be resisted by performing the body as the gendered or the classed body. Some forms of dis_ability, on the other hand, can interplay with certain aspects of gender and class.

The choreographies of humans and non-humans involved in these situations come with different consequences, and configure and reconfigure certain power relations (Moser, 2006; Thille et al., 2020). And this is where the politics in the name of Mol's framework comes forth. Enactments "carry modes and modulations" with them, other realities are always involved (Mol, 1999, p. 81). "Medicine should come to recognize that what it has to offer is not a knowledge of isolated bodies, but a range of diagnostic and therapeutic interventions into lived bodies, and thus into people's daily lives." (Mol & Law, 2004, p. 58). This makes a crucial point for my thesis, particularly, considering the following strand of STS scholarship.

2.3. Emphasizing: Feminist technoscience and the gendered power relations in biomedicine

When studying science as a form of knowing (McNeil & Roberts, 2011), it is vital to consider that its products might not be equally beneficial for everyone. In fact, scientific knowledge can even be used to establish and perpetuate social injustice (Subramaniam, Foster, Harding, Roy, & TallBear, 2017). Particularly for my case study, tending to the (gendered) power relations that shape and interfere with enactments of the body is indispensable. Therefore, in this section I am going to outline different strands of feminist technoscience (FTS) scholarship with a specific focus on biomedicine.

[1] Writing the term in such a way reflects the social model of dis_ability which "locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment" (Marks, 1997, p. 88). Through upholding of barriers, and refusal to provide resources that would allow participation, equality, and autonomy, a person literally becomes dis_abled by society (Murstein, 2018).

Rather than perceiving the body as a gender neutral entity being described by biologically natural facts, FTS scholars critically inquire into the manifold ways medical practices, technologies, institutions, and routines produce, shape, enact, and co-construct bodies, sex-gender, health, and illness (M. Bailey & Peoples, 2017; Fishman, Mamo, & Grzanka, 2017; McNeil & Roberts, 2011). Entangled into cultural and social norms, practices, and power relations such concepts are oftentimes loaded with and, thus, inevitably (re)inforce normative, stereotypical, and marginalizing ideas (Fishman et al., 2017) about certain bodies and forms of existence. While sex-gender is the main focus of this literature review, it is important to note that FTS inquiries attempt to not address these elements alone, but also considers the intersections with, and co-constructions of, race, ethnicity, nationality, dis_ability, class, etc. (see for example M. Bailey and Peoples (2017); Pollock and Subramaniam (2016); Subramaniam et al. (2017)).

As an answer to medicine's strive for determining relevant markers for sex-gender differences, FTS studies show how, for instance, the case of attributing the essence of sex to hormones, substances that can be quantified and measured, and for which particular thresholds can be determined, is strongly dependent on the thought collectives in which this knowledge is formed. These collectives include cultural and local contingencies, availability of research material as well as the network of involved actors (Oudshoorn, 1994). Whith hormones being designated 'messengers of sex', it is crucial to take into account that messages are always transmitted, received, and responded to not only within a biological, but also socio-cultural system (Roberts, 2007). Even our sensibility to difference and resulting ignorance of sameness when looking at sex-gender, is itself a product of our social understanding of it, be it in terms of hormones, brain composition, or anatomy (Friedman, 2013).

Consequently, FTS researchers emphasise that science is never apolitical (Fausto-Sterling, 1992). While biological markers are not arbitrary, one cannot deny that social and political norms, biases and roles, economic status, or legal constellations inevitably (and inadvertently) slip into researchers' work (Fausto-Sterling, 1992), or that they are even actively shaped to serve a certain social model (Haraway, 1989), thus doing *politics by other means* (Latour, 1988). Historically, representations and pathologization of bodies marked as female and their bodily functions, from anatomy to hormonal composition to menstruation, were always closely tied to assumptions on women's role and position in society, and in turn shaped and influenced prevailing political debates (Fausto-Sterling, 2000; Haraway, 1989; Schiebinger, 1989; Sherwin, 1992).

However, the notion of an objective and impartial science obscures such contributors. Biological models studying sex differences neglect historically changing notions of gender

and context of behavior, are fixated on dichotonomous structures of male/female, and are driven by dyadist[2], cis- and heteronormative thinking (Matusall, 2013). Consequently, research designs, scientific metaphors, and health imaginaries paint a very negative image of women, constructing them as either inferior to men, or destructive, dangerous and aggressive, while designating their bodily capability of bearing and birthing children an essential role that stands over their own needs and agency (Bordo, 2004; Fausto-Sterling, 1992; E. Martin, 1991, 1999). Through research practices and the knowledge they bring into being, such gendered images become naturalized (Haraway, 1989).

Ultimately, naturalistic sex-gender models function as a form of discipline and control. Bodies that do not fit into the dichotomous model, such as those of intersex[3] people, are marked as unruly and transgressive and in need of 'correction', which legitimizes violent genital surgeries, or invasive gender tests from a very young age (Fausto-Sterling, 1993, 2000). This controlling function is especially discernible when considering that practices of pushing and containing people within binaries, ironically, increased with the progression of knowledge on the complexities of sex (Fausto-Sterling, 1993).

However, as Anne Fausto-Sterling (1993, 2000), who did significant work on this issue, points out, rigidly holding on to this binary actually acts in defiance of nature, since human bodies are so complex that it is not possible to provide clear-cut answers on sexual differences. Sex is a continuum that significantly goes beyond two categories. Consequently, Fausto-Sterling imagines a utopia where scientific knowledge on intersex bodies is used to tear down sex/gender dichtotomies instead of solidifying them. Here, particularly, the attention to materiality in many FTS works comes forth. For instance, rather than viewing sex/gender as either stemming from natural or social causation, Frost (2014), discussing works by Fausto-Sterling, Butler or Fox Keller, calls for a refiguration of biology, which "re-imagine[s] ourselves as biocultural creatures, as permeable organisms whose living processes compel us to ingest, absorb, and respond to the variously material and social dimensions of our habitats" (p. 322), and hence, being a product of the interaction between matter and environment. Such thought resonates with other frames, such as Barad's (2007) *agential realism*, which perceives objects as emerging through their interaction, or Haraway's *cyborg*, which objects to any form of essentialism, and instead

[2]The term *dyadic* is used to refer to people who are not intersex ("Dyadic", n.d.). Thus, the adjective *dyadist* comes from *dyadism* which describes a kind of sexism that erases and ignores the existence of intersex people and assumes that human bodies are strictly dyadic, i.e. strictly classifiable into a binary structure of sex ("Intersex", n.d.)

[3]Umbrella term referring to variations in sex characteristics or reproductive anatomy ranging from genitalia, hormones, internal anatomy, or chromosomes (*What is Intersex? Frequently Asked Questions*, 2021). Oftentimes the term is used to invoke community and to unite all people sharing experiences living with variations in their sex traits (ibid.).

constitutes a hybrid between nature and culture.

To conclude this section I would like to point to Haraway's (1989) description of nature as simultaneously being myth and reality. Breaking free from this worship of scientific fact means being attentive to the kinds of stories science is embedded in and productive of, and it means acknowledging that science itself is a story-telling practice. Such approach blazes a trail for other kinds of stories that are usually obscured by an overly mystification of scientific practice.

2.4. Including: Patients' meaning-making and situated knowledge

The literature discussed above leads to STS's scrutiny and deconstruction of the idealized image of *scientific monotheism*, a theory which ascribes the role as knowledge producers and representatives only to scientists (Weinstein, 2001); instead, STS draws attention to a range of different forms of knowing.

Thinking along with Haraway (2001 [1988]), the claim that scientific knowledge is detached from social values, norms, and power relations means producing the *god-trick* of "being nowhere while claiming to be everywhere equally." (p. 176). However, vision is never impartial, but always embodied, and mediated by experiences, social practices, values, and the ways knowledge production is socially organized (Stoetzler & Yuval-Davis, 2002). Knowledge is therefore *situated* (Haraway, 2001 [1988]; Harding, 1991, 1992).

This is reflected in the various strands of standpoint theory which critically engage with the relations between the production of knowledge and practices of power (Harding, 2004). For example, illusions of relativism produced by the god-trick mainly favor so-called *unmarked bodies* (Haraway, 2001 [1988]), i.e. privileged social groups, which can be characterized by concepts like male, White, or/and cis. What is more, such knowledge not only fails to fully capture the lived experiences of those who are marginalized, such as female, Black or/and trans people (or as Haraway calls them, *marked bodies*), but oftentimes even acts to their disadvantage (Harding, 1991, 1992). At the same time, this *knowledge from below* gets systematically neglected and excluded in the name of 'purifying' science from the 'distortive' influences of politics (Harding, 1991, 1992, 2004).

Contrary to such notions of an 'impartial' science, standpoint theory argues for "starting off thought" from the position of marginalized groups (Harding, 1992, p. 445), empowering them and valuing their experiences (Harding, 2004). It points to the fact that experiencing the world from a marginalized position equips people with insights that are

commonly obscured within a hegemonial system, making them experts on their own lives. Additionally, in order to survive within this system, they also need to be knowledgeable about its rules and structures, as well as the living situations of those dominating the discourse (Katz-Wise et al., 2018). Consequently, taking the "partial perspective" of "feminist objectivity" (Haraway, 2001 [1988], pp. 174, 175) and giving the knowledge of marginalized groups more weight can, in many cases, provide a much richer picture of certain matters (Harding, 1992), particularly those directly affecting their lives (Harding, 2015). In doing so, standpoint theory is highly intersectional, as de Vries (2015) illustrates in the metaphor of a multidimensional prism depicting the intersecting experiences of trans people of Color: While focusing on one particular plane (such as gender), other social positions (such as dis_ability, race, or class) can be 'seen through', complicating and nuancing this standpoint rather than speaking of universal experiences.

Further, especially when it comes to asymmetrical power relations, it is critically important to stop treating marginalized people as passive 'objects', as is commonly done in scientific research, and instead make way for their active involvement in the process of knowledge production on their bodies and lives (Haraway, 2001 [1988]).

So, what can a lens emphasizing situated knowledge add to studying the medical realm? As soon as medical knowledge leaves the laboratory, it inevitably comes into interaction with the public (Casper & Berg, 1995), including those whom this knowledge is supposed to serve, the patients. Patients, especially those living with under-researched, uncertain and impalpable diseases, cultivate different approaches to navigating medical information and to effectively applying it in their management and risk reduction strategies (Lambert & Rose, 1996). By incorporating their own experience, clinical observations, general knowledge, and personal/family medical histories, they develop a set of situated understandings of medical knowledge (ibid.) that can be valuable for improving the quality of their own lives, and of those who are in similar situations.

Whether medical advice or a decision is 'good' is highly dependent on one's conceptualization of 'good' (Politi & Street, 2011). Pols (2014), for instance, demonstrates that the knowledge patients acquire through living with their condition is practical, highly situational, and might differ from the medical advice they receive from their health practitioners. While medicine prioritizes health, patients might consider other values more important, and hence sometimes reject certain measures, even at the cost of their physical well-being. Such behavior is not mere ignorance of the medical assessment of their state of health, but rather patients assessing and weighing such guidelines against their implications for their overall quality of life (Lambert & Rose, 1996).

Moreover, patients' situated knowledge, or *lay-expertise* (S. Epstein, 1995) can also be

highly valuable for medical knowledge production itself. This is illustrated by examples such as the *AIDS activists* of the *ACT UP* movement, who eventually gained access to the research on HIV medication trials (S. Epstein, 1995; Pinch & Collins, 1998). Similarly, the case of the French association for patients with muscular dystrophy (AFM) demonstrates how lay-expertise and scientific knowledge can exist in a complementary relationship. By forming hybrid collectives with medical experts and performing 'research in the wild' through usage of tools and methods atypical for standard laboratory work, AFM successfully collaborated with the researchers (Callon & Rabeharisoa, 2003).

2.5. Interluding: Non-knowledge and ignorance

A corollary of delving into the complexities of knowledge production and the practices that account for why something is known in a particular way, is acknowledging the inevitability of ignorance generated by these practices (Gross & McGoey, 2015; Tuana, 2004) and the many forms science is complicit in its un/making (Proctor, 2008). Because ignorance and non-knowledge are profoundly consequential in our lives (Proctor, 2008), and they significantly shape the ways both PCOS and the identities and lives of trans people are perceived and conceptualized by research and medicine, in this section I will briefly discuss the major viewpoints on this topic – specifically in regard to power and inequalities.

For, identities, social location, and modes of belief formation are, as Alcoff (2007) argues, deeply rooted in structural social conditions being, in some cases, epistemically disadvantaged or defective. Tracing ignorance's different topologies in works by Code, Harding, and Mills, she identifies it to be an inevitable consequence of the situatedness of knowers, that is specific to aspects of group identities, and oftentimes a structural product of oppressive systems. Ignorance, thus, is far from being merely an innocent lack of knowledge, but is instead deeply intertwined with power and prevailing value systems, privileging certain groups and disadvantaging others (Tuana, 2004). While oftentimes being a tacit by-product of our epistemological structures, ignorance can also result from different political interests, being willfully manufactured to generate authority, doubt, trust, silencing, and uncertainty, or deny the marginalization of certain groups (Gross & McGoey, 2015; Tuana, 2004).

The dynamics described above are, for instance, captured by Murphy's (2006) concept of *regimes of perceptibility*, which encompasses what phenomena can become perceptible within certain disciplinary or epistemological traditions. The material limitations of knowledge practices and their selectivity in focusing on a certain set of variables and not others, consequently, brings into being different *domains of imperceptibility*, i.e. what

can not be known within a particular knowledge system. Studying how the *sick building syndrome* – a term subsuming the various health issues experienced by office workers due to chemical exposure within their work environment – Murphy demonstrates how knowledge about this phenomena – being deeply embedded in different material cultures, arrangements of technologies, constellations of actors, histories and epistemological traditions and practices – simultaneously materialized what was imperceptible and considered unreal about it. Further, as this case is profoundly entangled in (gendered) power relations, imperceptibility was not always accidental but sometimes also actively generated and maintained, for instance, by industry-sponsored science.

Another illustration of the interplay of knowledge, power and ignorance is given by Tuana (2004) in her epistemology of the orgasm. Showing how conceptualizations of female sexuality and research on the clitoris were simplified, constraining, and primarily tied to reproduction, while the detailed and significantly more intricate feminist research on the clitoris was disregarded, she highlights how the things we attend to and the things we ignore are intertwined with specific values and politics, and thus solidify what we take for granted, what we eagerly accept as 'common knowledge', and what we neglect and render invisible. Her case study demonstrates how ignorance was a convenient tool to control (female) bodies and sexualities, because research was rooted into the notion of female desire being dangerous and controlling to men, while the fear of the degeneracy of the White race and and the fear of 'inverts', which referred to homosexual people, drew attention to specific notions of 'abnormality' in genitals.

While not the main theme of this research, ignorance is deeply woven into its different facets, particularly when it comes to research on the bodies and the identities of trans people, wich will be examined later in this chapter. But before delving into this strand of scholarship, I would like to draw some connections between the literature discussed above and the existing research on PCOS.

2.6. Bridging: Classifications, norms, and lived experiences of/with PCOS

Within the relatively scarce social science research on PCOS, two major strands that resonate with the themes introduced in this state of the art can be identified.

The first one is aligned with research on science as a form of knowing, its embeddedness into social value systems and power relations, and the limits of classificatory practices. Discussing the limits of applying Boorse's biostatistical theory of objectively defining

disturbances of biological function in practice, Doust, Walker, and Rogers (2017) point to the difficulty of clearly delineating the dysfunction of PCOS, especially as its diagnostic markers depend on three different criteria – circulating androgen levels, regularity of ovulation, and presence of cysts in the ovaries. For all three criteria, there are multiple means of measuring, varying thresholds indicating dys/function, different choices regarding what the 'relevant' function is, and all three criteria greatly fluctuate from person to person over time. Consequently, depending on the choices made in terms of these criteria the boundary between normality and pathology is constantly in flux. This is why, as the authors argue, it is not enough to focus only on naturalistic identifiers, but instead light should also be shed on the values diagnostic choices are laden with.

An example of the kinds of values that diagnostic choices are based on is given by Vleming (2018). Vleming draws on theoretical perspectives and methodologies from medical anthropology, feminist scholarship, history of science and STS, and analyses Western biomedical frameworks of conceptualizing PCOS and how these changed over time. The two main frameworks she identifies are both deeply rooted in the medicalization of bodies assigned as female. The first one, focusing on hormones and infertility, both essentializes women as mothers but also, neglects any further concerns they might have about their diagnosis. The second framework approaches PCOS as a metabolic disorder, and – despite a lack of consensus – highlights weight loss as the main treatment for PCOS. Consequently, this framework perpetuates a biopolitical rhetoric that regards the body (particularly the female body) as to be brought under control through diet and exercise.

The latter framework is also highlighted by Fisanick's (2009) work, which is situated in critical fat studies. The author emphasises that all bodies coded as female exist in the shadow of normative femininity, that is, in the matrix of socio-cultural norms, expectations, performativities, and enactments of 'the feminine'. Being based on negations (e.g. no hair or fat in the wrong places) and contradictions (e.g. do be lean and have toned muscles but do not be strong) it poses a highly restrictive framework for these bodies. Within this framework, the PCOS body is within a double bind situation. On the one hand, the "PCOS body – fat, irregular, infertile, and hairy –" (p. 107) is highly visible and considered "dangerous or disturbing or transgressive" (p. 108). However, by strong adherence to standards of normative femininity, such bodies are rendered invisible. Fisanick demonstrates this in the case of the *Polycystic Ovarian Syndrome Association* (PCOSA). PCOSA chose a spokeswoman fitting into the standards of normative femininity who presented her 'after' version following the adoption of an eating and exercise plan. Her 'before' version, the fat person in this scenario, was rendered invisible and with that, the possibilities of how people who have managed the syndrome can look become limited.

Thus, Fisanick criticizes that PCOS bodies, while having the potential to transgress the boundaries of normative femininity, are not given the chance to do so through practices like these.

The second strand of research is presented by a handful of qualitative inquiries into the lived experiences of women with PCOS, which reflect the struggles with the normative femininity outlined above. Many such studies structure their participants accounts into a trajectory, which begin with an awareness of PCOS symptoms like hirsutism, irregular or absent periods, or infertility, an awareness which is accompanied by feelings of being 'inadequate', 'abnormal' (Kitzinger & Willmott, 2002) or 'different from other women' (Snyder, 2006). Particularly Kitzinger and Willmott (2002) highlight how their participants struggle to bring these symptoms into congruence with their female identity, oftentimes referring to themselves with terms like 'freak' and referring to PCOS as the 'thief of womanhood'. Such feelings are commonly taken up as a sign that something is 'wrong' and spark a search for answers (Snyder, 2006). This state is followed by a journey to a formal and informal search for help, with participants often being forced to switch doctors multiple times and feeling abandoned by medical practitioners, being misunderstood, being not taken seriously, or receiving confusing and inadequate information (Crete & Adamshick, 2011; Snyder, 2006). Finally, this trajectory ends with gaining control of their knowledge, symptoms, and, eventually, the overall PCOS treatment, while letting go of guilt – especially in regard to weight gain – and finding coping strategies for dealing with the feeling of inadequacy (Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006). Moreover, there are several quantitative studies within the medical sciences and related disciplines identifying similar themes, like delayed diagnosis and the necessity to visit several health professionals (Gibson-Helm et al., 2014; Sterling et al., 2010; Tomlinson et al., 2017), or the lack of (sufficient) information on PCOS and associated health risks going beyond potential infertility (Gibson-Helm et al., 2014; Tomlinson et al., 2017). Further, there is high dissatisfaction with the scarcity of PCOS treatment options (Sterling et al., 2010), and high interest in alternatives that go beyond fertility drugs or birth control pills (Sills et al., 2001). Generally, such studies point to significant discrepancies between the beliefs of women with PCOS and how they experience the attitudes of healthcare professionals (Tomlinson et al., 2017).

In the second part of her study, Vleming (2018), too, explores the lived experiences of different people with PCOS. She contrasts the identified frameworks with her participants' accounts showing how they significantly vary and can even pose a danger to the patients' health, e.g. through the encouragement of eating disorders. Likewise, Ellerman (2012) criticises how medicine's authoritative stance on PCOS constructs the 'female' body as

deviant and abnormal, while ignoring and excluding the embodied knowledge of women with PCOS. Accordingly, Ellerman illustrates how she and her interview participants refused this objectification and rejected diagnoses that did not relate to their actual issues and experiences while claiming an active role in caring for their own bodies.

2.7. Elaborating: Trans-focused medicine as ...

Having outlined these different strands of literature, it is important to note that a large amount of STS research itself is very binary, and imbued in heteronormativity and bias towards trans and intersex people (Fishman et al., 2017). Thus, in order to do justice to the complexities of my research case, the following (sub-)sections will not only be limited to inquiries into the relationalities of trans people and the medical system from STS alone, but will also draw on insights from social science, anthropology, qualitative medical research, as well as the field of transgender studies.

2.7.1. ... constructing bodies, forming identities ...

In light of its role in our society Stryker (2017) describes medicine and medical science as a "two edged sword – its representatives' willingness to intervene has gone hand in hand with their power to define and judge" (p. 52). Without doubt, medicine significantly contributed, and to this day still contributes, to essentializing the axiomatic order of (binary) gender/ sex, and rigid gender roles (Garcia Nuñez et al., 2019). With the objective of upholding this 'normal' (ibid.), it classifies people who deviate from the 'norm' as mentally or physically ill and, thus, legitimizes medical intervention (Stryker, 2017).

Hence, medicine approaches trans people and their gender expressions through a narrow and simplified lens. As Hooley (1997) discusses in her comparison of gender representations and practices in activism and medicine, particularly sexology and psychiatry, medical understanding of trans people is strongly guided by dichotomous, biologistic and stereotypical notions, such as the 'being born in the wrong body' narrative.

Although the latter can grant access to vital medical interventions such as HTR or surgery, it is not based on trans people's right to decide over their own body, but rather on society's eagerness to correct 'sick' bodies and produce 'healthy' ones (Sullivan, 2008). On this basis, the so-called 'genital reassignment surgery' is presented as a 'technological fix' (Hooley, 1997) or a 'cure' (Garcia Nuñez et al., 2019), allowing trans people to 'correctly' express their gender. Oftentimes such interventions are described through a 'butterfly

metaphor'[4], in which the trans 'caterpillar' transforms into the 'butterfly' as analogous to the perfect representation of gender (ibid.). Further, surgical interventions contribute to the enactment of what is supposed to be considered as physically male and physically female (Jacke, 2019). As Hooley argues, such practices ignore and erase the multifaceted, nuanced, and fluid ways of expressing one's gender that she identifies within trans activist circles, a finding which is reflected in many analyses of trans-specific medicine.

Analyzing contemporary medical guidebooks, Latham (2019), who employs the lens of ontological politics in many of his works, identifies four axioms by which medicine understands trans people, their genders, and their sexualities. According to these axioms, *transexuality*[5] "is a disjuncture between mind and body; [...] [means] hating having the wrong genitals; [...] [is] painful and debilitating; and [...] treatable with surgical and hormonal body modifications" (Latham, 2019, p. 2). By constantly relying on such axiomatic notions and refusing to attend to other ways of being trans, medicine reiterates and constitutes what Latham refers to as *trans singularity*, "a singular notion of what transexuality (and sex-gender) 'is'" (p. 2). This singularization of trans people's experiences is further highlighted in Latham's (2017a) examination of how clinical practices, particularly the justification for the mandatory psychological evaluation trans people need to undergo before receiving access to transition-related surgeries, participates "in the making of trans realities" (p. 40). By relying on a common-sense realism of binary sex-gender normativity, medicine automatically constructs trans people as 'other', as 'special cases' that are different from other patients (such as for instance, those seeking plastic surgery) rather than looking at individual cases. Even though Latham identifies many parallels, differences in medicine are solely made on the basis whether the person is trans or not, obscuring the complexities of individual cases. Thus, the very system that is designed to 'treat' trans people produces transexuality as a stable and definite disorder preceding clinical encounters. This *trans exceptionalism* (Heyes, 2007) produced through the dis/analogy between trans and cosmetic surgery, further perpetuate, as Heyes and Latham (2018) argue, a *politics of ressentiment* in which trans people's need and access to transition-related health-care services is tied to narratives of suffering and an aversion to the own body.

On the one hand, this is further perpetuated by the thought collective of medical research itself. In psychological literature, for instance, Ansara and Hegarty (2012) identify an invisible college consisting of a small number of researchers regularly citing

[4]"Schmetterlingsmethaphorik" (Garcia Nuñez et al., 2019, p. 37)

[5]Latham (2019) uses the term 'transexual' to capture the process of multifaceted trans identities becoming singular through the ways in which they are understood by medicine.

each other and thereby increasing each other's impact. In comparison to less cited authors, their articles all have a similarly cisnormative and pathologizing tone, and thus, too, reproduce and legitimize a biased view on trans people (Fishman et al., 2017).

On the other hand, trans people need to adhere to these norms in order to overcome gatekeeping, which, in turn, bolsters the feedback loop (Latham, 2019). Gatekeeping, thus, functions as a further instrument for upholding rigid gender norms (Garcia Nuñez et al., 2019). Within this legal framework, medicine acts as a control authority for gender[6] that is supposed to distinguish between 'true' and 'false' transsexuals (ibid.). Considering the ways in which medicine conceptualizes gender, it is no surprise that there is little room for diverse and nuanced gender identities and expressions. All these administrative structures and practices, bureaucratic tracking, and sanctions all are pushing a population into specific categories, vesting gender with a biopolitical function (Stryker, 2014).

As Spade (2003) points out, recounting his own experiences with medical transition: "I was experiencing acutely the gulf between trans community understandings of our bodies, our experiences, and our liberation, and the medical interpretations of our lives" (p. 24). In his essay he highlights how the diagnosis of *gender identity disorder* (GID) enacts a fiction of normal and natural gender with clearly defined, designated gender roles that traverse every domain of life. To fit into this medical model trans people need to 'successfully' perform a desire for gender normativity.

Particularly, this institutional disciplining of gender performances significantly contributes to the creation and stabilization of concrete, binary and stereotypical categories of male/female (Linander, Alm, Goicolea, & Harryson, 2019). As noted above, in order to obtain access to specific medical procedures trans people need to present and perform their gender in line with such categories, which in turn constantly (re)constructs their gender according to cisnormative and binary norms (ibid.). In addition to such 'normalizing' practices[7], 'non-normative' bodies[8] and ways of living[9] are marginalized and misrecognized, which further pushes people into binary, heteronormative categories (Houben et al., 2019). Correspondingly, in his autoethnography on undergoing transition-related medical procedures, Latham (2017b) draws on Mol's ontological politics to illustrate how sex and transexuality are enacted in narrow and limiting ways by different medical practices. Conversely, these multiple enactments demonstrate a counterargument against the presumed stability and singularity of transexuality.

[6] "Geschlechterkontrollstelle" (Garcia Nuñez et al., 2019, p. 38)
[7] "Normierende medizinische Praktiken" (Houben, Dennert, Athenas, & Ohms, 2019, p. 108)
[8] "nicht-normative Körper" (Houben et al., 2019, p. 108)
[9] "nicht-normative Lebensläufe" (Houben et al., 2019, p. 108)

2.7.2. ... and erasing lived experiences.

Considering such medical conceptions of trans people, their identities and their ways of living their lives it is no surprise that medical care disparities go beyond trans-specific care alone. When seeking medical care, patients who do not fit into hegemonic notions of gender have the experience of not being listened to when voicing health concerns, such as back pain or colds, but instead their appearance or hormonal levels are alleged to be the issue at stake (Houben et al., 2019).

This is also referred to as the 'trans broken arm syndrome,' where every malady or health concern, ranging from mental health issues to literally broken arms, are claimed to be a result of the person's gender identity and potentially corresponding medical interventions (Payton, 2015). This comes with the danger that trans patient's are not sufficiently examined and thus subjected to further health ramifications (Houben et al., 2019).

Further, as Bauer et al. (2009) illustrate, medical care is deeply riddled with informational and institutional erasure. Informational erasure is signified by a lack of knowledge and information on trans people and trans (health) topics, as well as ignorance of knowledge and resources generated by trans communities. It is based on the assumption that all patients or participants are cis and their gender is and has always been stable, while trans people are considered a rare phenomenon. Medicine's rigid view on how trans people ought to be, as discussed above, further perpetuates this erasure because people who do not fit into the clinical stereotype are not regarded as trans and, thus, are made invisible. Hence, research studies, curricula, textbooks, or information learned by, or readily accessible to, health care providers and policy makers are entirely void of issues related to trans people's health care. Institutional erasure is manifested by the lack of policies accommodating trans people, their bodies, and identities, along with the neglect of necessity of such policies. Commonly, this type of erasure occurs through bureaucratic applications and documents such as referral forms, administrative intake forms, or prescriptions. Sex designation in the files of trans patients, for instance, might pose the risk of outing the person against their will, if they are not assumed to be a mistake. What is more, sex designation within electronic medical files might pose an obstacle to specific procedures, such as pregnancy tests for trans men (Gupta, Imborek, & Krasowski, 2016). But lack of access to health care services can also result from hostility and transmisic behaviour of medical practitioners (Bauer et al., 2009). As Samuels, Tape, Garber, Bowman, and Choo (2018) demonstrate, reasons why trans people avoid going to the emergency department are, among those above mentioned administrative issues, experiences with and fear of

misgendering, inappropriate questions, transmisic mockery or harassment. Many patients even have to weigh whether revealing their gender identity is significant for the health care they receive, or whether this would put their life and safety at risk (Dutton, Koenig, & Fennie, 2008). Further, people experience it as tiresome when having to constantly explain and educate others on their lives when seeking for medical care (Samuels et al., 2018). Such practices of erasure not only result in inadequate and inappropriate care for trans people, but also end up in a vicious cycle where trans people avoid seeking medical care, which in turn creates the assumption that there are only few trans people (who need a particular health service).

Medical sites focusing on gynecology and reproductive medicine are particularly places in which trans and other queer[10] people are not expected (R. Epstein, 2018). By using Judith Butler's (1990; as cited by R. Epstein, 2018) concept of the *heterosexual matrix*, Epstein describes the fertility clinic as a highly gendered space in which hetero- and cisnormative performativities are constantly reiterated, and thus become an invisible norm. LBGTQ+[11] people who do not align with such norms are immediately noticed and their identities and family configurations are perpetually misrecognized and made unintelligible. They, thus, become *space invaders*[12]. This is, for instance, signified by being misgendered when called into the doctor's office or made uncomfortable by other patients' stares for being the only men in the waiting room (Wingo, Ingraham, & Roberts, 2018). Further, while trans people share many reproductive capabilities and obstacles with cis parents, their pregancies are constantly exceptionalised and rendered impossible by reproductive institutions, policies, and practices (Dietz, 2020).

Including trans people's needs into medical care, thus, means asking questions such as "What norms would be reimagined if the needs of trans people were met? What ethical questions would be at stake? What would go unchallenged? For whom would possibilities arise?" (Dietz, 2020, p. 9). As Baker and Beagan (2014) demonstrate, their LGBTQ+ participants preferred medical practitioners who are open-minded, eager to

[10] I use the term 'queer' as an umbrella term referring to those gender identities and sexual and romantic orientations, behaviours, and self-expressions that are rendered 'other' and 'marginal' within a cis-hetero-normative society (Jackson, 2005). Correspondingly to intellectual thoughts of queer theory, I understand 'to queer' as a range of practices of implicitly and explicitly subverting, deconstructing, crossing, or moving in adverse or opposite direction (Light, 2011) to those identities, behaviours, expressions, kinship structures, and other forms of cis-hetero-normativity which are considered normal and desirable, and are organizied, ritualized, and institutionalized within our society (Ingraham, 2005). These practices of queering also always bear critique of the stigma, violence, and exclusion brought upon by such structural and foundational relations (Light, 2011; Love, 2014).

[11] lesbian, bisexual, trans, queer, and other sexual/ romantic orientations, and genders

[12] The author borrowed the term 'space invaders' from Nirmal Puwar and Sara Ahmed (2004; 2012; as cited by R. Epstein, 2018).

learn, and willing to admit uncertainty, rather than presenting as a neutral and detached expert. Instead of cultural competency which assumes learning cultural attributes of the Other, the authors suggest an approach of cultural humility, which regards learning as a life-long relational process that is sensitized to power structures and inequalities and the embeddedness of one's own knowledge within such. It would mean learning with, rather than learning about queer people. Such piece-by-piece provision of resources could be a step towards dismantling the heterosexual matrix within the medical system, and in lieu of that, assembling a space which recognizes the complexities and hybridity of gender and kinship relations (R. Epstein, 2018).

2.7.3. Searching: What about trans people and PCOS?

So far, research on trans people's experiences with PCOS has been scarce. A few medical sources point out that some trans people might be content about facial hair growth or absence of periods (Deutsch, 2016; Guss & Pitts, 2018), while perceiving prolonged menstruation as distressing (Guss & Pitts, 2018). Hereof, Guss and Pitts (2018) argue for special considerations when treating trans people with PCOS, and stress that medical practitioners should always assess the gender identity and treatment preferences of their patients.

Within both social science and STS literature, the only account is presented by Vleming (2018). Among her six participants, Vleming interviewed Logan[13], a trans man with PCOS. In regard to his transition, Logan perceived most of his medical care providers as respectful and competent, but getting health care that is assumed to be limited to women's bodies came along with different, uncomfortable experiences. Such experiences included being the only man in the waiting room, doctors' puzzlement when learning what type of treatment he was supposed to receive, or pink forms at the obstetricians' and gynecologist's office. Vleming also criticises the framing of PCOS as a 'women's health' issue and the ways it is discussed through normative gendered terms as exclusive of trans and nonbinary people with this diagnosis.

Worth of note, there are a small number of medical studies investigating the correlation between PCOS and trans men who have not received HRT (see for example Baba et al., 2007; Balen, Schachter, Montgomery, Reid, and Jacobs, 1993; Calvar, Fernandez, Duran, Ballester, and Landini, 2016; Mueller et al., 2008). While there are no consistent conclusions to this question, it is striking how strongly many of these studies play into the stereotypical notions of gender and trans people which are described above by speaking

[13]Pseudonym given by Vleming

of 'gender-(a)typical behavior', referring to the way their trans participants dressed and comparing them to women with 'normal female gender identity' (Vleming, 2018).

2.8. Speculating: De-subjugated knowledge

As outlined in this chapter so far, medical knowledge about trans people is imbued in pathologizing and rigidly binary categories, rendering those who diverge from its conceptualizations invisible. Trans scholars' and activists' responses and objections to such a lens, their efforts to be taken seriously and not be pathologized and dismissed developed into the field of transgender studies (Bettcher & Garry, 2009; Stryker, 2006a). To phrase it in Susan Stryker's (2006a) words:

> Most broadly conceived, the field of transgender studies is concerned with anything that disrupts, denaturalizes, rearticulates, and makes visible the normative linkages we generally assume to exist between the biological specificity of the sexually differentiated human body, the social roles and statuses that a particular form of body is expected to occupy, the subjectively experienced relationship between a gendered sense of self and social expectations of gender-role performance, and the cultural mechanisms that work to sustain or thwart specific configurations of gendered personhood. (p. 3)

This quote reflects the many bridges and intersections between the different themes outlined earlier in this chapter. It manifests how transgender studies, too, challenges binary concepts of the gendered body, be it male/female, authentic/real, or constructed/mutable, and instead embraces nature-culture hybrids in which sex-gender is nonlinear, contingent, self-organizing, open-ended, and becoming (Lane, 2016). Further, in studying this intersection between material and discursive, the field is strongly guided by trans people's embodied experiences and knowledges, either elaborated by trans scholars themselves or witnessed and represented by others in an ethical fashion (Stryker, 2006a). Thus the field, as Stryker theorizes, exemplifies the *insurrection of subjugated knowledges*. Coined by Michel Foucault, the term subjugated knowledge encompasses, on the one hand, historical contents that have been obscured and rendered invisible through predominant societal structures, and, on the other hand, a range of knowledges that have been dismissed and disqualified as nonconceptual, hierarchically inferior, or insufficient knowledge. By excavating such buried knowledges and generating new ones from embodied experiences, transgender studies actively intervenes into the common research patterns, *de-subjugating* these *knowledges from below*.

When it comes to medical research, besides highlighting the many discrepancies and health disparities that trans people face within the medical-industrial complex (as I have thoroughly illustrated above) scholars also point to the multifacetedness of trans bodies and identities, illuminating how things can be otherwise, and how maneuvering within the system conceives novel forms of embodiment.

In contrast to the axiomatic construction of transexuality as based on a politics of resentment towards the own body as presented in **section 2.7**, Latham (2016) sheds light on trans men's meaning-makings of their corporeality and the diverse ways their maleness materializes in their sexual narratives. By showing how trans men utilize a range of coordination practices, like mutual exclusion, alignment, or translation (Mol, 2002), and how they materialize and assemble their sexual practices, pleasures and embodiments to achieve maleness in multiple forms, Latham demonstrates how sex-gender is always (sexually) situated. Horncastle (2018), too, opposes an essentialization of the self, and instead prioritizes the political significance of feeling, particularly feeling at home, in regard to one's gender. Their reflection is contoured through Horncastle's own experiences of accessing a mastectomy[14] through the side door, i.e. within the framework of cancer treatment, and thus as a by-product of disease, which they conceptualize as *trans-peripherality*. While this domain offers an opportunity for genderqueer paradigms, living within trans-periherality also brings about invisibility and correspondingly, constant need for burdensome self-advocacy. As Horncastle argues, focusing on feeling in genderqueer subjectivity discpalces the 'big P' politics of difference that is commonly found within queer activism. As it merges the boundaries of politics with "imagination, fantasy, myth, poetry, the unnatural" (p. 254), this *poetics of self* not only offers novel epistemic value, but also functions as a stabilizing and restorative feature of genderqueer and trans-peripheral life. This turn away from the 'big P' is also reflected by Singer (2015), who argues that, while vital for the access to much needed resources, demographic categories can simultaneously act as confining for socially marginalized people. In studying trans-specific HIV prevention public health programs, he demonstrates how restrictive administrative conditions can be circumnavigated through different tactics and mobilization of alternative classificatory schemas. While coming across systemic erasure and exclusionary practices within the examined clinics, Singer observed how these programs made use of vernacular terms and street slang, and thus took into account a more nuanced and intersectional variety of trans-related categories, identity terms, and embodiment practices. He refers to the resulting proliferation of trans visibility as the *transgender matrix*. Further, and in line with the works outlined above, specific medical procedures can have different connotations

[14]Mastectomy is the procedure of surgically removing the breasts.

for different trans people. Irni (2017), for instance, applies a Baradian (2007; as cited by Irni, 2017) approach to conceptualizing the risk of HRT "as a 'phenomenon' that materializes only within the conditions of a certain '[treatment] apparatus'" (p. 109), and is therefore highly contingent on the context. In her study on Finnish trans people's experiences with HRT, Irni demonstrates how the risks associated with the medication is less based on the chemical actions the pharmaceutical substances cause in the body. Instead, her trans participants perceive risk in regard to the lack of, or contradictory, information on the use and side-effects of the pharmaceuticals, or the gatekeeping that is established by the gender binary limiting the access of adequate hormone treatment to individuals not fitting into these categories.

While the outlined studies merely give a glimpse into this rich academic field, they corroborate the significance of agency when studying trans-related subject matter. These articles reflect trans people's own knowledge that they gathered through their own lived experiences. Their stories highlight the manifold ways of countering, of going athwart (Helmreich, 2009) dominant socio-cultural narratives. As so much of this is expressed in Stryker's (2006b) famous essay *My Words to Victor Frankenstein above the Village of Chamounix*, I would like to end this section with a longer quote from it. In her essay Stryker mobilizes this literary meeting between Frankenstein and his monster as a metaphor for a critical confrontation between a radicalized transgender subjectivity and the normalizing gaze of medical science. In doing so, she reclaims the term 'monster' in various ways. Her own trans body is 'monstrous' as it is situated outside the categories deemed natural, but it is also a warning not to get too comfortable within such orders:

> Hearken unto me, fellow creatures. I who have dwelt in a form unmatched with my desire, I whose flesh has become an assemblage of incongruous anatomical parts, I who achieve the similitude of a natural body only through an unnatural process, I offer you this warning: the Nature you bedevil me with is a lie. Do not trust it to protect you from what I represent, for it is a fabrication that cloaks the groundlessness of the privilege you seek to maintain for yourself at my expense. You are as constructed as me; the same anarchic Womb has birthed us both. I call upon you to investigate your nature as I have been compelled to confront mine. I challenge you to risk abjection and flourish as well as have I. Heed my words, and you may well discover the seams and sutures in yourself. (p. 247)

What makes Stryker's words particularly powerful is the way she rechannels the rage and experience of suffering many trans people feel over being made social and natural outcasts

and transforms it into a foundation for self- affirmation, intellectual inquiry, moral agency, and political action. Particularly in the absence of research on trans people and PCOS, it is a vital angle from which to study this case. While medical research produces knowledge about trans people, stereotyping and pathologizing their embodiment, transgender studies emphasizes the significance of their agency and knowledge that ultimately shatters such maginalizing structures.

2.9. Sensitizing: How to tend to the neglected?

Drawing on the themes elaborated throughout this chapter begs the question of how to tend to those who have been neglected, (willfully) ignored, and rendered invisible in the discourse on PCOS. An answer is provided by the strands of scholarly work on care in STS, which notoriously critically upends, and intervenes in such matters.

"'Care' is a slippery word" that comes in multifaceted forms; it is highly context specific, perspective dependent, and attached to a variety of political commitments (A. Martin, Myers, & Viseu, 2015, p. 625). As illustrated by Lindén and Lydahl (2021), care in STS developed from a buzzword, that at some point, had run out of 'buzz', but which has recently begun being embraced again, and which can be attributed, to a not insignificant amount, to the current *COVID* pandemic. From the manifold scholarly work on care, two particular strands can be determined (Lindén & Lydahl, 2021).

The first one, kicked off by Mol (2008), is concerned with the multiple forms of care that come forth in different situated practices, particularly within the medical context. In her eponymous book, she juxtaposes the *logic of care* with the logic of choice, which assumes a neoliberally framed scenario in which the patient, an enlightened and emancipated citizen, is no longer subject to the doctor's paternalistic power. Instead, in a consumer-like setting, the patient can make a free and informed choice from a range of health care services, or 'products', backed up by all the necessary facts and information on their health condition. While sounding promising in theory, this logic is not operable in practice. When engaging in medical treatment, it is neither possible to define a clear-cut, confined product, nor enough to focus on singled-out aspects. Especially when approaching health conditions as multiple enactments which, in turn, involve and interfere with enactments of other objects in the patient's life, it becomes clear that 'facts', target blood values, or treatment methods are highly contingent. How to make an informed choice if so many, partly unforeseeable elements are involved? Further, choice itself is highly contingent because it depends on the patient's ability and resources, be it physical, emotional, or financial, as to whether they can make a (good) choice.

In contrast, the logic of care is not about simply applying scientific 'facts', but rather about finding what works for a specific patient in a given setting. In the face of multiple and entangled realities care is flexible, resilient, and adaptable. Patients are not blamed for having made a 'bad' decision if something goes wrong, but instead their experiences are carefully attended to and treatments are tweaked and fine-tuned according to their needs. And even if in the logic of care the patient is not primarily a subject of choice, they are not at all passive. When living with and tending to their health conditions, patients are involved in all kinds of activities. But in contrast to the logic of choice, they do not have to go about these activities alone. As care practices are shared between different actors involved in the care process patients can simultaneously be taken care of and care for themselves. Care is an ongoing process, an activity that always involves and includes a network of different objects and people.

In tracing the cosmopolitics of care, Schillmeier (2017), too, opposes the bifurcation of care-giver and care-receiver, conceptualizing care as allocated to different actors, thus, being a constantly shifting and contingent process. Within this care network that, while stable in one moment, can change, break apart in the next, humans are *precarious selves*. In spite of the impression this term might convey, precarious selves should not be understood as passive subjects in need of help; in fact, they function as crucial cosmopolitical actors. In order to meet their ever-changing requirements and allow them to live well with and within particular care constellations, environments, and practices, they demand their adjustment, and thus "disrupt and alter the common, normal and taken-for-granted — be it biographical, physical, mental, institutional as well as their diverse interlinking." (Schillmeier, 2017, p. 60). Through constantly challenging prevailing care relations, highlighting their fragility and vulnerability, and thus, requiring them to shift and be adapted towards new constellations, precarious selves unravel learning situations for all the actors involved.

Similar observations on the complex entanglements between carer and cared-for were made in the collective volume *Care in Practice*, edited by Mol, Moser, and Pols (2010), which explored different care situations in order to bring to the fore its multifacetedness. Works in this volume, to give a few examples, show how situations like wheelchair testing require a significant amount of tinkering with the entire arrangement, including not only the technology itself, but also the person in the wheelchair, their closed ones, or their living situation, in order to assemble a care constellation in which all these elements are well adjusted (Winance, 2010). They highlight how, when it comes to caring for conditions like the syndrome of a vegitative state, 'good' care can simply mean moving a person when they need to be moved, how the patients themselves actively engage in

these care practices, be it through exhibiting sweating, mucus production, or muscle spasticity, but also how complex it can be to delineate this fragile line between 'good' and 'bad' care (XPERIMENT!, Kraeftner, Kroell, & Warner, 2010). But these works also emphasize that, in order to ensure a more open and attentive approach to care (for instance when caring for patients through a telecare service) incidents and failure should be regarded as normal, rather than being negated in their possibility (López, Callén, Tirado, & Domènech, 2010).

After having analyzed PCOS diagnosis and treatment through a lens of Foucauldian biopower, Vleming (2018), at the end of her article, argues that in order to obtain a more adequate picture of the lived experiences of people with PCOS "considering practices of caring for the body and self" (p. 507) can be a valuable approach. She, thus, examines different self-care practices of her informants that function as a response to the biopower exerted upon them. While partially taking up Mol's care approach, Vleming criticizes it for obscuring the power relations at play when care is provided or denied. Here, the second important strand in STS work on care comes into play, one that can be summarized as *critical care* (Lindén & Lydahl, 2021).

This line of scholarly work was particularly stimulated by María Puig de la Bellacasa (2011; 2017) who extended Latour's work on *matters of concern* (2004b) to *matters of care* by arguing that, while 'concern' implies thinking with an involvedness into things, care adds a sense of attachment and commitment to as well as affection for a matter. In contrast to 'concern', 'caring' contains a notion of doing, and, for that reason is an ethically and politically charged practice. It "joins together an affective state, a material vital doing, and an ethico-political obligation" (Puig de la Bellacasa, 2017, p. 42), thus, making us care even without being forced to do so by a moral order or policy (Latimer & Puig de la Bellacasa, 2013). Further, care takes into account the prevailing power relations and inequalities, acknowledging that if a concern is not part of a political common sense, it is likely to be ignored and marginalized. Taking up feminist discourses on situated knowledge and standpoint theory, Puig de la Bellacasa (2012; 2017) argues that considering the situatedness of knowledge implies that "knowing and thinking are inconceivable without a multitude of relations that also make possible the worlds we think with" (Puig de la Bellacasa, 2017, p. 69). Thus, care is always relational and interdependent. If one cares for a certain thing, one inevitably cares for a multitude of humans, non-humans, issues, and networks this thing is intertwined with. What is more, such relationalities are not stable, nor do things or beings preexist their networks. Instead, "reality is an active web" (Haraway, 2003, p. 6; as cited by Puig de la Bellacasa, 2017), it is "continuously in the making [and] in the process of becoming" (Puig de la Bellacasa,

2017, p. 72). Hence, how care and affects are brought and positioned into a network also brings along consequences for this network. When caring for something one should always be attentive to what is encouraged, and "[w]hat worlds are being maintained and the expenses of which others" (p. 44) by such care.

Due to this relationality, care is also highly future-oriented. As networks and relationships are not static, but are in constant temporal change, through caring for something we are encouraged to continuously tend to it in order to provide what it needs to thrive within its network (Adam & Groves, 2011). Caring is a speculative commitment, as it is not always possible to know where it can lead to and how it might develop (Puig de la Bellacasa, 2011, 2017).

Further, it would be counterproductive to define in advance what the care for something should look like. Care is not about merely accusing and moralising. Instead, it is about being attentive and responsive to the things one cares for and the relations they are entangled with. In doing so it is important to note that care should not be regarded as an ideal and neutral term, nor should it only be connoted with love (Puig de la Bellacasa, 2011, 2017) or feel-good attitudes (Murphy, 2015). Care is not innocent; it is a consequential practice that can bring about dire effects (Puig de la Bellacasa, 2011, 2017), thus, it has a *darker side* (A. Martin et al., 2015). As Murphy (2015) points out, instead of upholding this narrow and naive notion of care, one should rather be attentive to the hegemonic structures and narratives that are (re-)produced by specific ways of caring, and thus, embrace the discomfort and non-innocence that arises through such critical engagement. Rather than being discouraged by this 'bad feeling' that accompanies conflict and dissent, one should stay involved – *stay with the trouble* (Haraway, 2016) – and embrace its productive incentive to re-create new patterns and relations (Puig de la Bellacasa, 2012, 2017). This also implies reflecting on the things and issues we as researchers care for and decide to ignore, and which values and sensitivities are thus articulated in our research (Felt & Davies, 2020).

Coming back to Lindén and Lydahl's argument, rather than making care a buzzword again, this revitalised interest in care needs to be used as an opportunity to find new ways in thinking with care and being responsive to "the worlds of, and beyond, the pandemic and its accompanied crises." (2021, p. 8). They suggest employing a *double vision of care* that "is both situated and critical, staying with the practices, specificities and potentialities of care while simultaneously critically interrogating those practices when needed" (ibid., p. 8).

Notably, among the strands of feminist research on care, trans care practices remain relatively invisible (Seeck, 2021). But especially in trans and queer contexts, be it within

activism or self-organized peer groups, such practices of care act as a crucial element in closing the gaps of institutional care (Seeck, 2021; Seeck & Dehler, 2019). As Malatino (2020) writes, the "queer and trans care web has no center, but in some significant ways it has emerged because of the way the normative and presumed centers of a life have fallen out, or never were accessible to or desired by us in the first place" (p. 2). Rooted in transgender studies, his book *Trans care* critically inquires into the ways trans practices of care themselves run the risk of reproducing hierarchies of attention and deservingness, and how, in order to ensure trans survival and flourishing, care needs to be radically reconfigured beyond normative orders and kinship constellations.

Drawing on Puig de la Bellacasa's theorization of care, Seeck and Dehler (2019), too, highlight how not only institutionalized medical trans care is unsupportive and violent, but also how internalized transmisia, shame, and re-production of norms can further exacerbate uncare. Exploring collective and non-institutionalized care work as done by trans activists, friends, and peer groups, the authors illustrate how overcoming such internalized norms, dismantling dichotomies between carer/cared-for, and emphasizing the community as a crucial element of mutual support, guarantees more robust and embracing trans care relationalities.

This research is further extended by Seeck (2021) in the book *Care trans_formieren* (trans_forming care), where the author conducts a *caring ethnography*[15] within different contexts of non-institutionalized trans care work. The premises of this approach are the blurry lines and the fragile hierarchies between the giver and receiver of care. As a queer researcher, Seeck becomes part of the studied field and gets entangled into mutual caring relations. Throughout the fieldwork, be it getting a haircut at a queer barbershop, partaking in caring exchanges at the kitchen table, or witnessing endeavours to open up a queer/feminist retreat center for burned-out activists, Seeck encounters different forms of care, encompassing *self-care*[16], *care-for*[17], their entanglement expressed in the term *self-caring care-for*[18] or *care_for*[19], paid and unpaid *care work*[20], as well as *community*[21] or *collective*[22] care, and explores how the boundaries between these types of care are in constant flux, continuously re-configuring the caring roles and relations.

[15] "Sorgende Ethnographie" (Seeck, 2021, p. 35)
[16] "Selbstsorge" (Seeck, 2021, p. 19)
[17] "Fürsorge" (Seeck, 2021, p. 19)
[18] "Selbstsorgende Fürsorge" (Seeck, 2021, p. 19)
[19] "Für_sorge" (Seeck, 2021, p. 19)
[20] "Sorgearbeit" (Seeck, 2021, p. 19)
[21] "Community-Care" (Seeck, 2021, p. 20)
[22] "kollektive Fürsorge" (Seeck, 2021, p. 20)

2.10. Devising: Outlook for this research

As thoroughly elaborated in this chapter, the (STS) research my project is embedded in is attentive to rejecting the stable, the fixed, the objective and the static, and instead is concerned with embracing the multiple, the open-ended, the complex, the situated and the contingent. From these various strands of literature four major gaps can be identified in regard to the research case studied in this thesis.

First, although the presented scholarly work offers an excellent lens for studying such an uncertain, highly debated, and slippery object as PCOS, little social science research has been conducted in regard to this topic.

Second, as pointed out in this chapter, matters and meaning-makings of trans people, especially related to issues going beyond trans-specific medical care, are relatively understudied in STS. This is particularly unfortunate, as STS offers the suitable theoretical and methodological tools to upheave and draw attention to the knowledge of those situated outside of institutionalized contexts of knowledge production, while simultaneously indicating and unsettling prevailing relations of power.

Third, comprehensive research on trans people's meaning-making of PCOS is virtually non-existent. As medical discussions on both trans people and PCOS-bodies are deeply rooted in norms on sex-gender, health, and the body, an approach sensitized to their materialization within socio-cultural and techno-scientific context is more than appropriate to fill in this identified gap.

Lastly, STS literature on trans care practices is relatively scarce. This lens, however, offers a valuable approach for highlighting those elements marginalized by dominant discourses, as well as intervening in such.

3. Approaching: Research Question

In the previous chapter, I have provided a detailed framing of my case study within the current research environment, as well as identified the gaps in the existing literature. The following chapter is concerned with the research question and sub-questions through which I approach the field in order to contribute to these strands of scholarly work and fill in the described gaps.

In consideration of the current tensions in trans-focused PCOS medical care touched upon in **chapter 1**, as well as the case's intellectual scaffold erected in **chapter 2**, the objective of this research project is to shed light on trans people's knowledge on and lived experiences with PCOS, and thus, strengthen their voices, voices that commonly tend to be ignored and silenced within this discourse. My ambition is to provide a point of departure for a conversation on a syndrome that is so tightly intertwined with gendered standards of health/illness, a point of departure from the perspective of those who already transgress the boundaries of what is considered to be the norm in regard to gender. Therefore, I enter this case through the research question:

> *(RQ) How do trans people enact PCOS, and what does that tell about care for their bodies within the framework of standardized medical practices?*

As will be further elaborated in **chapter 4**, I approach this question through a lens combining ontological politics, situated knowledge and theoretical frameworks on care, thus tending to the multiple realities of PCOS, while specifically illuminating those of trans people living with the syndrome. While studying the enactments of PCOS, my concern is particularly targeted at three aspects, the first one focusing on the question:

> *(SQ1) How do trans people make sense of PCOS?*

As the wording already implies, I intend to gather insights into trans people's lived realties with regard to PCOS. What is PCOS according to them? What is an issue and what is not? How do they narrate their experiences with PCOS, and how do they situate themselves into this diagnosis? What does it mean to have/ live with/ get diagnosed with PCOS? It is important to note that I do not intend to present the findings from this

sub-question as a singular reality applying to all trans people. Instead, by employing the lens of ontological politics, multiple, sometimes even contradicting realities that vary from individual to individual can be brought to the foreground. Of course, some consistencies might be noticeable, but not only.

However, such enactments do not exist in vacuum. When people interact with others, seek medical help, when they undergo a certain treatment, or even when they research the internet for advice, they encounter differing enactments of PCOS. What happens when such enactments meet and how this matters is what I study by the second sub-question:

> *(SQ2) How do their meaning-makings interact with medical conceptualizations of PCOS?*

By 'medical conceptualizations' I mean the various ontologies of PCOS trans people come across when seeking medical consultation, diagnosis, or treatment, or other encounters within the medical context. By 'interaction' I address the practices and events of coordination, distribution, separation, inclusion, or clash which Mol (2002) describes in her study, and which will be explained in the following chapter. Hence, I delve into the ways my participants coordinate the differing enactments of PCOS to 'make them work' in accordance to their own narrative meaning-making of their bodies and identities. By doing so, I investigate whether there are some consistencies and whether these are actively sought and highlighted, whether inconsistencies between enactments can coexist, whether they are separated, or whether enactments are incommensurable and clash. Further, my inquiry is targeted towards the ways medical enactments of their bodies interfere with their sense of identity.

Ultimately, this question explores what it means that other people have (differing) enactments of PCOS and how this matters for the participant. While appearing rather broad at first glance, it is still centered around trans people's perspectives on the case, because it focuses on how they perceive the medical enactments they encounter and what tensions and frictions might come along with such interactions.

Lastly, I intend my research to be not only descriptive, but also productive. As Mol argues, different enactments bring along different ontological consequences. What such ontological consequences would entail in the case of trans people's enactments of PCOS is studied by the third, and last sub-question:

> *(SQ3) How do trans people care for PCOS, and what do they consider 'good' PCOS-care?*

Rather than 'treatment' I deliberately chose to focus on 'care' and the theoretical

conceptualizations connected to this term, since it entails so much more than just treating a set of symptoms. While treatment can be a part of care, not everyone necessarily wishes for their PCOS body to be treated, not all symptoms might be regarded as requiring treatment, and maybe only specific aspects are wished to be managed. Further, maybe there are other things beyond treatment that my trans participants wish from their medical practitioners. The term 'care' encompasses all these aspects and more. Essentially, this sub-question focuses on trans people's ways of living and dealing with PCOS. What does it require and entail to care for their PCOS body? What needs to be done about it? What is an issue that needs care, what aspect needs to be left alone? Further, this question captures their own coping strategies they developed to manage both unpleasant PCOS symptoms, and pathologizing views on their bodies.

In summary, this project investigates trans people's meaning-making of PCOS, their interactions with medical understandings of the syndrome, and their ways of living with PCOS as well as their envisionings of what is needed to foster a PCOS care inclusive of their needs, wishes, and embodied identities. Notably, it is not my intent to answer these three sub-questions in a clear-cut manner. In fact, as will be observable in **chapter 6**, it is not possible to clearly separate them from each other. Rather, they serve as the main points of inquiry in the exploration of my overarching research question.

4. Glancing through: Sensitizing concepts

My theoretical lens, the lens through which I look at my case consists of a combination of ontological politics, feminist inquiries into situatedness of knowledge, and STS conceptualizations of care.

Mol's (2002) framework, as outlined in **section 4.1**, helps me to examine the multiple realities of PCOS and their implications for the people and objects involved in different enactments. Her logic of care (Mol, 2008), introduced in **section 4.2**, further sheds light on the day-to-day practices participants, their medical practitioners, and other people close to them are involved in while tending to their body-minds. Moreover, Haraway's (2001 [1988]) situated knowledge and Puig de la Bellacasa's (2017) critical lens on care sensitize me, as described in the same section, towards prevailing power structures and the limits of care practices, while giving this study an interventive character. Further, these frameworks draw attention to my own situatedness into the case as well as the risks my own care brings along as reflected in **section 4.3**.

4.1. Seeing the multiple: Ontological politics and coordination practices

As already outlined above, Annemarie Mol's framework of ontological politics theorizes the ontology of an object as actively created, or enacted, through the multiple practices by which it is handled, talked about, interacted with, or classified, thus, resulting in the enactments of multiple realities of one and the same object.

This also holds true in regard to disease, as demonstrated by her ethnographic inquiry into diagnosis, management, and treatment of lower-limb atherosclerosis at different sites of a Dutch hospital (Mol, 2002). At one site, for instance, at the vascular surgeon's consulting office, a patient complains about lower-limb pain when walking their dog, which is alleviated again after having rested for a while. Through the conversation between the doctor and patient, intermittent claudication, an early stage of atherosclerosis is enacted.

Before consulting the surgeon, the patient did not have this condition as it was just a nebulous pain. Additionally, the doctor might examine the patient's legs by feeling the pulsation in their arteries. If the pulsations are weak, and the patient has cold feet, and thin, poorly oxygenated skin, what has been a vague idea of intermittent claudication becomes "extended and strengthened" (Mol, 2002, p. 25) through this cooperation of doctor and patient. In the pathology laboratory, however, things are different. Here a piece of an artery is cut out of an amputated foot, and embalmed with preserving fluid by the pathologist. Afterwards, it is decalcified, sliced into thin sections, and fixed onto glass slides by the technician preparing it to be examined under a microscope. All these steps eventually lead to a different atherosclerosis as the one in the example given above. It manifests itself through a furred artery with a thickened intima. It is atherosclerosis enacted under a microscope.

The two cases demonstrate how at each site, atherosclerosis becomes a different object. Each practice and each form of diagnosis leads to a different version of the disease without necessarily revealing characteristics of a pre-existing object (Michael, 2017). They do not necessarily need to align. A patient might not experience each typical symptom of a disease and results obtained by a certain diagnostic technique might not match expectations (Mol, 1999). Hence, there can be "different versions, different performances, different realities" of a disease "that co-exist in the present" (ibid., p. 79). These versions might hang together, coincide, complement or influence each other, get in conflict, or clash (Mol, 1999, 2002).

However, since diagnostic decisions still need to be made, a consistent picture has to be created through *coordination practices*. Along with such coordination practices different enactments are negotiated, added up, or translated into "[a] patchwork singularity [of] the disease-to-be-treated of a specific patient. A *composite reality* that is also a judgment about what to do" (Mol, 2002, p. 72, emphasis added by the author).

In the most straight-forward case, different enactments, for instance in the form of different diagnostic techniques, *coincide* with each other and fuse into a common, singular object. Since this is rare, other coordination practices need to be applied. For example, in order to decide what treatment approach would work 'best' for the patient, different enactments (e.g. those stemming from the social aspects of a disease) might be *added* to the medical enactment. Likewise, enactments and practicalities, such as specificities of the patient's body, conditions of a diagnostic measurement, or aspects that came up during the clinical interview, can be *unbracketed* from an enactment, which, again would result in a single object. In cases like these, one reality wins over the other(s) and a *hierarchization* is established. Commonly such hierarchization takes place when different enactments

do not coincide, but instead contradict each other or do not fit together. If differing enactments fail to be coordinated into a single one or if they are simply incommensurable, it comes to a *clash*, which sometimes can have detrimental consequences. For instance, this is illustrated by Mol's example of a patient's sudden death, who, while appearing completely healthy when alive, was retrospectively diagnosed with severe atherosclerosis during the autopsy.

However, "[s]ometimes the incoherences between different [enactments] aren't smoothed away. They are lived with" (Mol, 2002, p. 87). In order to avoid a clash, competing enactments are *distributed* over different localities, for instance, over different hospital departments. Different versions of a disease can be treated at the same time in the same patient, or enacted independently in each individual, thus, giving each variant a site of its own.

Nonetheless, this is not a straight-forward endeavor. That is to say, multiple enactments are reciprocal, intransitive, and interdependent. They can not be ranked from small to large or rigidly stratified. Objects can contain one another, have circular dependence, and at the same time, still be incompatible in certain ways. Here, practices of *inclusion* take place. As Mol describes, such inclusion can be manifested by a constant switching between different enactments, such as in the case when a doctor examining a patient continuously switches between their arteries and the patient themselves as an object of focus. But they can also be situated next to one another, like it is in the pathology lab, where a corpse is dissected, thus being an object of study, while simultaneously its humanity and dignity are maintained through practices like putting a cloth over its head, or cleaning it up after the autopsy.

Such cases manifest the intricacies of the interaction of different enactments. As there are no stable elements, everything involved in an enactment is simultaneously also enacted by certain practices. Every object, every actor, from patient, to artery, to surgical knife is multiple. Enactments, thus, *interfere with* and shape one another.

And this is where the 'politics' of 'ontological politics' comes into play. For the interferences of different enactments have actual implications for people's lives. How a disease is enacted determines which treatment and care a patient receives, and it even brings along with it consequences for their identity. If, for instance, atherosclerosis is enacted as a result of an unhealthy lifestyle, the patient might become accused of being irresponsible, which is not the case if the enactment assumes a genetic predisposition. As enactments "carry modes and modulations" with them, other realities are always involved (Mol, 1999, p. 81).

The outlined theoretical lens provides a toolkit equip to examine the multiplicities of

PCOS and other objects linked to its enactments, such as the body, sex-gender, health, etc. In my analysis I utilized it to delve into the participants' coordination practices to handle such multiplicities and create a composite picture fitting into the theme of their narrative. Here, I particularly focused on questions of why participants need coordination practices, how such practices matter, what interferences and clashes are to be avoided, as well as what new interferences arise. Further, I applied these tools to compare the enactments of different participants in terms of how PCOS is multiple considering the different accounts, what it implies for treatment and care of PCOS, how it affects PCOS as a 'whole' and what should be considered if we want to coordinate PCOS (care)?

Indubitably, coordination practices are also important when it comes to the interaction of participants' enactments of PCOS with those of medical practitioners. Here I was particularly interested in whether there are consistencies that mutually support each other, or whether such consistencies are actively sought and highlighted during the doctor-patient interaction? Are inconsistencies allowed to co-exist through practices of separation and distribution? Or are there enactments so incommensurable that they can do nothing but clash? And what interferences do such interactions bring along? What does it mean for the patient if their medical practitioner enacts PCOS, or even their identity as a trans person in a different way?

4.2. Positioning: Bringing in situated knowledge and care

Since there are multiple realities of one and the same object, the question arises how to know which ones should be granted more weight? While touching upon this question, Mol (1999) leaves it open in her essay. In my research design, the strands of feminist technoscience provide me with an answer, as my research focus is directed at those whose realities are commonly silenced and made invisible. By applying this lens, I, hence, favor the situated knowledge of my trans participants.

Through this theoretical lens, I witness my interlocutors' knowledge, experiences, and the enactments brought into being through their own accounts. This lens is not solely theoretical, but also methodological. It sensitizes me to the diverse ways how people are situated in the narration of their experiences, from what standpoints they speak, and how this is articulated in their stories, be it through categorization work, references to presumably shared images, or the conveyance of emotions. The refusal of self-invisibility of the knower in the knowledge-making process that is emphasized by feminist frameworks focusing on situatedness (Haraway, 2001 [1988]) is crucial here, as the listed aspects always take place in relation to me as the researcher.

The framework of situated knowledge perfectly blends in with the theoretical lenses of care I implement in my approach.

On the one hand, I strongly build my inquiry on Mol's (2008) logic of care. As she argues, there is no ultimate definition of 'good' or 'bad' care. Instead, we need to tell stories and share cases in which care practices come forth in order to learn from them and improve our care. Thus, through this lens I am attentive to the day-to-day practices of tending to PCOS that came to the fore in my interlocutors' accounts, be it their self-care approaches or the care they received from others.

In combination with ontological politics, this framework also raises awareness of the inseparable entanglement of enacting the ontology of PCOS and caring for it. Tending to PCOS in a certain way simultaneously brings about a specific reality, and enactments of PCOS also imply what needs to be done in order to care for the syndrome. Therefore, in my elaboration of the results, I refrain from speaking about "PCOS" and "PCOS care" as two separate entities, and use the term *PCOS-care* instead.

On the other hand, Puig de la Bellacasa's (2017) lens on care makes up for the lack of attention to power dynamics and standpoints in regard to gender, class, race, etc., that is voiced by Vleming (2018) as a critique of Mol's framework. In her appeal to tend to practices, things, and people that have been devalued, taken for granted, or rendered entirely invisible, Puig de la Bellacasa – building on Haraway's work – features power as a key part in her argument. Similarly to Haraway's point, being attentive to neglected human and nonhuman subjects can expand our understanding of science, technologies, and the different networks they are entangled in. In this particular case, drawing ontological politics, situated knowledge, and care together, offers an insight into the different activities and practices trans people go about to care for PCOS. It sensitizes to being attentive to all the actors, elements, and relations that are part of these care practices. Ultimately, focusing on this neglected perspective sheds light on how things can be otherwise to the dominating discourse on PCOS.

There is, however, more to it than mere theoretical interest. According to Puig de la Bellacasa it is not only about producing 'more accurate' knowledge, but also about actively generating care for those "participants and issues that have not managed or are not likely to succeed, or even do not want to voice their concerns, or whose voices are less or not perceptible" (2017, p. 57). Care, thus, always comes with intervention. The ambition of my master's thesis was to include this interventive character and incite a discussion on how 'good' care for trans people and/or PCOS could look like. Drawing on participants' enactments of PCOS-care, I examined what practices and activities should be included and who and what should be part of this network of care, how alternative

care practices are envisioned in light of health care disparities, as well as what people need, wish for, or imagine in a particular situation. Undoubtedly, as already mentioned above, there is no definitive answer to such questions, but, as Puig de la Bellacasa argues, it is rather a speculative commitment of thinking about how things could be otherwise if they generated care. Therefore my question regarding 'good care' aims at stimulating speculation about what worlds and relationalities should be created to foster an inclusive, adaptive, and resilient PCOS care, also in light of an unforeseeable future.

At this point it is important to note that care can never be practiced from an 'outside' position. Care is an involved, affective activity and mode of knowing that conveys a strong sense of attachment and commitment. Thus, as a researcher, one is also always involved in one's case. This, on the one hand, has the potential of being a productive source of inspiration that improves the quality of our research, and ultimately serves as a means of "re-affecting an objectified world" (Puig de la Bellacasa, 2017, p. 64). On the other hand, care is a consequential practice that can bring about dire effects. Therefore, a major element in Puig de la Bellacasa's framework of care is being reflexive about one's own situatedness in the case, and paying attention to the implications and potential pitfalls of one's own care.

4.3. Stirring up: Unsettling my own categories, situatedness, and care

In line with the critical nuances of care as outlined in **section 2.9**, this section is concerned with unsettling my own research by reflecting on my use of the term 'trans', the pitfalls of my own care, as well as my position as a non-binary researcher.

Among the different cissexist pitfals Johnson (2015) emphasizes to avoid in the framework of a transfeminist methodology (as elaborated in **subsection 5.2.1**) are the objectification and overgeneralization of trans people. Gender is not a stable, fixed, and delineated category, but instead multifaceted, nuanced, and fluid, and can be regarded as "porous and permeable spatial territories" (Stryker et al., 2008, p. 12). While the term 'trans' describes people who do not identify with the gender they were assigned at birth, it is both multiple and evolving and encompasses a vast variety of multidimensional individuals who, aside from their gender-diverse bodies, practices, performativities, and identities, otherwise might have little in common (Labuski & Keo-Meier, 2015). Further, not everyone who is not cis might identify with the label 'trans', and instead use other self-assigned labels to describe their gender identity (Thompson & King, 2015).

In this thesis I try to keep the term 'trans' as open as possible, using it as an umbrella term for everyone who does not identify with their gender assigned at birth, be it within the spectrum of binary or non-binary gender, or something completely beyond these spheres. Keeping the term open offers the possibility to combine it with other terms indicating individual labels (e.g. transgender, trans non-binary, transfluid etc.) (Appenroth & Castro Varela, 2019). For my interview sampling, this means that everyone who feels addressed by my call for participants is welcome to take part in this research.

Having said that, awareness of the pitfalls of my research needs to be raised. For, by studying the lived experiences of 'trans people' I run the risk of reproducing the very trans exceptionalism criticized in **subsection 2.7.1**. While trans and cis people share a range of bodily and lived experiences (Labuski & Keo-Meier, 2015), singling trans people out as a distinct group can lead to their construction as *other* (Spivak, 1985) than cis people. Further, it is important to note that gender identity is not the only aspect shaping one's experiences (within the medical system). Being trans can have multiple intersections with other domains (Stryker et al., 2008). Focusing on gender as the sole variable in sampling comes with the risk of obscuring the complexities of biosocial bodily experience (Labuski & Keo-Meier, 2015).

As such, I am by no means implying that trans people have entirely distinct experiences and conceptualizations of PCOS-care than cis women. While differences certainly exist, especially in terms of systemic oppression, there are as well similarities since 'cis women' is not a homogenous category either and femininity can be expressed and experienced in various shades. However, following Puig de la Bellacasa's notion of care, my ambition in this thesis is to highlight these eminently neglected positions and give them space in this thesis. Therefore, my aim in regard to this study is to shed light on what we can learn if we look at this neglected group of actors in a large network around the matter of PCOS. Such insights might not only teach us about how to care for trans people with PCOS, but also PCOS in general, and what a more *care-ful* approach to PCOS, that is inclusive of multiple realities and positionalities, can look like. Further, I mobilize my theoretical and methodological tools to avoid an isolated view on my case and instead take into account and be reflexive of positionalities that go beyond or intersect with gender.

In doing so, reflexivity on my own position as researcher is indispensable. As a non-binary person, I have a certain understanding of how to adequately talk to, and write about trans people. I am, for instance, through my own experiences, sensitized to common cissexist pitfalls (Johnson, 2015), and hence am less likely to reproduce them. Further, living in a PCOS-body makes me attentive to what aspects in regard to this topic might be important to study in more detail. Concerning the interview

process, my shared experiences with my interlocutors also contribute to the creation of a more familiar atmosphere. Ultimately, this project is another small fragment in the range of contributions emphasizing the knowledge and agency of trans people themselves. While the gaze on my body is skewed and normativizig, I am resisting its confinement by highlighting viewpoints that unsettle its prescribed order. I am mobilizing my own embodiment of, attachment to, and involvedness in this case in order to raise up the knowledge of those sharing certain lived experiences with me. Thus, I am taking a small step towards the insurrection of subjugated knowledge (Stryker, 2006a) of our lived experiences with PCOS.

Nevertheless, it is important to be aware that my involvedness in this case also brings about certain risks. As already said, there is no such thing as *the* trans experience. We all come from different backgrounds and live with different struggles and privileges. Although I might share experiences with my participants, as a researcher, I am still in a position where I can inflict harm upon them, especially since interactions with the medical system can be hurtful and traumatic. Further, there is the likelihood of me projecting my own assumptions onto my interlocutors' stories. Participants might not go into detail in some aspects assuming that I already know what they mean, and likewise, I might run into the risk of asserting too much interpretation to an answer, thus rendering certain nuances of their stories invisible.

While I endeavor to reduce the possibilities for harm and othering as much as possible in my research design, it cannot be obscured that, like every product of science, my thesis, too, is an artifact – and it definitely has politics (Winner, 1986). As A. Martin et al. (2015) write, "[c]are is an affectively charged and selective mode of attention that directs action, affection, or concern at something, and in effect, it draws attention away from other things" (p. 635). And caring for something or someone does not mean that your care is immune to inflicting harm (Puig de la Bellacasa, 2017). It is therefore crucial to be aware and keep unsettling the various forms of othering, neglect and uncare re-produced by one's study. Especially since this master thesis is merely a small fragment in the inquiry into (trans experiences of) PCOS, it is vital to keep stirring up the waters and keep the conversation going. A first step into this direction is made in my discussion of my findings in **chapter 7**.

5. Getting involved: Methodological approach and empirical work

Having reflected on my theoretical lens above, this chapter provides a detailed account of my methodological approach. To obtain my data, I conducted qualitative face-to-face interviews by means of a semi-structured narrative approach sensitized by (trans-) feminist methodology. The gathered material was coded by a grounded theory lens, and subsequently analyzed applying Clarke's (2005) situational analysis.

A brief outline of my initial steps in **section 5.1** is followed by two main parts. The first part, presented in **section 5.2**, consists of a reflection of my field work process, encompassing choice of interview approach, sampling, preparation, conduction, and transcription. Subsequently, my analytic process, including coding, ordering into situational maps, categorizing and theming the obtained data, will be described in **section 5.3**.

5.1. Kicking-off: Exploratory document analysis

In an effort to immerse myself deeper into the topic and obtain a more thorough and encompassing overview of its different angles and elements, I conducted a very raw document analysis of forum conversations on *Reddit*.

Accordingly, I searched the entirety of the website for the keywords "trans", "trans man", "transgender", "transmasculine", "transmasc", "afab", "ftm", "non-binary", "nonbinary", "enby", "agender", "genderfluid", "genderqueer" in different combinations with the terms "PCOS", "PCO", and "polycystic ovary syndrome". This search yielded 29 posts from five different Subreddits[1] which either serve as discussion and communication spaces specifically for trans people, or PCOS. While going through the collected material, I noted down my first impressions into a messy situational map (Clarke, 2005). Along this process, I discarded posts which had no or only a few answers, or were thematically too similar to previous ones. Eventually, I ended up with six posts which I selected for further coding.

[1] "r/ftm", "r/asktransgender", "r/NonBinary", "r/PCOS", "r/childfree"

I coded the material by means of inductive coding, mostly relying on process and in-vivo codes, and along the way, again, placed them into a messy situational map. Subsequently, to obtain a better overview of the different elements at stake, I decided to sort the codes into overarching themes. To do this, I, again, created a map. However, this time I traced the relations between different elements by connecting them with each other. Based on this map, I carved out different research angles that I considered interesting for further exploration through qualitative interviews. As a means to avoid embedding them too deep into my assumptions and interpretations, I formulated these research angles as questions. The results served as a guidance for formulating interview questions and designing the structure of the questionnaire.

5.2. Diving in: Qualitative interviews

5.2.1. Approaching through stories

A crucial aspect to consider in my methodological choices was that the applied tools allow me to grasp the ontological multiplicity of participants' experiences. Mol (2002) conducted an ethnography in an outpatient clinic closely observing medical examinations, analyses, and consultations between doctors and patients. However, as this is not feasible in the framework of a master thesis, I have to rely on the accounts given by the interview participants.

Thinking with Mol, people's stories can be listened to "as if [they] were [their] own ethnographer[s]" who "tell you about events" (2002, p. 15; p. 20). Interview participants do not simply reveal their perspectives, but also illustrate how living in their bodies is done in practice. Through listening to their accounts "an illness takes shape that is both material and active" (p. 20) – it is an act of doing illness. Thus, interviews have the potential to foreground how people enact PCOS. To access a more vivid picture of the events participants have lived through (Mol, 2002) and thereby get a hold of the different actors, objects, practices, emotions, interaction, etc. involved, I chose a combination of semi-structured and narrative interviews.

Through the practice of narrating "a teller [...] takes a listener into a past time or 'world' and recapitulates what happened" (Riessman, 1993, p. 3). Usually, narratives are structured chronologically or episodically (Riessman, 1993) and "connect events in a meaningful way for a definite audience, [...] thus offer[ing] insights about the world and/or people's experiences of it" (Hinchman & Hinchman, 1997, p. xvi). In essence, narrative interviewing aims at reconstructing social events from the participant's perspective as

straightforwardly as possible (Jovchelovitch & Bauer, 2000; as cited by Bates, 2004). As the plotlines of their stories extend through time and space (Sharf, Harter, Yamasaki, & Haidet, 2011), different events and feelings confronting everyday life are alleviated, or at least made familiar (Jovchelovitch & Bauer, 2000). Focusing on narratives, hence, offers insight into different events of the participant's life with PCOS, such as the time pre-diagnosis, their past with exploring different treatment options, their reflection on such events in the present, or their outlook into the future. Throughout the story, the narrator brings the listener to different sites, such as their home, the doctor's office, or the public sphere. Moreover, different characters and their relations with one another are featured (Harter, 2009) and an "account for [...] motives, points of orientation, plans, strategies and abilities" (Jovchelovitch & Bauer, 2000, p. 60) is given. Consequently, a narrative approach affords insight into different sites, settings, conversations or interactions encompassing a variety of actors, objects, or discourses.

Nevertheless, it is crucial to beware the 'fetishism of words', i.e. refrain from treating the participants' accounts as an 'authentic truth' without acknowledging the constructive dynamics that take place along the interview process (Miczo, 2003). Firstly, paraphrasing Riessman (1993), telling a story is an act of representation. Rather than simply mirroring reality, "storytelling inevitably involves selectivity, rearranging of elements, redescription, and simplification" (Hinchman & Hinchman, 1997, p. xvi). Further, as touched upon above, a narrative is always told to and, thus, highly contingent on a particular audience. Whilst telling about personal experiences the narrator inevitably creates a self shaped by how they want to be perceived and known by the listener (Riessman, 1993). Additionally, the informed consent, the context and setting of the interview, the questions and probes, and various other metacommunicative norms are involved in structuring the conversation (Miczo, 2003). Secondly, putting it in the words of Sharf et al. (2011): "No story is solely personal, organizational, or public; personal stories cannot escape the constraints of institutional interests, nor are they separate from cultural values, beliefs, and expectations." (p. 38). Thus, personal narratives are always deeply entrenched into master narratives that arise from and exist within wider culture (Sharf et al., 2011). Identifying such master narratives can be beneficial for elucidating their role in trans people's meaning-making of PCOS and its care. Lastly, it is important to note that this 'ethnography' primarily features the participant's perspective. Because there is choice in what is noticed and what is filtered out, attending an event already is a level of representation (Riessman, 1993). Especially when telling about undergoing a medical procedure, patients can be 'bad' ethnographers as they do not necessarily have the vocabulary to articulate its specificities, or they do not remember its details due to being under influence of anesthesia (Mol,

2002). On the other hand, as informants "describe an event(s) as they saw it, in their own language, using their own terms of reference, and emphasizing actions or participants which they regard as being significant" (Bates, 2004, p. 16), they manifest how they construe, perceive, and make sense of what happened. Thus, narratives emphasize the subjective experiences and interpretations of the storyteller rather than revealing 'objective truth' (Miczo, 2003).

This goes hand in hand with a feminist interview approach which particularly aims at gaining insight into people's subjective, lived experiences of a given situation or set of circumstances (Hesse-Biber, 2007). Combining both approaches, ultimately, gives access to participants' situated knowledge, as well as their counternarratives to "widely accepted truths" (Mutua, 2008, p. 132) about their bodies and lives.

However, as Johnson (2015) argues, to "engag[e] with the multiplicity of lived experiences of transgender people" (p. 25), one should be cautions not to stumble into common cissexist pitfals and thus reproduce authority over them. Such cissexist pitfalls include ciscentricity (i.e. understanding and reconstructing the world from a cisgender perspective), cissexist double standards (such as highlighting the experiences of trans people as exceptional while leaving cis people's experiences unquestioned), as well as objectification and overgeneralization of trans people. Since many feminist approaches do not take these aspects into acctount (Johnson, 2015), I chose to employ a transfeminist lens, not only in terms of my interview approach but also in terms of my overall methodology.

5.2.2. Sampling

My strategy to obtain access to potential participants consisted of three approaches. First, I got in touch with different LGBTQIAP+[2] institutions, organizations, and initiatives in Germany and Austria asking for their support in spreading the word about my project. However, while some of them replied and were eager to help with my research, this approach did not prove to be particularly fruitful.

The next step was asking for participants via Twitter. Fortunately, I gained a solid number of retweets, and received several messages from people expressing their interest in taking part in my research. For my third approach, I posted a call for participants into different Facebook groups serving as community spaces for LGBTQIAP+ people in Germany and Austria, while asking the group admins for permission to share my post beforehand. After exchanging messages with potential informants and providing them with further information on the interview process, six people agreed to participate. Since,

[2] lesbian, gay, bisexual, trans, queer, intersex, asexual, pansexual/ polysexual, and other sexual/ romantic orientations, and genders

as elaborated above, the project aims at understanding the processes of how trans people make sense of and navigate through a cis-normative medical system, rather than making generalizations about trans people with PCOS, this smaller sample size is absolutely adequate within the framework of a master thesis (Hesse-Biber, 2007). While I intended to recruit participants both from Austria and Germany since I am familiar with the medical systems of both countries and they are relatively similar in regard to trans-specific medical care, the participants eventually agreeing to partake in my study ended up to be all from Germany, which is why I limited my focus to this location.

While searching for participants online proved as successful, it certainly comes with its limitations, particularly in terms of demographic. For instance, since only people using social media can be reached it automatically targets people with a certain amount of technology literacy, and thus likely privileges a certain age group. Further, many Facebook groups are focused on specific regions and larger cities, which again narrows the background of potential participants.

5.2.3. Preparing

To give participants enough time to go through all conditions in detail, I sent the letter of consent in advance via email. Each participant was asked about their preferred date, time, and platform for the online interview, as well as form of compensation.

As described above, the interview guidelines were designed according to the findings of my perfunctory document analysis. An example interview guideline in Germany and English can be found in the Appendix.

Further, I reflected on my own experiences as a non-binary person with PCOS by writing them down in the form of a chronological narrative. While writing, I tried to describe specific situations, encounters, and related thoughts I remembered as detailed as possible. After finishing my narrative, I closely read through each section describing a particular event or thought and noted down all impressions and aspects that I considered interesting from the perspective of my research question underneath in bullet points. The aim of writing my story down was to develop a stronger awareness of my experiences and perspectives and, thereby being able to delineate them more clearly from my participants' narratives, and retain them from tacitly slipping into my analysis. This personal queer PCOS narrative was continously updated as I remembered more events and details along the entire research process.

5.2.4. Conducting

Due to the global *COVID* pandemic of 2020 it was not possible to meet participants in person, especially as all are from different parts of Germany. Consequently, interviews were conducted by means of *Zoom* and *Skype*. In total, I conducted six interviews.

To ensure the participants' anonymity, pseudonymization of their names was key. In order to avoid potential correlation with any nickname or username used by the participants in other contexts, and thus risk their identification, I decided to chose the pseudonyms myself. However, it is important to note that chosen names can be a vital source of empowerment and resistance, strengthening one's (gender) identity, and even act as a way to distance from trauma (Kinney & Muzzey, 2021). As several of my participants had chosen their names themselves, I did not want to take away these elements by assigning them a name that potentially diverges from their gender identity. Therefore, I decided to appropriate Schmidt's (2021) approach of randomly assigning tree names to my participants, since they are relatively ambiguous, while still being personal and memorable. The pronouns and gender labels by which I refer to my interlocutors are their own.

My participants were Rimu, and Oleander, who both are trans men, Ash, who refers to themselves by non-binary or transmasculine, Aspen who uses the label 'de-trans' as a political statement[3], Spruce, a trans non-binary person, and Elm, who has not found a fitting label yet but describes the own gender identity as located somewhere beyond the binaries. The participants' ages ranged between early twenties and mid thirties. While most were based in urban areas, some participants had experiences living within the rural area. Ash had experience with migrating between Ukraine, the US, and Germany. Two of the participants are currently undergoing HRT and two have done so in the past.

The interviews were audio recorded and lasted between 50-90 minutes. The *Zoom* interviews could easily be recorded through the program's built-in function. However, since *Skype* does not feature an option to only select the audio track, and immediately upon recording uploads the video file into its chat, which I did not consider as a secure option, I used an external recording tool.

Undoubtedly, online interviews have their limitations, especially for the context of my research focus. Senses might be filtered through the computer screen, which can disrupt bodily rhythms and result in different affective and emotional responses than during in-person interviews (Adams-Hutcheson & Longhurst, 2017). Also, different parts that assemble a specific affective atmosphere, such as shaking hands and other forms of touch,

[3] "politischer Kampfbegriff" (Interview 3)

or sharing drinks and food together (ibid.) do not take place (notably, however, most of this would not be possible anyway during in-person interviews due to the COVID pandemic). To nevertheless provide a pleasant interview experience, I tried to emphasise the possibilities that were given by this format. In the beginning of each interview, I introduced myself again, asked the participants how they were feeling and established a casual chat to create a more relaxed atmosphere. I went through the informed consent again, described the process of the interview and provided the option to ask questions. Because not being able to see what happens outside of my camera frame might feel irritating to my interlocutor, I explained where my notes are located and why I, therefore, might sometimes look in certain directions. Since a large part of the overall body language is not visible, I expressed non-verbal cues through facial expressions, nodding, and sounds (such as 'mhm', 'uh-hu', etc.). After finishing the interview and stopping the recording I asked the participant how they were feeling, how they experienced the interview process, and offered to answer any questions they had, be it in terms of my research or my own experiences with PCOS. This resulted in friendly and casual conversations, and thus, was a good approach to end the interview on a more relaxed note.

Depending on the person, the distancing affect created by online interviews can be an advantage, since being in their own home, and able to quit any time can make participants more relaxed and gives them more control over the interview situation, especially when speaking about personal topics (Adams-Hutcheson & Longhurst, 2017), which is also the impression that I had from conducting my interviews. Probably the biggest drawback was the quality of the recording. While during the interviews our internet connection was relatively stable and we were hearing each other clearly, some words on the recordings were cut off and therefore incomprehensible.

After starting off with a question on their thoughts sparked by my research focus, I initiated the narrative by asking participants to describe the moment when they first came across PCOS. From there, I let the participants take the lead in the conversation by encouraging them to say whatever came to their mind disregarding any chronological or thematic structure. Together we jumped back and forth between past, present, and future, as well as different scenes and sites, while I asked the main questions listed in my interview guideline whenever they were fitting. Most of my inputs were focused on stimulating the narrative and animating the participants to describe, remember, and reflect on further details, thoughts, emotions, conversations, actions, etc. involved in specific events. At the end of the interview, I shifted the narrative setting towards the future by asking what participants would change in regard to the way how PCOS is dealt with if given the chance. Lastly, I finished off with asking what advice they would give to

a fellow trans person with PCOS who is just at the beginning of their journey.

As Ayata, Harders, Özkaya, and Wahba (2019) argue, interviews are situated affective encounters. An interview situation "is a relational process in which both the researcher and the researched are open to affecting and to being affected" (ibid., p. 68), and in which their affects and situatedness significantly shape the interview dynamics. In the interviews I conducted I could also observe how my positionality as a non-binary researcher with PCOS affected the interview process. Along with telling their stories, participants made use of terms and phrasing that belong to a certain repertoire and engaged in categorization work that conveys certain meanings and images that – presumably – are shared between me and them. They, thus, conveyed certain (shared) emotions, frustrations, and struggles.

To name an example, by bringing up categories like 'cis male gyno' or 'this behavior is typically Russian', Ash, on the one hand, ordered their own experiences in the categories that are familiar to them – e.g. as a trans person going through the cisnormative medical system, as a person from Ukraine. At the same time these categories also contained collective experiences. Through bringing them up, Ash also conveyed such experiences, emotions, and frustrations to me as they assumed that I – as a non-binary person, as a person with PCOS, as a person from Russia – also share them. And, indeed, I did share them – or at least there are certain images, emotions, and frustrations that came up when hearing these categories. Although my own story was not present in the interview, my nodding, nervous laughter, the way I shook my head, or the tone of my voice acted as means of transmitting my affects to the participants who just shared theirs. They all signalized that I understood and that I too shared emotions and experiences like these.

Hence, similarly to Seeck's (2021) observations, the interviews became encounters of mutual exchange of affects and care. Participants were cared for by having the chance to tell their story, being listened to, and being signalized understanding, while in turn by bringing up different images and emotion, by sharing their stories with me they were also caring for me. This relational encounter was further amplified by the possibility to share my own story and engage in casual chat that I provided after the interview which functioned as a more informal and balanced form of exchanging affects and experiences, all contributing to the formation of caring moments.

5.2.5. Post-processing

Immediately after conducting each interview, I started writing research memos reflecting on the interview process. My reflection encompassed my overall impressions of the interviews, what mistakes I made and where I failed to follow up on specific topics and

how this could be improved next time, as well as how certain stories and statements made me feel and how this relates to my personal perspectives on the topic.

Subsequently, after finishing the research memos, I started transcribing the interviews by means of the transcription software *f4*. Along the transcription process, I stumbled upon further aspects which I considered important to include into my reflection.

Considering that transcribing audible data into written form is both a level of representation (Riessman, 1993) and an interpretive process and, thus, already a first step of analysis (J. Bailey, 2008), I decided to transcribe the interviews verbatim. This transcription also included the participant's interactions with me, pauses, false starts, and non-lexical expressions ('mhm', 'hmm', etc.). That being said, it is important to note that a transcript is always merely a partial account of a much richer interaction, which is why, rather than aiming for an one-on-one mapping of the conversation, it is much more beneficial to consider the transcript's function in the analytical process (Poland, 1995). As I found my non-verbal listening cues that I gave through the conversation as disturbing the narrative flow in the analysis, I decided to leave them out in the transcript.

5.3. Analyzing

5.3.1. Coding

Following Clarke's suggestion, I started coding the material by means of grounded theory. After finalizing each interview transcript, I closely read through it while listening to the recording several times, noting down my first impressions. Subsequently, I started the initial round of coding using the coding software *Atlas.ti*. In order to stick to the data as closely as possible and keep the codes action-oriented, I mainly relied on in-vivo and process coding (Charmaz, 2006). This was followed by a round of focused coding. While still remaining relatively open and action-oriented, the codes in this round were more directed, selective, and conceptual (Charmaz, 2006).

Fundamentally, this coding process was aimed at grasping the questions "What are these data [*sic*] about? What is going on here? What are these stories of?" (Clarke, 2005, p. 187). During these two rounds of coding, codes were treated as always provisional and were continuously reworked and adapted along the mapping process described below.

5.3.2. Situating

To further engage with my material, I used tools from Adele Clarke's (2005) situational analysis, a methodological approach that is open and explorative in character, while at

the same time, stimulating reflexivity and helping the researcher position themselves into their research. Such tools can be used to deeply contextualize and situate personal narratives, and "analytically explain what the specific personal narrative taken up is a 'case [study] of' where it comes from and why it matters" (p. 182).

The first tool I utilized from this methodological framework is the messy situational map. Creating a messy situational map basically means engaging in a brainstorming process during which all actors and elements that are part of the studied case are randomly written on a piece of paper, or as in my case, in the digital whiteboard *Sketchboard*. Hence, messy maps are handy for inciting first reflexivity, while moving "into and then around the data" (Clarke, 2005, p. 84). Consequently, after each initial coding round, I went through my notes and created a messy map for each interview. After the second coding round, these maps were further revised and refined. In this initial stage of analysis, I tried to include all elements that were articulated in the participants' narratives, even if appearing less relevant at first glance. By doing so, I made sure to track as many elements and actors involved in different enactments as possible to avoid overlooking them in further steps of my analysis. Following Clarke, my guiding questions along this process were "who and what is in the situation? Who and what matters in this situation? What elements 'make a difference' in this situation?" (2005, p. 87). An example of such messy map can be found in **section A.2** of the Appendix.

Subsequently, I sorted the different elements of each messy map into an individual ordered situational map. As the name implies, this step focuses on ordering the identified elements into overarching categories. For my maps, I mainly relied on the ones suggested by Clarke, such as individual human/ nonhuman elements, collective human elements, temporal/ spatial elements, etc. This mapping exercise helps getting a hold of the 'messiness' of the previous maps. Second, along the process of ordering, further elements that might have been overlooked in the previous process can be identified. Third, it indicates the role of specific elements and actors in the studied situation, and might draw attention to aspects that have been considered irrelevant in the beginning of the research. In addition to that, these maps brought to my attention all the different reference points, overarching themes, sites, actors, and events in the participants' narratives.

Lastly, I utilized Clarke's tool of relational maps. As the name implies, this type of mapping serves as a strategy for identifying the relations between identified elements and actors. While Clarke's approach requires focusing on each element on the situational map in turn and thinking about its relation to the other elements, I tweaked this step to adjust it to my research focus. Since I am interested in the participants' situatedness in the case, I chose them as the starting point for each map. Accordingly, relations between

all other elements were drawn from the perspective of the participant's narrative, i.e. correspondingly to the relations they draw in their story. Creating maps this way helped me identify and trace connections and plot-lines in the participants' stories. An example of a relational map created during the analysis can also be found in **section A.2** of the Appendix.

Throughout the entire analysis, I adhered to Clarke's emphasis that maps are always provisional. Thus, with every new type of map the other was automatically altered and updated. Further, since I applied all three map-making steps to each individual interview in turn, this resulted in an iterative process, where findings from later maps influenced the maps I made in the beginning of my analysis. Indeed, this entire process also influenced some of the codes I chose in the first rounds of working with the material.

It is important to note that a crucial pillar of situational analysis is writing research memos throughout the entire duration of research. Thus, besides describing the contents and relations of the different maps, I documented my research process, wrote down my impressions, recorded new insights I received along analysing the data, reflected on analytic choices I made, and noted down my positions, thoughts, and biases.

5.3.3. Categorizing and theming

After finalizing all maps, I started connecting the findings from the individual narratives to each other, and carving out first argumentative strands. Therefore, I went through my list of codes, and, to avoid losing context, again closely read through each interview transcript, while grouping several codes into overarching categories.

With the help of my findings from the mapping exercise, I was sensitized to specific aspects relevant to my research focus, sensitizing concepts, and methodological approach. On the one hand, I paid close attention to rhetoric and structuring elements of the participants' narratives. This encompassed different timelines and temporalities, different forms of comparisons that were drawn and contradictions that were made, the categorization and ordering work that participants were engaged in while telling their stories, the situatedness of what has been said, as well as the broader discourses that were connected to different events. Further, I was guided by a set of analytic questions related to the content of the narratives. These analytic questions were: What and who is involved in an enactment (e.g. diagnostic measures, visuals, documents, actors, assumptions, emotions, ...)? What (care) practices are the actors in the narratives engaged in? What role does the body play in this? How and in what context is something enacted as 'normal'/'abnormal'? What role does the diagnosis play for the participant? What is the cause and issue of

PCOS (for the participant/ for the medical practitioner)? What role does expertise and knowledge play and who is considered an expert in what context? What is the role of the future? What can and can not be anticipated by the participant?

Having obtained a collection of categories, I then proceeded to sort them into overarching themes closely related to my analytic and research questions, from which I, then, proceeded to carve out my argumentative structure as presented in the result described in **chapter 6**.

6. Unfolding: Results

"[D]iagnosis is a tool rather than a fact, an action rather than a state of being, one story among many."

– Eli Clare, *Brilliant Imperfection*

This quote by Eli Clare articulates the ontological multiplicity underlying medical practices, such as in this case, the diagnosis. Following Mol (2002), ontological multiplicity implies that a multitude of different stories can be told about one and the same object, each opening up and highlighting different values, practices, and possibilities. As the stories we tell shape how we see the world, it is important to trace these different stories.

Storytelling and writing, while not necessarily being linear, are, as Ingold (2016) argues, practices of line-making. Lines, that in the form of interconnected threads, or traces are drawn upon surfaces, subsume a variety of aspects of "everyday human activity and, in so doing, bring[...] them together into a single field of inquiry" (p. 2). This multiplicity of stories, thus, can not be fully grasped in a linear way. To paraphrase Haraway (2016), tracing different stories "is about life lived along lines – and such a wealth of lines – not at points, not in spheres" (p. 32).

Haraway, too, illustrates the approach of story-telling as line-making through her sign of *SF*. Among various other things, SF symbolizes the practice of playing a game of string figures. String figures "is about giving and receiving patterns, dropping threads and failing but sometimes finding something that works, something consequential and maybe even beautiful, that wasn't there before, or relaying connections that matter, or telling stories in hand upon hand" (p. 10). Crucial here is which knots we weave, which stories we tell.

In the following chapter, I would like to trace different lines threaded into the participants' narratives. In doing so, I am going to focus on eight different situations from the participants' experiences that manifest specific practices resonating with my inquiry.

Notably, these situations do not appear in any particular order, nor can they be regarded as distinct, enclosed moments. Rather, they spill out of any linear structure, they overlap, are intertwined with, and sometimes even contradictory to each other. What they have in common is that they all point to particular practices involved in participants' meaning-making of, engaging with, and caring for PCOS. Highlighting this variety of

practices can give a flavor of the multiplicity of PCOS and it's contingency on, and interrelatedness with, enactments of health, gender, identity, or the body.

In what follows, I will examine how medical enactments of PCOS shape and enact the care participants seek when consulting their medical practitioners, and how such enactments clash with their own embodiment of PCOS. Conversely, I will also highlight how there can be no clear-cut distinction between participants' and others' enactments of PCOS-care, but that rather, they are all interrelated, situational, fluctuating, and evolving. I will trace various different actors and elements that, besides medical practitioners, are involved in the enactment of PCOS-(self-)care, be it participants' friends and family, art and media, the internet, teas, hot-water bottles, queer organizations, categories, labels, stories, or their own body. Further, I will highlight practices of queering PCOS and illustrate how they afford an affective, tentative, and inclusive care for the syndrome and it's multiple nature. Lastly, I will shed light on the role of the future, what practices are oriented toward or belong to it, but also approaches of speculating about the future of PCOS care.

Intermittently, the chapter's body will be accompanied by text boxes containing lines that diverge from the sections' main threads. These outgrowing branches provide insights into further forms of enacting the subjects at focus in the current section and, thus, emphasize their tentativeness and multiplicity.

6.1. Caring or curing?: The singularizing effect of medicine

Medicalization, in the Foucauldian sense, is entrenched into every domain related to bodies, health and illness. Since every body is constantly subjected to categorization and classificatory practices, put into boxes, shaped through discourses and practices, and examined through the *clinical gaze*, there is no such thing as an 'authentic' human body (Lupton, 1997) – it is always informed by diagnostic and medical practices. As such, there are helpful and unhelpful sides of medicalization (ibid.). To express it in Eli Clare's (2017) words medical practices of perceiving and understanding the body can be regarded "[a]s a tool and a weapon shaped by particular belief systems, useful and dangerous by turns. As a furious storm, exerting pressure in many directions" (p. 41). As will be elaborated on in the following, the drag of a PCOS diagnosis in this concrete case is most strongly exerted in one particular course.

In his book *Brilliant Imperfection*, Clare (2017) specifically challenges the dangerous contours of medicalization by critically engaging with the notion of *cure*. Cure, according to Clare, captures medicine's ambition to repair 'defective' bodies, and thus bring them

to their (initial) 'natural' and 'normal' state. However, what is considered ab/normal, un/natural or un/healthy is deeply rooted in societal norms, value systems, and power relations. Thus, bodies informed by certain markers, such as sex, gender, race, or dis_ability, are likely to be shoved into classifications of 'abnormal', 'defective', and in need of 'correction', which, at their peak, justify and make essential the eradication of such bodies.

As has already been touched upon in chapter 2, and as is encountered in the participants' stories, a PCOS diagnosis is tightly entangled with specific norms of sex-gender. 'Curing' PCOS, as illustrated in the following, means aligning bodies assigned as female with notions of normative femininity. It is expressed in practices of removing facial hair, losing weight, 'balancing' out hormonal levels, and fulfilling the bodily 'purpose' of bearing children, or at least upholding its ability to do that. Within this framework, PCOS bodies are strictly regarded as in dire need of cure – but to the benefit of whom?

The following two juxtaposed fragments from Aspen's story indicate the discrepancies arising from a stringent focus on cure. Tracing the role estrogen plays in these two moments that take place at different points in Aspen's life vividly manifests how strikingly cure is situated within particular enactments of sex-gender and vice versa.

When Aspen was a teenager she started experiencing slight facial hair growth, acne, and increased libido. Together with the detected polycystic ovaries and increased testosterone levels, these symptoms were enacted as a PCOS diagnosis at the gy-

After three years of hormonal contraception, Aspen decided to stop taking the pill. Around that time she also started transitioning, first by means of things that were relatively accessible to her, like buying a binder[4] or engaging in weightlifting, and

[1]"[...] für ihn war eigentlich auch recht klar, dass mich meine Akne und [...] mein Oberlippenbart stören müssen und auch meine Körperbehaarung, das war für ihn irgendwie so klar, das fand ich ziemlich scheiße. Ich konnte es damals [...] als eingeschüchtertes fünfzehn-jähriges Kiddi nicht sagen, aber ähm das war halt schon auch eine cis-normative ähm (pausiert) wie sagt man also (pausiert) er wünschte sich eine Behandlung, die mich cis-normativ richtig machen sollte in seinen Augen, ich war aber gar nicht eigentlich richtig interessiert an diesem Ding [...] Ich mochte halt, wie gesagt, meinen Oberlippenbart damals schon (lacht) und auch wenn ich auch ähm ich wurde auch gebasht, also ich hatte auch ähm Hänseleien oder negative Bemerkungen von ander'n Leuten erfahren, aber für mich war das auch irgendwie so halt mein Ding bisschen [...]" (Interview 3)

[2]"weil ich da schon eigentlich ein Bewusstsein für die Transidentität hatte so mehr oder minder" (Interview 3)

[3]"aber macht es Sie nicht auch ausgeglichener?" (Interview 3)

[4] "Binding is the act of pushing the breast tissue down to create the appearance of a flat chest. " ("Binding", n.d.)

[5]"das war echt super also ich empfand das tatsächlich als ähm so das was ich wirklich unbedingt wollte und ich war total high vor Glück einfach an dem Tag an dem ich die erste Spritze bekam" (Interview 3)

necologist's office. A diagnosis which was straightforwardly followed by treatment. To 'correct' Aspen's 'androgenizing' symptoms, her doctor prescribed her *Androcur*, a pharmaceutical often taken by trans femme people during their medical transition.

"[...] for him it was also relatively clear that my acne and [...] my moustache must be bothering me and also my bodily hair, this was for him somehow clear, I found this rather shitty. Back then I couldn't say it [...] as an intimidated fifteen year old kiddy, but uhm that was also a cis-normative uhm (pauses) how to phrase it (pauses) he wished for a treatment that in his eyes would correct me in a cis-normative way, but I actually wasn't really interested in this thing [...] As I said, I already liked my moustache back then (laughs) and even if uhm I was also bashed so I also experienced teasing or negative comments from other people, but for me it was also a little like my thing [...]"[1] (Interview 3)

What was declared as a problem, was not experienced that way by Aspen. While back then she did not have much knowledge on PCOS, she enacted it in a different way. Having, as she phrases it, already a more or less awareness for her trans identity[2], Aspen was content about the effects the extra androgens had on her body. This hormonal state was right for her body, her gender. The resulting clash between her and her gynecologist was resolved rather then at some point undergoing mandatory therapy to get access to HRT and mastectomy. As Aspen describes, she was 'high on luck'[5] when receiving the first testosterone shot, back then it was what she wanted and it made her feel good and happy in her body. Three and a half years from that time, Aspen slowly started questioning her gender, and gradually went through a process that she describes as *de-transition*. From a male gender identity, Aspen lived as non-binary for two years, and then, at some point came out as a woman. Today she describes herself as being both woman and man, a form of non-binary identity that she labels as *de-trans*. The term de-trans embodies the ambiguity and fluidity of gender. By referring to herself by that label, Aspen articulates that she is still trans, that de-transitioning itself is a form of transitioning. In contrast to normative, sometimes even transmisic, narratives on that process (M., 2021), for Aspen de-transition does not imply a return to an 'initial' state, but rather a step forward, a new chapter in her trans gender identity. However, within the medical framework, gender is not supposed to change. It is enacted as a static fact, rather than a fluid process. As she noticed that, after stopping testosterone her estrogen production was suppressed, resulting in various health issues, such as malnutrition, 'weirdly thin' skin, or recurring UTIs due to underdeveloped mucosa, Aspen wanted to get a prescription for estrogen therapy. Her HRT

quickly. The doctor's medical authority supported by the insistence of her mother, to whom, as Aspen tells me, she had a complicated relationship, on taking the medication won over Aspen who was being intimidated and not able to clearly communicate her needs. However, Aspen did not benefit at all from this treatment. The hormonal medication led to various (mental) health issues. As she elaborates, her body did not feel right, it was as if her personality, and her body were changing, it took away parts of her strength, and made her feel depressed. But when trying to articulate this body-mind state to her doctor, he still acted within his enactment of PCOS as he simply asked *"but doesn't it also make you more balanced?"*[3] (Interview 3).

provider at that time, however, seemed to be conflicted about her decision to live as a woman and denied her the treatment she wanted and needed. As Aspen points out, she had the impression that he took her decision as a personal offense. Even though in this situation Aspen actually experienced health issues she sought treatment for, her shifting gender identity clashed with the notion of gender as a stable and binary entity. Strikingly, the medical practitioner in this story actually cared, he was emotionally involved in Aspen's case. However, the things his care was directed at obscured the things Aspen (needed to be) cared for. The result, actually being harmful to Aspen's health, exhibits the *darker sides* of care (A. Martin et al., 2015) – a care that denies Aspen's agency in regard to her own body, and, instead speaks and acts on behalf of her.

In the first situation, estrogen treatment is not wanted, but imposed; in the second, it is needed but denied. That is because estrogen is involved in the ways bodies, gender, and PCOS (treatment) are enacted in these cases. In the first one, estrogen is a PCOS treatment, as it 'corrects' the hormonal levels of a body assigned as female and brings it back to its 'natural' state. In the second, the need for estrogen should not exist as transition is enacted as a one-way process from one binary state to the other. Thus, in both situations estrogen takes on a different role in congruence with what is momentarily enacted as a to-be-cured body, while overshadowing the actual care for my interlocutor.

The example outlined above is a common theme in participants' narratives. When seeking medical care, they are oftentimes met with normative, pathologizing, and binary notions of PCOS, their bodies and identities, while they themselves enact their PCOS bodies in differing ways. This is where clashes inevitably come, because such medical enactments do not allow for nuanced and multifaceted ways of living, and they do not allow for the existence of queer (PCOS) bodies because these bodies do not align with the medical notion of how 'healthy' bodies assigned as female ought to be. Medicine's

notion of 'cure' is based on a singular teleology which does not leave room for other ways of (medically) caring for the body. It is a *singularizing medicine*. Notably, I use this term in reference to Latham's (2017a; 2017b; 2019) concept of trans singularity. While Latham explicitly examines how being trans is made a singular phenomenon through medical enactments, I extend my focus to the convergence of PCOS and (trans) gender including all the different elements encompassed within the intersection of these two spheres. By using the gerund form, I emphasize how the singular reality is actively done through the practices at play during the very moment of the doctor-patient interaction. By tweaking Latham's concept in this way I intend to highlight the very process of how an entire conglomeration of multiple realities is truncated into one singular enactment, while everything not fitting into this particular picture falls out of the frame, and the unmaking of multiplicities decisively interferes with my participants' lives.

Paradoxically, in both cases demonstrated above, the medical practitioners' strive at upholding a seemingly 'natural' bodily state in their patient, resulted in detrimental effects for Aspen's health. As Clare elaborates, this seeming opposition between denial and imposition of body-mind trouble converges at what medicine considers necessary to be cured and what falls out of this scheme, while at the same time being dismissive of what people know about their own visceral experiences – or, speaking through Haraway's lens, their situated knowledge.

Such denial of situated knowledge was also experienced by Oleander, with the difference that his story focuses on the dys/function of a particular set of organs. Since Oleander has PCOS and endometriosis, his reproductive organs are causing him severe pain and discomfort, and they even put his life in danger, as one cyst became so large that it was about to rupture and cause a hemorrhage, and thus needed to be surgically removed. After this emergency surgery, Oleander's leg was paralyzed and took several months to recover. Further, his bodily discomfort also affects his mental health. Still, his condition is not 'severe enough' and only if he needs to undergo surgery again (with potential for further complications) would a hysterectomy[6] and an oophorectomy[7] be considered. Although Oleander insists on these interventions, stating that he does not need these organs, that he never wished to have children, even though his fertility is already reduced through the PCOS, medical practitioners still insist on thinking about the future and the participant's potential change of mind in regard to getting pregnant. The way Oleander talks about it during the interview enacts PCOS and the issues he has with it unambiguously as a disease, where the right care approach would be a straightforward intervention:

[6] A hysterectomy is the procedure of surgically removing the uterus.
[7] An oophorectomy is the procedure of surgically removing the ovaries.

> "*I mean if I have a benign tumor which somehow bothers me aesthetically, so it doesn't do anything but it hurts and it bothers me then that gets removed. It's bening and it doesn't do anything terrible, but it gets removed and the same is also, well, it's not life-threatening in most cases (pauses) except one has this mega (pauses) sac uhm in there (pauses) but uhm (pauses) I think one should really give the people the choice, do I want this shit inside of me and do I want to endure this shit every month or not [...]*"[8] (Interview 2)

While Oleander actually enacts his body as in need of 'cure', i.e. cure from painful and life-threatening cyst-bursts, medicine still tries to uphold the functionality of these organs, orientating the cure towards a constructed natural in an improbable future, while neglecting the person in the present (Clare, 2017). This is also strongly connected to the enactment of the uterus as a vessel for childbearing (Bordo, 2004). At any cost this 'biologically given purpose' needs to be fulfilled, or at least the potential for its fulfillment needs to be upheld, even if it means suffering and potential threat to the patient's life. This situation also illustrates the shortcomings of the logic of choice that Mol (2008) discusses in her work. The only option he is offered to reduce his pain is the hormonal contraceptive pill, however Oleander is intolerant to hormonal medication and he experienced various unpleasant side-effects when taking it. While he is given a choice whether he wants to take oral contraceptives or not, the options given to him are not palatable leaving him at an impasse: *"[...] and yeah his statement was yeah then we cannot help you any further [...] so if you refuse then it is how it is [...]"*[9] (Interview 2).

As illustrated in the two stories, these clashes between what is enacted as ab/normal, un/healthy, or un/necessary result in the de-problematizing of issues participants seek medical help for, while producing, or even enforcing, dis-order with regard to things participants are not worried about – both of which are effects of an interference of gender norms with health care. A byproduct of this interference is double standards between (assumingly) cis and trans people. Medical practitioners' tenacity in terms of their patients' (in)fertility ceased as soon as participants disclosed their trans identity. Rimu, who like Oleander, experienced massive pressure to care for his reproductive capabilities observed

[8] "ich mein wenn ich 'n gutartigen Tumor hab der mich optisch oder irgendwie stört, also der macht nichts aber der tut weh und der stört, wird der ja auch entfernt. Er ist gutartig und er macht nichts schlimmes, aber er wird entfernt, und das selbe Spiel ist das halt auch, es ist jetzt nicht lebensbedrohlich in den meisten Fällen (pausiert) außer man hat halt eben so 'n mega (pausiert) Beutel ähm drinne (pausiert) aber ähm (pausiert) ich finde da sollte man wirklich den Leuten die Wahl überlassen möcht ich den Scheiß in mir haben und möcht ich diesen Scheiß jeden Monat ertragen oder nicht [...]" (Interview 2)

[9] "[...] und ja seine Aussage war dann ja dann können wir Ihnen halt nicht helfen [...] also wenn Sie sich verweigern dann ist das halt so [...]" (Interview 2)

that *"[...] from this moment it wasn't a big issue anymore [...] with the pregnancy and so on because of my PCOS and so on (laughs) [...]"*[10] (Interview 1). Having started transitioning very early, Aspen, who actually wishes to have children at some point in life, is sure that the topic was never brought up by her doctors because of her trans identity. On the contrary, despite Aspen's clear and multiple utterance of her stance, her therapist – whether out of habit or out of ignorance – included the removal of her reproductive system into her indication. When correcting this referral at the hospital, where Aspen had her mastectomy, her medical providers were surprised to learn that she wanted to keep her reproductive organs. Aspen recalls them saying "*[...] oh, uh-huh, oh yeah that's also been possible in Germany since 2011 [...]*"[11], by which they referred to the abolition of the mandatory sterilization trans people had to undergo in order to obtain legal recognition of their gender by the German federal court in 2011 (Giese, 2019; Karsay, 2018). Such a medical enactment of Aspen's reproductive capabilities and wishes are rooted in stereotypical assumptions and violent legal structures that determine how trans people ought to live their lives. Within this framing, trans people are not eligible to have children and, thus are still expected to revoke their reproductive rights.

Enacting Blame

Since Rimu was a child his weight was constantly pathologized and claimed to be the reason for multiple health problems. In elementary school, for example, Rimu experienced constant headaches and had trouble focusing which, when seeing a doctor, was blamed on his weight. However, several years later it turned out that Rimu needed glasses. Today, Rimu's weight is also enacted as the cause for his PCOS as well as other health problems he is having. Thus, to improve his health, according to his medical practitioners, he needs to change his lifestyle, start dieting and exercising. The fact that Rimu always used to be overweight and never had an 'unhealthy' lifestyle does not matter here. If he fails to lose weight, it is his own fault, while no other treatment option is offered, making Rimu's health his own responsibility. Again, this example highlights the limits of choice. Rimu either loses weight or lives with the issues as no other form of care is being considered. Consequently, since this enactment marks Rimu's body as it is as 'wrong' and the cause of all his health problems, it brings about a lot of pressure and self-blame upon him.

For Oleander, this double standard in regard to what is normal for cis and trans bodies, ironically, grants him access to the treatment he wishes for. While still trying to receive

[10] "[...] ab dem Moment war's auch nicht mehr so groß das Thema [...] wegen der Schwangerschaft und so wegen meinem PCOS und so (lacht) [...]" (Interview 1)

[11] "[...] ah aha ahja das ist ja jetzt auch möglich seit 2011 in Deutschland [...]" (Interview 3)

this intervention as soon as possible, Oleander's dawn of hope is the moment when the mandatory waiting period of eighteen months has passed and he can undergo hysterectomy and oophorectomy in the framework of his transition. Oleander's PCOS care is thus inextricably entangled with his gender identity and the societally inflicted expectations of it.

What further significantly shapes and complicates the interaction between participants and their medical practitioners are power relations, ignorance, and transmisia. Without exception all participants experienced situations in which they were not taken seriously, sensed their doctor's lack of interest in helping them, were met with confusion and misrecognition regarding their gender identities, treated with lack of respect and empathy, or misgendered. Consequently, participants learn to adjust to a dynamic in which the medical practitioners do not *care*. Being mistreated or not taken seriously is already anticipated when visiting a new doctor. Further, unpleasant situations, such as gynecological examinations or neglected PCOS symptoms, are, as participants tell me, just 'lived with', 'went through', or 'tolerated'. But acquiescing to mistreatment is draining to capacities that participants do not always have, making them delay care practices, such as searching for new gynecologists or going to consultations with their doctors.

Furthermore, even if doctors are eager to care for their patients, oftentimes their lack of knowledge on PCOS, as well as in resources and expertise, or even their limited time to talk to and care for their patients significantly compromises participants' health care and leaves them with unclarified questions and uncertainties. This lack of resources even goes beyond the doctor's office because material like forums, books, or self-help groups are mainly targeted at cis women who want to adhere to a certain norm of femininity, which is perceived by my participants as discouraging and comes with a feeling of being disconnected.

Outlining the characteristics of 'bad' care, Mol (2008) argues that "care is bad when people are being neglected. When there is not enough time to listen. When physical parameters are isolated from their context; when patients' daily lives are not taken into consideration [...] [, w]hen professionals fail to carry out careful experiments, but hastily follow protocols instead, or – even worse – lazily fall back on old habits" (p. 84). In the case of PCOS such default protocols are firmly entangled with norms on sex-gender, and thus, do not allow the existence of bodies diverging from these norms. The strong emphasis on curing PCOS bodies obscures and neglects care for the actual person. It singularizes the multifaceted shades of care.

While the framework of the singularizing medicine highly informs the participants'

experiences, it is merely one strand within this bundle of threads. At the intersection of the social, the personal, and the medical, participants are pushed and pulled between different enactments, while they themselves are simultaneously being situated in, and shifting between domains, assemblages, and value systems. These different, sometimes converging, sometimes disjoining, threads are explored in the sections to come.

6.2. Enacting and being enacted: Making sense of identity

Reality, through Puig de la Bellacasa's (2017) lens, is an active web in which ontology does not preexist its relationalities, but rather, through the interweaving of different strands and threads, is continuously involved in a process of becoming. Thus, reflecting on such relational ecologies discloses how they are affected and shaped by different care practices. In this section I would like to shed light on the entanglements of PCOS-care with one particular strand that already came up in the examples discussed above, namely sex and gender, or, as I have been using throughout this thesis, sex-gender.

The examples illustrated here actually give a flavor of the difficulty of clearly keeping these two entities apart. In fact, they show how identity is always also embodied and vice versa. Rather than being stable, clearly delimitable fixa, participants' perceptions and meaning-making of both PCOS and gender shift and co-evolve throughout their lives. In this process the ways PCOS is understood, described, referred or tended to assign it a certain role in this interwoven net. This is not only limited to own narratives, but also how others, particularly those in a position of authority, explain, problematize and tackle PCOS. Therefore, delving into this mutual inclusion provides deeper insight into the political implications stemming from a certain PCOS care.

For Elm, PCOS was for a long time – and partially still is – connected to feelings of stigma and shame. Particularly, Elm's increased facial and bodily hair growth was something considered in need of confinement and control. The practices of 'taming' Elm's 'unruly' body were taking up a significant amount of Elm's life; throughout the interview Elm refers to different situations in which Elm was worrying about not being able to hide the hirsutism from others – involving sleepovers, school trips, and even a week in prison. But also the tension between the pathologizing framing on the one hand, and the uncertainty and vagueness of PCOS on the other is described as unsettling and worrisome by Elm.

In contrast to such PCOS enactments infomed by notions of defectiveness, Elm speaks about how queer contexts present an alternative way of perceiving PCOS, and bodies in general. Especially enacting PCOS bodies as inter* rather than as 'sick' and in need of curing is

a move towards opposing the pathologizing framework. While having used the term 'intersex' when speaking about the subject matter in general, I am using the term 'inter*' when referring to the participant's enactments, in order to capture the multiplicity and openness conveyed by their usage of different terminology and evocation of different perceptions on why PCOS is (not) intersex. The asterisk is meant to symbolize the in vivo nature of the term – the inter* embodiment and experience is actively enacted in the participants accounts and, thus, is open-ended and contingent.

Location matters – movement matters

Ash thoroughly engaged with the question whether PCOS can be considered inter*. In their own understanding, identifying with the label does not require any medical diagnosis as it captures and conveys lived experiences and allows connecting to others in similar situations. Personally, Ash does not consider their experiences to align with what the inter* label conveys, which they attribute to their migration history. Since, as a teenager, they migrated with their mother from Ukraine to the US, they describe their relationship to medical practitioners as relatively reserved due to the cultural and language differences. Referring to an encounter with a gynecologist who problematized their increased bodily hair growth, Ash tells me that they and their mother did not care what the doctor thought about them, and vice versa. This reserved relationship dampened the effect the gynecologist's opinions had on Ash's perception of self. If however, they would have shared the same culture, had remained in Ukraine even, Ash suspects the impact of the doctor's statements would be different both on them and their mother. While Ash describes most medical experiences they had as, at worst, weird and retrospectively even funny, they can imagine that they would have made experiences closer aligned with their understanding of inter* if their grew up in Ukraine, where they assume to be subject to medicalizing and scrutinizing gazes more persistently.

> "*I somehow had the feeling oh maybe [...] it would be really cool and empowering if I'd had such a label [...] that for me is not such a health-related syndrome-thing, but if I could say that I'm inter then maybe it could be something empowering [...]*"[12] (Interview 6)

The inter* label in this case would shift Elm's body away from a notion of disease

[12]"Ich hatte irgendwie das Gefühl oh vielleicht [...] wär's irgendwie ganz cool und empowernd wenn ich jetzt so'n Begriff habe, [...] der nicht für mich so'n gesundheitliches Syndromding ist, sondern wenn ich sagen kann [...] dass ich inter bin, dann könnt es vielleicht was empowerndes haben [...]" (Interview 6)

or syndrome, and instead articulate that this is just the way Elm's body is. At the same time Elm is hesitant about using this term and unsure whether claiming this label would mean appropriating something that does not 'belong' to Elm. Elm's enactment of Elm's PCOS body as inter* is unstable, as Elm is not sure whether Elm's embodied experiences match the object. This is further complicated by the fact that 'inter*' itself is not a stable entity, but rather enacted in multiple forms. Instead, such categories in regard to the self are in a continuous state of becoming. Along Elm's trajectory of exploring PCOS and what it means for Elm's own body and identity, Elm comes across and interacts with various people, organizations, internet sources, and artworks that shape and strengthen Elm's enactments thereof. Thus, webcomics, theater plays, queer friends and partners, compilations of inter* stories, or trans and inter* organizations come together and assemble into an affective network that fosters the care Elm wants and needs. Contrary to medical diagnoses, these queer ecologies of care enact PCOS bodies as variations of the multifaceted ways how human bodies can be. Within these ecologies, 'unruly' bodies are not in need of taming. Instead, these bodies are allowed to exist and be cherished (Mol, 2008) as they are beautiful, precious, and do not require correction. They provide Elm with empowerment, self-validation, and strengthen Elm's confidence, and thus, are like puzzle pieces that partake in Elm's enactment of Elm's own identity.

Ontology 'expressed in the genes'

In the question on whether or not they are inter* the decisive aspect for Spruce is whether they really have PCOS or rather *late-onset Adrenogenital syndrome* (AGS). As Spruce explains to me, AGS is a 'disease' that has almost the same symptoms as PCOS, but only occurs later in life. Because of a mutation in the adrenal glands, there is an excess of testosterone in bodies assigned as female. Basically, as Spruce elaborates, it is a condition expressed in the genes and therefore is also classified as 'classically intersex'. While both PCOS and AGS are treated in a similar way, this small difference means a lot to Spruce, as the one is enacted as inter* and the other is not. According to Spruce the inter* category would validate their gender identity more.

Elm's entanglement into this caring web also makes Elm retrospectively question past interventions, particularly the professional epilation Elm underwent to tame Elm's facial and bodily hair:

> "*So today I sometimes think wow if I would've engaged with queer uhm non-binary people sooner, then I probably wouldn't have started with it. If I would've*

> *seen such cool videos of female-coded persons with beards sooner and uhm would've gotten that uhm bodies are just that different and the two gender norms do not really make any sense, then I just wouldn't have done a lot of it [...]*"[13] (Interview 6)

This quote very vividly depicts how enactments of values, bodies, and identities are deeply situated. From the position within a queer relationality, Elm retrospectively revises the own past decisions and practices that, back then, Elm had to go at great lenghts for – a situatedness that will be discussed in more detail in **section 6.4**.

However, living in a society pervaded by binaries of male/female and health/illness can be a daily endurance test for enactments deviating from such patterns. Hoping to receive some 'expert' insights on gender identity, PCOS, and its categorization as inter*, Elm saw an endocrinologist specialized in trans-specific health-care. However, this endocrinologist had a completely different enactment of these categories. *"So 'n Quatsch" – "such bullshit"* (Interview 6) is what he had to say about PCOS as inter*. Since in this meeting Elm asked for a prescription for facial hair epilation, he also questioned Elm's gender identity and stated:

> "*[...] yeah but then you would not get a facial hair removal uhm (pauses) you are a woman with PCO syndrome because otherwise you would be non-binary [...]*"[14] (Interview 6)

This interaction illustrates a clash between differing enactments of PCOS and related labels to describe sex and gender. A clash that does not come without consequences:

> "*I was stunned because he simultaneously put something over me, took something away and then even uhm said what my definition [...] would be instead and he has so much knowledge [...] that he can tell me yeah then you would be this and that uhm and I found it super insensitive [...]*"[15] (Interview 6)

[13] "Also heute ist es schon so dass ich irgendwann denk krass wenn ich früher [...] mit queeren ähm nicht-binären Menschen zutun gehabt hätte, dann hätt ich damit vermutlich, denk ich nicht angefangen. Wenn ich früher so coole Videos gesehen hätte von ähm weiblich gelesenen Personen mit Bärten und ähm gecheckt hätte dass ähm Körper halt so unterschiedlich sind und die zwei Geschlechternormen irgendwie überhaupt keinen Sinn macht, dann hätte ich glaub ich ganz viel von dem einfach nicht gemacht [...]" (Interview 6)

[14] "[...] ja aber dann würden Sie sich ja die Gesichtshaare nicht entfernen lassen ähm (pausiert) Sie sind 'ne Frau mit PCO Syndrom weil sonst wären Sie nicht-binär [...]" (Interview 6)

[15] "Fand ich irgendwie krass weil er gleichzeitig mir sowas übergestülpt hat, was weggenommen hat und dann noch ähm gesagt hat was meine Definition [...] sonst wär und er hat ja so viel knowledge dass er [...] mir sagen kann ja dann dann wären Sie das und das ähm ja das fand ich super unsensibel [...]" (Interview 6)

By enacting PCOS as well as sex-gender categories in such a way, the endocrinologist stripped Elm from Elm's self-chosen label, and along with it, Elm's self-empowerment. Through putting the label of 'cis woman with PCOS' over Elm, he not only misrecognized and denied Elm's gender identity but also pushed Elm back into a pathological framing. In this interaction Elm's gender and body are not possible forms out of many diverse variations. Instead, the categorization of 'woman with PCOS' renders Elm's body as an entity that would fall under the binary category, but is deviating from it because of its characteristic 'with PCOS'. This enactment also takes away Elm's autonomy and self-determination in giving Elm's own gender identity a name, while the endocrinologist's role as an 'expert' is elevated over any form of situated knowledge. Such acts of misgendering, as Malatino (2020) reflects through Hayward's (2017, p. 191) words, function as an "attack on ontology of beingness". In Elm's case, it had profound repercussions, because Elm stopped using the inter* label after this encounter. As easily as certain ontologies can assemble, they can also break – or be broken – apart.

The ontological consequences of this interaction even go beyond the individual. While in the previous example such labels convey notions of identity, belonging, and finding solidarity in (proudly) having a body and gender that does not follow cis distinctive norms, the other label classifies people's bodies along normative genders. The binary gender categories in this case function as the preferable benchmark, while 'inter*' and 'non-binary' are kept as small and specific as possible. Such enactments have importance for the broader population, as it amplifies the othering of (any) inter*/non-binary people while upholding a medical binary useful for regulating people's lives in expected forms. Through such enactments trans, inter*, and queer lives are rendered an exception, and thus, become "expendable, disposable, dismissible, even killable" (Malatino, 2020, p. 14).

The above-described moments are examples of how enactments of PCOS or the own identity are not taking place intrinsically, but arise through the interplay of many different elements and actors. Throughout the interview, Elm tells me about moments that materialize either as feelings of empowerment or as feelings of shame:

> "*[...] because I had moments where I thought wow it would be actually so cool to also run around with a full beard and then even thinking now I dye it blue and then I am the walking example uhm (laughs) that your categories do not fit and uhm these are moments in which I feel strong [...] And then again,* of course! *And now I walk through the city like this! (laughs) Noo.*"[16](Interview6)

[16]"[...] weil ich Momente hatte in denen hab ich echt gedacht wow es wär so cool eigentlich auch so mit so 'nem Vollbart rumzulaufen und dann noch zu denken so und jetzt färb ich den mir noch blau und dann bin ich hier das wandelnde Beispiel ähm (lacht) dass eure Kategorien nicht passen und ähm das

Going through life, Elm is ambivalently situated within this tension of enactments perpetuated by clashing value systems. It is a constant shift back and forth between wanting to express one's own body and gender identity and being confined by normative ideas of femininity, while from moment to moment the one wins out over the other, depending on the constellation of things, people, and practices one is currently involved in. This example is not telling a linear story about, initially, trying to tame and control the body, after some time finding acceptance, and, finally, being happy with oneself. Instead, it illustrates how one's identity and relation to the body is entangled in a manifold of ambivalent relationalities and is contingent on temporary assemblies that all bring about their own consequences.

6.3. Acting and re-enacting: Making sense of and with one's (changing) body

As many effects of PCOS on the body and its interaction with other interventions, such as HRT, can oftentimes not be grasped by medical knowledge due to a variety of reasons elaborated above, participants need to find their own techniques to make sense of their body. Indeed, their body is itself actively involved in these practices. For instance, noticing side effects of certain treatments is described as a reason for why this treatment does not work. Often, this is the moment when participants have to listen to and care, or seek care for, their bodies. It is as if the body is an actor who actively rejects an intervention, while the participant, in turn, needs to be attentive and cooperate with their body. On the other hand, the notion of the body as re-acting is also taken up to determine and point out when a certain intervention or health care approach can be considered as 'helpful' or 'right'. A vivid example of these embodied and situated practices can be found in Ash's story on their HRT experience:

> "*[...] like the normal range that was, it's like, well, I was talking to the uhm my endocrinologist, the normal range that we're going for it's like you know three hundred to eleven hundred of the units uhm and like that's great and I was within the first two shots I'm like at thirteen hundred like you know I'm just I'm just my body was ready for this my whole life [...]*" (Interview 4)

Ash not only interprets the quick and smooth adaptation of their body to HRT, but also the exceedance of their bodily testosterone levels as a sign that their body has always

sind halt Momente in denen ich mich grad stark fühl [...] Und dann wieder *ja klar*! Und damit lauf ich jetzt durch die Innenstadt! (lacht) Nee." (Interview 6)

been ready to receive and process 'additional' testosterone. PCOS here is enacted as a jumpstart for undergoing hormonal transition, while Ash's body is an active element that is positively re-acting to it. As Mol (2008, p. 39) argues "[t]he body in the consulting room is not a causally coherent entity. It is not even a passive object of measurement and treatment practices. Instead, in the logic of care the body is active. It has to be". This notion of the body being actively engaged in practices of enacting and caring for PCOS particularly comes forth in Ash's further elaboration of their experiences:

> "*[...] and also testosterone was super euphoric, it was, if anything I feel like that interaction of testosterone and [PCOS] was that (pauses) I don't know I just felt like (pauses) my body was super ready for this like, it was like oh this was what it was supposed to do the whole time, like this is fine uhm like it was it was a very cool kind of thing.*" (Interview 4)

Transmitting and processing testosterone, and thereby being changed and affected in various ways, is what Ash's body was *supposed to do the whole time*, it just required the necessary resources, i.e. the testosterone shots provided by Ash's endocrinologist.

But this short quote conveys so much more about ontological enactments. Through listening and being attentive to their body, Ash feels how it reacts to HRT in a positive way. A key aspect here is, as Ash describes, experiencing this hormonal transition as super euphoric. While being a multifaceted experience, gender euphoria can be described as being oriented towards those bodily, and performative (Butler, 1988) aspects that are experienced to be in congruence with one's gender. It is about what feels good, what creates joy (Stryker, 2017). Ash experiences the way their body acts as aligned with their gender identity; it makes them feel euphoric, and, thus, is enacted as a desired and almost natural interaction between their body and HRT.

Thus, in Ash's narrative, many different actors – PCOS, their body, their gender identity, the external testosterone, Ash themselves, and many more – come together and are coordinated into an assemblage where each has its own function and simultaneously enacts and is enacted by the others. This enactment is further strengthened and stabilized through narratively contrasting it to an intervention that was not received that well by their body:

> "*[...] I mean Ukraine is also very very religious in a very strange way uhm it's not like Western Europe it's pretty specific uhm (pauses) and one of the things it's like most of the criticism is about like things like tattoos or being gay or being trans and like well you're going against god's will uhm and I think I didn't realize how much that actually affected me internally, like externally*

> *obviously I had like a million things to say about that and [...] like I can argue about that all day and it's fine uhm but internally I totally had that question I was like what if I was going against god's will uhm and it was really interesting to compare the relationship between the testosterone and the Mirena IUD which is, the Mirena was, if anything that was going against god's will, that was a terrible time (laughs) like my body did not enjoy that experience I was happy to get the thing out uhm and the testosterone was great like it was so clearly like everything just, it was so smooth as a transition [...]*" (Interview 4)

In contrast to the medical practitioners' enactments of hormonal contraceptives and their interaction with the body, the Mirena IUD was overall an unpleasant experience for Ash, as it gave them severe cramps and discomfort. At another point in the interview Ash also mentioned mysterious and medically unexplained lymphs in their breasts, which worsened while using hormonal contraceptives, while disappearing during HRT. As they describe, their body did not *enjoy* the Mirena IUD, it actively rejected it.

As Mol (2008, p. 50) argues, "[t]echnologies do not subject themselves to what we wish them to do, but interfere with who we are.". Both the body and the person inhabiting it play a crucial role in making sense of this interference. It is a constant process of being attentive to the body, responding to its needs and adapting and adjusting things involved in its care. Through this continuous interaction with their body, Ash determines which of these technologies – the progestin intrauterine device or the testosterone shots – are parts of their body and which are not. Which interventions are part of their care repertoire and which are not.

Moreover, this meaning-making is not confined to the body alone. Strikingly, Ash frames their comparison of the two medical interventions within a religious narrative. Referring to 'god's will' when speaking about bodies and identities conveys the meanings of purity and naturalness within this context. Noticeably, the elements listed as associated with defectiveness in this framework, i.e. tattoos, being gay, or being trans, say more about culture than religiousness in a scriptural sense. Ash's narrative, as they remark themselves, depicts a particularly local sense of religion traversed by deep inculturation which shapes the dominant enactments of the body in Ash's life, consequently, influencing their own enactments thereof. Having said that, this interview fragment points to another considerable point in the interplay of culture and the body, namely that the acting and re-acting of Ash's body also contributes to the re-enacting of these broader socio-cultural narratives in the participant's life. By framing their experience in such a manner, Ash subversively reconfigures and queers what in this particular religious sense is considered

un/natural. In this story, the overarching cultural narrative of how a 'normal' person ought to be, which Ash resists in various ways, is also resisted and objected by the body, giving Ash the agency in determining what is natural and what is not. Consequently, the described cultural narrative becomes re-enacted, and thus functions as a coordination practice between Ash's cultural upbringing and their transition.

6.4. Collecting and recollecting

What the last two sections demonstrate is how participants, as they go through life, engage in a variety of practices of acting, enacting and re-enacting their stories of PCOS as well as its role and relationality within these stories, and their role in and relationships with them. At the same time, other people, practices and things also interfere and contribute to these narrative meaning-makings.

Therefore, it is useful to pause, take a step back, and explore the meta-level of this. In this section, I am going to discuss the different mechanisms at play as participants look back and reflect on past events.

Describing the moment of her PCOS diagnosis, as recounted in the first section, Aspen reflects on the reasons for starting the suggested treatment even though it did not match her enactment of her body. This segment will be further analysed in the subsequent section, but for now it is important to note that Aspen described her past teenage self as too anxious and inexperienced to communicate her needs to the doctor and that her gynecologist's medical authority, as well as the pressure from her mother, who was present during the consultation, intimidated her and made her agree to something she now, retrospectively, would not have done. In this recollection of the event of the first gynecological visit, the three actors, Aspen herself, her gynecologist, and her mother, as well as the relations between these actors become part of this memory practice and function as justifications for why the treatment was started anyway.

A similar situation is presented in Elm's reflection on undergoing professional epilation as presented in **section 6.2**. Looking back on this medical intervention, Elm elaborates:

> "*[...] and I find it retrospectively really terrible that I actually did this [...] I understand that people do this and I also understand that I wanted to do this and I would also understand if I would decide to do it again because society is just shit (pauses) but it's stunning how much time [...] and how much strength and energy I've invested in uhm adjusting to something I actually never even found reasonable and [...] at some point I also had a-, I still know, because the*

> *health insurance didn't want to cover it anymore, I consulted a lawyer, was in court to get the court fees covered and lot's of these really annoying things.*"[17] (Interview 6)

There is a striking discrepancy noticeable in this interview segment. On the one hand, Elm describes having had to go to great lengths in order to receive the electrical epilation. It reads as if this intervention was needed so much that it even had to be fought for. On the other hand, Elm's choice of words describing it as 'terrible', 'annoying' and something Elm never saw as reasonable does not really match with the prior impression. What happens here is that, as already alluded to in the respective section, two different value systems meet in this account. Elm looks back at Elm's past self who was eager to adhere to societal norms and expectations from a standpoint in the present in which Elm, being entangled in a queer network, regards them with scrutiny. These two versions of Elm meeting in this retrospection clash with each other as they hold contrasting enactments on PCOS and the body, leading to these contradictions in Elm's account. This segment, thus, distinctly demonstrates how even in a narrative reconstruction the self is never homogeneous. Recollections of a past moment are never temporally or spatially confined. Instead, different enactments of the self come up and meet in the moment of narrating. Belonging to different points in time and different value systems, these different enactments are not always coordinated. They are in constant tension with each other as the hierarchy between these enactments fluctuates from moment to moment, making the self constantly fluctuate as well.

A reflection on shifting value systems can also be encountered in Spruce's interview:

> "*So there were definitely times in my life with 17, 18, 19 where I found it super important to take the pill and not get acne [...], now I also think differently about that.*"[18] (Interview 5)

Here, Spruce's past self who wished to undergo a certain treatment to obtain certain promised results is juxtaposed with their present self, who does not hold to these standards

[17] "und ich find's auch im Nachhinein auch richtig schrecklich dass ich das gemacht hab eigentlich [...] ich verstehe wenn Menschen das machen und ich versteh auch dass ich das machen wollte und ich würde das auch verstehen wenn ich mich jetzt wieder dafür entscheide weil die Gesellschaft halt einfach so kacke ist (pausiert) aber ich find's schon krass wie viel Zeit [...] und wie viel Kraft und Energie ich da reininvestiert hab irgendwie ähm mich da anzupassen an was ich eigentlich überhaupt nie sinnvoll fand und [...] zwischendurch hat ich halt auch 'ne-, weiß ich noch, als es die Krankenkasse es nicht weiter übernehmen wollte hat ich dann 'ne Rechtsanwältin eingeschalten, war beim Gericht um die Gerichtskosten irgendwie übernehmen zu lassen und lauter so richtig nervige Sachen." (Interview 6)

[18] "Also es gab auch definitiv Zeiten in meinem Leben mit 17, 18, 19 da fand ich das super wichtig die Pille zu nehmen und keine Akne zu kriegen [...] da würd ich jetzt auch anders drüber denken." (Interview 5)

anymore. While this small segment is, again, a practice of looking back at past events and re-evaluating them in light of current value systems, these enactments of the self are much more coordinated. By clearly contrasting their past and present self, Spruce distributes the two different enactments to different points in time to hold them apart and keep them from clashing.

What these three examples show is that medical consultations, treatment, and care are highly situated. Something considered unavoidable, necessary, or even desired at one point in time does not need to remain static. This needs to be considered when caring for PCOS. To appropriate Mol's (2008) argument, the linear trajectory from establishing (neutral) facts, making some (value-laden) choice, executing it in a (technical) action, and being 'finished' with the treatment cannot account for the twists and turns that time might bring. What appears stable at a certain point in time can as easily fall apart again in the next.

But comparisons are not only drawn between past and present, but also between what happened and what could have been. As Ash starts telling me their story in the beginning of the interview, they at one point mention:

> "*I generally had a fine experience in life with most things, so like it could've gotten also much worse, but it also could've gotten much better [...]*" (Interview 4)

Here, Ash compares their experience with two hypothetical alternatives, using them as a benchmark for evaluating their situation. Although their experience with medical PCOS care could have been better, it is nevertheless marked as fine in light of some much worse outcomes. A more concrete idea of this much worse situation is then given at a later point in the interview when Ash reflects on how their experience would differ if they would have stayed and grown up in Ukraine (as presented in **section 6.2**). In weaving this hypothetical scenario, Ash incorporates different kinds of comparisons. They juxtapose different cultures and medical systems, i.e. US vs. Ukraine, as well as different processes and attitudes, i.e. migrating and trying to navigate within a new cultural context vs. being born into and raised as a stable part of a culture.

The other, 'much better' outcome is imagined by retrospectively looking back at situations that happened in the past and, in light of the experiences and knowledge one gathered up to this point in the present, speculating about how things could have been otherwise. Especially in terms of negative experiences with health care providers, such reconstructions invite participants to envision alternative care practices and, thus, become aware of what good care means to them. Ash, for example, recollects an event when,

as a teenager, they sought out a gynecologist because of a yeast infection. While not offering any advice or treatment, the doctor simply concluded *"your vagina is angry at you"* (Interview 4). Looking back at this experience, Ash infers that it would have been much more helpful to receive some basic advice on proper hygiene and diet, which are both things they learned about later in life, and now see how they matter in gynecological care.

Another instance of recollecting past events is how participants retrospectively assign PCOS a role within parts of their life when they had no knowledge of this diagnosis yet. An example can be found in Rimu's recollection of childhood and puberty:

> "*[...] apart from me being trans [...] my adolescence was like that from the start I was very masculine and so on also in the uhm puberty this testosterone really came forth and it was always like (pauses) why is it like this and [...] yeah in comparison to my cousins for example I was completely different [...] and uhm for me it was not because- uhm because I had a reasonable diet, was relatively active and so on and still I was, since I was a baby [...] it was that both my cousins and I we were born a few months apart [...] and I was just (pauses) uhm even though I was two months older I was double as fat which was just (pauses) not normal for my family and therefore I was always viewed and treated as deviant because of that.*"[19] (Interview 1)

In this fragment, Rimu recounts how he was constantly under scrutiny by his family, for not fitting into the role and norms expected of him. By, as he refers to it, treating him as an 'anomaly' and comparing him to his female cousins, he was given the feeling that something about him and his body was not 'normal'. Strikingly, in this elaboration, Rimu refers to events he is unlikely to remember himself. What he looked like and how he was regarded as a baby is already an ex post reconstructed narrative told by his family. It is a form of how Rimu's family enacted his development as a child, one that now becomes part of Rimu's enactment. How this broader social context informs his recollection of his adolescence can also be seen in the conflation of bodily characteristics and gender norms

[19] "[...] abgesehen davon dass ich halt trans bin [...] meine Jugend war halt so ich es war von vornherein halt sehr maskulin und so weiter halt auch durch die ähm Pubertät kam halt dieses Testosteron wesentlich mehr zum Vorschein und war halt da schon so von wegen so (pausiert) wieso ist das so und [...] ja war halt schon so im Vergleich zu meinen Cousinen zum Beispiel war ich halt komplett anders [...] und ähm bei mir lag's halt nicht daran ähm weil ich hab mich vernünftig ernährt, war auch einigermaßen aktiv und so und trotzdem war ich halt seitdem ich 'n Baby war [...] es war einfach dass meine beiden Cousinen und ich sind innerhalb von wenigen Monaten auseinander geboren [...] und ich war einfach (pausiert) ähm auch wenn ich zwei Monate älter war ähm war ich halt einfach doppelt so dick was halt einfach so (pausiert) unnormal für meine Familie war weil dementsprechend ja schon immer so etwas aussätzig dann so gesehen behandelt aufgrund dessen." (Interview 1)

that takes place when Rimu brings up his elevated testosterone levels as an explanation for his 'very masculine' behavior. His family's ex post reconstruction becomes part of his own ex post reconstruction of his childhood within the context of the PCOS diagnosis he received in early adulthood. In this moment, the diagnosis, thus, functions as an explanation for things that back then were likely to be interpreted differently.

Further, the PCOS diagnosis for Rimu also functions as a relief. Although his abdominal pain and stomach problems were pervading his quality of life, through the diagnosis they are brought into reality. As he says *"I am not crazy that I make this up"*[20] (Interview 1). Instead, his symptoms materialize in the PCOS diagnosis. What is more, the diagnosis also acts as a relief from constant (self-)blaming he had and has to experience because of his weight:

> "*[...] that I'm not just lazy because I'm fat, that it's not because I only eat fast food, even though I don't do that and never did [...] but that there's a medical reason, that was (pauses) actually a relief [...]*"[21] (Interview 1)

This is also another example of how one's identity perception of oneself is included in the enactments of PCOS bodies. Even though Rimu knew that his diet does not correlate to his weight, this embodied knowledge was constantly denied by medical practitioners, making himself deny it. Being constantly told that one needs to diet and exercise in order to lose weight, especially if done by medical practitioners, who are in a more authoritative position, at some point makes one question one's own self-perception. The PCOS diagnosis worked as a protection against this self-scrutinizing and relieved Rimu from blaming himself.

These insights into Rimu's story, again, demonstrate the situatedness of enactments. Experiences, bodies, identities, and diagnoses are re-constructed and brought into being through practices of storytelling, while being informed by other's narratives, collected knowledge and experiences, as well as the interview situation itself.

Gathering knowledge and experience was a major theme in this section. Therefore, in the following, I am going to return to focusing on the practices described in participants' stories with a particular attention to self-care.

[20] "[...] ich bin nicht bekloppt dass ich mir das einbilde und so [...]" (Interview 1)

[21] "[...] dass ich nicht einfach nur faul bin weil ich dick bin, dass es nicht daran liegt, dass ich einfach nur Fast Food esse, obwohl ich's halt auch nicht tue oder getan habe [...] sondern das halt ein medizinischer Grund bei ist, das war so 'ne (pausiert) schon 'ne Erleichterung dann [...]" (Interview 1)

6.5. Tinkering with self-care – navigating the system

Cooperating with one's *active body*, as described in Ash's story on their HRT experience, is a process of picking up and trying out techniques and 'tools' of managing and navigating PCOS, as well as embedding them into one's self-care repertoire. Such experimenting with embodied knowledge is part of a broader process of what Mol et al. (2010) describe as *tinkering*. Participants' stories are abundant with vivid illustrations of tinkering with self-care practices.

This multifacetedness of practices particularly manifests in Elm's reflection to my question and prompts on Elm's own approaches to PCOS care. In the following, longer sequence of fragments taken out of Elm's interview, different plotlines that evolve and are strung together condense into an illustrative narrative on trial and error, on the different twists and turns and the limits of caring for one's own body in light of uncertainty.

> "*Yeah so I bought this [PCOS] book, then [...] it was definitely recommended to me [...] a low carb diet, I also have a book for this, [...] where I am also sometimes a little scared so when I start extremely engaging in these diet things, that I somehow could relapse in this anorexia pattern [...], although I think that by now I am super far away from this but there are relatively high recidivism rates uhm and [...] so a friend of mine who also has PCOS uhm she has a mother who is a dietician and I also [got] some tips from her [...], then I was in this self-help group [...] at the very beginning where I didn't know anyone else which, however, was not really helpful. But I also had this PCOS association, there is this association where I was in contact with a person who did stuff with alternative medicine, with uhm chinese healing medicine and for me it was also always that I thought that I actually would like to try it out, but this was always connected to high costs and uhm oftentimes far ways and therefore I haven't done it yet.*"[22]

[22] "Ja also ich hab mir dieses [PCOS] Buch gekauft, dann [...] wurde mir auf jeden Fall empfohlen [...] Low Carb Ernährung da hab dann auch so 'n Buch dazu, [...] wo ich halt manchmal so 'n bisschen Schiss hab so wenn ich mich jetzt so krass mit diesen Ernährungssachen einfach beschäftig', dass ich dann wieder in diese Anorexie Schiene irgendwie reinrutschen könnte [...], obwohl ich glaub inzwischen bin ich echt super weit davon entfernt aber es gibt halt schon relativ hohe so Rückfallquoten ähm und [...] also 'ne Freundin von mir die auch PCOS hat ähm die hat 'ne Mutter die ist Ernährungsberaterin und von der hab ich dann auch so Tipps gesagt [bekommen] [...], dann war ich ja in dieser Selbsthilfegruppe ganz [...] am Anfang wo ich halt niemand anders kannte was, was mir aber wirklich nicht viel geholfen hatte. Hatte aber auch da diesen Verband PCOS, da gibt's irgendwie so'n Verband da hat ich auch Kontakt zu 'ner Person die irgendwie mit Alternativmedizin Sachen gemacht hat, mit ähm chinesischer Heilmedizin und das war bei mir auch immer so dass ich mal dachte so das würde mich eigentlich interessieren mit chinesischer Heilmedizin das mal ausprobieren, das war aber halt immer mit krassen

"*[...] and through my training as gardener (unintelligible) person who also did more of such studies of healing plants [...] yes, I also talked to her about it, then for some time I drank this red clover tea and tried out such teas and I think that I also somehow wasn't really patient enough but after one year thought well no, doesn't work [...]*"[23]

"*[...] uhm very recently I, I think I did this five times or something like that, then I dropped it again uhm PCOS yoga (laughs) uhm this account on Youtube, [...] this person is also super nice, [...] she really wants to [...] give people tips also how they can increase their fertility, this fertility yoga and stuff like that. But now I did this a few times and I also think that it can be helpful if you [...] do these exercises on your belly and that then the ovaries are uhm activated, I can imagine that.*"[24]

"*[...] monk's pepper that was great and I just stopped it five months or three months ago because uhm so the gynecologist also said yeah try leaving it out uhm and it was also a little expensive (laughs) uhm buying it every month, I also find it stunning that these things are not covered. The hormones were completely covered uhm that was, this annoys me (pauses) because uhm I think for me it really worked and I also know from others that monk's pepper really helped them but hormones are covered but things like these aren't.*"[25] (Interview 6)

Kosten verbunden und ähm oft weiten Wegen so und deswegen hab ich das bisher nicht so gemacht." (Interview 6)

[23]"[...] und durch meine Gärtnerausbildung (unverständlich) Person die sich einfach die so mehr Heilpflanzenkunde auch gemacht hat [...] genau mit der hab ich darüber auch gesprochen, hab dann 'ne Zeit lang so Rotklee Tee getrunken und versucht mit so Tees und ich glaub da war ich irgendwie auch einfach nicht so richtig geduldig genug sondern hab dann irgendwie nach 'nem Jahr gedacht boah nee funktioniert nicht [...]" (Interview 6)

[24]"[...] ähm ganz neu hab ich, ich hab das glaub ich fünf Mal gemacht oder so, dann hab ich's wieder sein gelassen ähm PCOS Yoga (lacht) ähm so'n Account bei Youtube, [...] diese Person ist auch super sympathisch, [...] sie möchte voll [...] Leuten so Tipps geben auch wie sie ihre Fruchtbarkeit erhöhen auch so ähm fertility Yoga bei ihr und so. Aber jetzt hab ich das so 'n paar Mal ähm gemacht und ich glaub auch dass es was bringen kann wenn man so [...] auf den Bauch ähm irgendwie so Übungen macht und so dass das dann irgendwie ähm die Eierstöcke so ähm aktiviert, kann ich mir gut vorstellen." (Interview 6)

[25]"[...] Mönchspfeffer das war super und das hab ich erst vor so vielleicht fünf Monaten so oder drei Monaten hab ich aufgehört damit weil's ähm also die Gynäkologin auch meinte ja probieren Sie's doch mal wegzulassen ähm und es war halt auch 'n bisschen teuer (lacht) ähm das jeden Monat zu kaufen, find ich auch krass dass dass sowas dann nicht bezahlt wird. Die Hormone wurden mir vollends bezahlt aber der Mönchspfeffer was eigentlich viel billiger ist wird dir nicht bezahlt ähm das hat, das regt mich auf (...) weil's halt ähm glaub ich bei mir auf jeden Fall voll gewirkt hat und ich von anderen auch weiß dass ihnen Mönchspfeffer schon voll geholfen hat aber Hormone werden dann gezahlt aber sowas nicht." (Interview 6)

Caring for one's PCOS body can take many different shapes, ranging from adjusting one's diet, drinking herbal teas, trying out yoga, or participating in self-help groups. These forms of care are obtained through reading self-help books, watching Youtube videos, or talking to friends and acquaintances. From this assortment of objects, people, and practices that one seeks and encounters living with PCOS, different bits and pieces are collected, added to one's care repertoire, or discarded if considered unhelpful. "As a result care as tinkering is always experimental and tentative, reflexive of its own presence and limits" (Ureta, 2016, p. 1535). While changing one's diet might come with beneficial effects, Elm, having a history with an eating disorder, needs to be cautious with this form of care. Thus sometimes care is a balancing act of finding approaches that fit one's individual needs without the risk that caring for one body-mind state worsens – or in this case reawakens – another. Other forms of (self-)care simply do not work. As Elm explains at an earlier stage in the interview, the self-help groups Elm went to primarily were centered around women sharing experiences on how, despite PCOS, they managed to lose weight and get pregnant – a form of care, that, while potentially helpful for some people, did not align with Elm's needs and which Elm could not identify with. Conversely, herbal remedies, like the red clover tea, are something that Elm generally is interested in and open about, which however, as Elm states, need patience. While care, indeed, is also future-oriented, some tinkering practices are focused on the "here and now" (Moreira, 2010, p. 136). Although the teas are promised to have potential benefits when applied with patience, this care approach does not align with Elm's expectations and needs in the present, and is therefore considered as not useful.

Further, this collection of interview fragments presents the multiplicity of knowledges Elm mobilizies in caring for PCOS. While implementing some medical insights, such as the recidivism rates of anorexia or the gynecologist's suggestion to terminate the use of monk's pepper, as guidance in Elm's self-care approaches, Elm also utilizes a range of 'alternative' medical knowledge, like traditional Chinese medicine, yoga, or different herbal remedies, as well as tacit explanations like Elm's statement of belly exercises 'activating' the ovaries, to make sense of the PCOS body and the care it requires. All these different knowledges provide different information about the body and PCOS, enacting these entities in different ways. By focusing on their applicability, Elm engages in the very form of coordination that is also described by Mol (2002) when exploring the decision-making processes of treating atherosclerosis in an individual patient. Through tinkering with different practices and forms of knowledge, Elm aligns these multiple enactments in accordance to their practicability, thus, patching them together into a new enactment, Elm's enactment of PCOS-care. Consequently, Elm, to paraphrase Mol,

creates a patchwork singularity, a PCOS-to-be-cared-for of Elm's own body, enacting "[a] composite reality that is also a judgment about what to do" (p. 72).

Moreover, Elm's reflection on herbal PCOS treatments also sheds light on a particular limit of care, as is further elaborated on in the last interview fragment reflecting on the use of monk's pepper. While this herbal medication was something that worked for Elm without being as invasive as the mixture of hormones Elm received prior to it, this treatment is not covered by insurance, and therefore can not be part of a sustainable care repertoire. It again points to the discrepancies arising from a singularizing medicine, as the linear notion of diagnosing a hormonal imbalance, adding the missing hormones, and thus, achieving a cure, blocks alternative roads on the health care trajectory. Such limits of (self-)care are further illustrated in Oleander's narrative:

> "*[...] yeah such things like if you make a hot water bottle, you put it on your back, that is on the lower back that I noticed actually helps more than if I place it on the front so uhm I actually found this really helpful it was one of the few tips that I found somewhere on the internet (pauses) apart from that (pauses) breathing so I do breathing exercises if I am in pain then I try to direct my breath in a way that the pain is better directed out of my body so to say (pauses) uhm so that I don't immediately have to take painkillers (sighs) which actually I don't really like but I mean who likes this anyway, and I try to take them only if I notice that it doesn't work any other way, if I notice that it's this, yeah, this pain which at some point also goes away again I really try to breath it away and reduce it through breathing exercises, I also try a few yoga exercises or something like this, so things like these also help but essentially you cannot do much.*" [26] (Interview 2)

Since Oleander does not like taking too many painkillers, he has acquired a variety of tactics to circumvent it while still being able to manage his discomfort and reduce his

[26] "[...] ja so Sachen wie 'ne dass man wenn man 'ne Wärmflasche macht, macht man's halt an den Rücken also unten im Kreuz das das hab ich gemerkt hilft auch mehr tatsächlich auch wenn ich's vorne hinlege also ähm das fand ich sehr hilfreich tatsächlich es war so eine der wenigen Tipps die ich irgendwo im Internet gefunden hab für (pausiert) ansonsten (pausiert) Atem also ich mach Atemübungen wenn ich halt Schmerzen habe versuch ich meinen Atem halt so zu leiten dass der Schmerz besser aus meinem Körper rausgeleitet sag ich mal (pausiert) ähm also dass ich halt nicht direkt immer ähm Schmerztabletten nehmen muss (seufzt) mag ich halt eigentlich halt auch nicht so aber ich mein wer mag das schon und versuch ich halt echt nur zu nehmen wenn ich merk es geht nicht anders wenn ich merk es ist so, ja so 'n Schmerz der geht halt irgendwann wieder weg versuch ich's wirklich weg zu atmen und über Atemtechniken das runterzukriegen versuch halt auch 'n bisschen so 'n paar Yogaübungen oder so, also sowas hilft dann halt aber grundsätzlich sonst kann man ja auch nicht viel machen." (Interview 2)

pain. These self-care practices range from positioning the hot-water bottle in a certain way to doing breathing or yoga exercises. However, it needs to be emphasized that such approaches oftentimes are merely workarounds and do not suffice in providing care that participants actually want and need. They merely pose "layers of labor that get [him] through the day" (Puig de la Bellacasa, 2012, p. 210). In studying non-binary activist forms of care, Seeck (2021) mobilizes this quote to express the role of (self-)care in the absence of institutional ressources. Likewise, while Oleander's approaches help him in managing his intake of painkillers and partially relieving his cramps, care that really would improve his quality of life would be having access to the hysterectomy and oophorectomy.

This is an important point because many care approaches that participants would like to receive, be they herbal medication or transition related healthcare services, are compromised by a lack of access, a medical practitioner's lack of knowledge on, or an unwillingness to care for their patient. This, again, reflects the skewed logic of choice manifested in Oleander's story. As Sara Ahmed (2014, para. 28) states "[y]our choices are compromised when a world is compromised". In her essay *Selfcare as Warfare*, Ahmed engages with Audre Lorde's (1988, 1997; as cited by Ahmed, 2014) work on care within an unequal social system. Self-care, as Lorde writes, is not self-indulgence, but rather it is self-preservation: "This kind of self-care is not about one's own happiness. It is about finding ways to exist in a world that is diminishing" (Ahmed, 2014, para. 23). The story of Oleander and other participants embody what Ahmed refers to as an unjust requirement of people who are being marginalized to become more resourceful in order to cope and manage within the system. Tinkering, thus, is not a refinement of the quality of care, but oftentimes it is a way to stay afloat (until access to much needed resources is obtained).

And even to achieve this access, participants have to become resourceful. They not only tinker with their bodies, they not only learn how to listen and react to them, but, over time, they also gather knowledge on how to articulate this bodily awareness to others:

> "*I think I was too young and inexperienced and also too anxious to back then communicate my interests so clearly as today, right, so today I have underwent uhm almost ten years of trans treatment, that is medical treatment, I roughly know how to tell medical practitioners where it hurts (laughs) or what I wish and back then I just didn't have a plan or an awareness for my body as I roughly have today as I would say.*"[27] (Interview 3)

[27]"Ich glaube ich war zu jung und zu unerfahren und auch zu ängstlich über meine Interessen damals so klar zu kommunizieren wie heute, ne, also ich hab heute ähm fast zehn Jahre trans Behandlung, also medizinische Behandlung hinter mir, ich weiß ungefähr wie ich ärztlichen Behandelnden sagen kann

Contrasting her early experiences with medical care with her current stage in her health journey, Aspen highlights her process of gathering a *Körperbewusstsein*, a corporeal awareness. It is another process of learning how to be attentive and listen to one's own body. But what also made Aspen more confident in interacting with medical practitioners were the nearly ten years of 'trans treatment' that equipped her with a sense for verbalizing her embodied knowledge in order to receive the care and the resources she needs. Articulating one's bodily state in a particular way, thus, is also a skill that needs to be acquired when undergoing medical care.

6.6. Collectivizing: Care as a collective practice

A broader theme that spanned the last sections, but has not been specifically addressed yet, is the involvement of different people in participants' PCOS care. Care can not be done alone, but always is a collective and relational practice (Puig de la Bellacasa, 2017).

Looking again at Elm's quotes in the previous section it becomes clear how people in Elm's life take part in Elm's self-care practices, for instance by connecting Elm with health care practitioners, or by suggesting teas to try out. In Rimu's case, his friends helped him find and get an appointment at an endocrinologist, make sense of his symptoms, and even receive his PCOS diagnosis. Accounts like these illustrate what Puig de la Bellacasa (2017) means when writing that care is an affective state and ethico-political obligation. People close to the participant become sensitized to PCOS by witnessing their life with it. Through their relationships to the participants, they also start caring for their struggles related to PCOS. They become part of the participants' caring networks.

As already demonstrated in Elm's story, queer communities play a particular role in this. The importance of exchange with people in similar situations is, for instance, manifested in Spruce's answer to the question: *What would you recommend a hypothetical fellow non-binary person who just received a PCOS diagnosis and does not know where to go from there?*:

> "*So I think what uhm would make super sense is, what for me added very very much is [...] to communicate with other non-binary and trans people, so trans, non-binary people in general, but also those who have PCOS themselves uhm because I think this is what I perceived as most comforting uhm also because, or the hope that what I actually was looking for to get from doctors uhm with*

wo's zwickt (lacht) oder was ich mir wünsche und damals hatt' ich einfach noch keinen Plan und noch kein Körperbewusstsein wie ich heute hab ungefähr würd ich so sagen." (Interview 3)

> *these appointments, I actually received from friends who somehow, yeah were able to assess it better.*"[28] (Interview 5)

While meeting with a singularizing PCOS enactment within the medical system, Spruce received the help they needed through connecting to queer contexts. Here, an affective relational assemblage is formed through shared experiences and struggles. To express it in Ahmed's (2014, para. 39) words, "that is why in queer, feminist and anti-racist work self-care is about the creation of community, fragile communities, assembled out of the experiences of being shattered. We reassemble ourselves through the ordinary, everyday and often painstaking work of looking after ourselves; looking after each other. This is why when we have to insist, I matter, we matter, we are transforming what matters."

Such assembling of affective communities is not merely limited to people from one's circle of friends and acquaintances. In particular, the internet is also an important tool to connect to people who are in similar situations, i.e. to (trans) people sharing and exchanging their experiences with and knowledge on PCOS. Oleander, for example, tells me how he prefers interacting with others through forums where people share their experiences in a more open and honest way. This exchange with others does not always need to be done in a direct manner. Some participants, like Aspen, just explore other's experiences through listening to their stories shared on YouTube, or silently reading through forum posts:

> "*So uhm it's called QPCOS, [...] I'm already part of it for a while and mainly only reading but it is definitely very interesting because it, it's input coming directly from people who write something about themselves and if you read that over a long time then you somehow get a more complete picture I would say as if you just read a dry Wikipedia article (laughs) or something like that uhm (pauses) yeah so this is definitely a cool insight because the people there also write about their own struggles and or maybe also what they like about it.*"[29] (Interview 3)

[28] "Also ich glaube was ähm was super sinnig ist, was für mich ganz ganz viel ausgemacht hat ist [...] dich mit anderen nicht-binären und trans Personen darüber austauschen, [...] also generell trans, nicht-binäre Personen, aber auch die halt selber PCOS haben ähm weil ich das glaub ich so mit am, oder für mich am wohltuendsten empfunden habe ähm so auch grade, oder so die Hoffnung dass was ich eigentlich mir bei ähm Ärzt*innen gesucht habe ähm mit irgendwelchen Terminen, hab ich eigentlich dann von Freund*innen bekommen, die's irgendwie, ja besser oder anders einschätzen konnten." (Interview 5)

[29] "Also ähm die heißt QPCOS, [...] ich bin da schon seit 'ner ganzen Weile dabei und hauptsächlich am mitlesen nur aber es ist auf jeden Fall total spannend weil es, das ist halt Input von Leute direkt die irgendwas von sich schreiben und wenn eins das liest über lange Zeit dann bekommt eins auch irgendwie 'n ganz vollständigeres Bild würd ich sagen als einfach nur jetzt 'n trockenen Wikipedia Artikel (lacht) oder sowas ähm (pausiert) genau also das ist auf jeden Fall 'n cooler Einblick weil da

The Facebook group Aspen describes here is full of diverse accounts and stories of PCOS told by many different people within the LGBTQIAP+ spectrum. In contrast to 'dry' explanatory texts which commonly present PCOS in a singularizing way, reading these posts over time enacts PCOS in its multifacetedness and multiplicity, and therefore is considered more helpful and insightful. Further, by sharing their struggles with or aspects they like about PCOS, people disclose their own relationship to it. What makes such enactment of PCOS 'more complete' is not only the richness of knowledge and experiences, but also the richness of affects embedded in these posts. Reading them, participants become affectively involved in the forum users' accounts, they can identify and relate to different stories, and they are cared for, not only because they receive practical advice, but also because there is a sense of collectivity being produced. It is an affective interweaving of thought and bodies (Seeck, 2021). Thus, even though being fragmented, heterogeneous, and temporary (Seeck, 2021), such online forums assemble into affective spaces of care.

However, as highlighted in the previous section, 'good' care also requires certain resources that are limited in lay domains. While participants had many negative experiences seeking medical care, they wish that medical practitioners would take a certain role in their PCOS care.

> "*I don't know, maybe I'd be, like an anti-vaxxer level, like sceptic about everything. I have no idea, that's, 'cause that's what happens when you go online and read all the medical information (laughs) so like, it's like it's like if you're not qualified, right like I'm not qualified, I should be trusting doctors, I shouldn't be making the decisions by myself uhm so it's, I don't, I honestly don't know what would be, like I think we should be able to trust our healthcare practitioners with basic risk assessment. I think human beings are horrible at risk assesment, like historically uhm and practically and this what doctors need to be able to do with these things without being uhm (pauses) kind of biased by their own weird hang-ups.*" (Interview 4)

As Ash describes, they do not consider themselves as qualified to make sense of symptoms and information they find on the internet, but in fact, consider it potentially dangerous to research everything on their own. Doctors' 'own weird hang-ups' should not stand in the way of developing a trusting relationship with their patients, although this is unfortunately often the case. While participants should be listened to and taken seriously in their needs and wishes, they should not be abandoned by medical practitioners. Rather, they wish

die Leute auch schreiben über ihre eigenen Struggles und oder halt was sie auch gut finden vielleicht daran." (Interview 3)

for guidance and support along their journey of caring for PCOS. What participants wish for is that their medical care providers are attentive, adaptive, and responsive in their inter-actions. A 'good' doctor-patient interaction, for Mol (2008), is an active "exchange of experiences, knowledge, suggestions, words of comfort" (p. 76). In this logic of care both medical practitioners and patients are crucial members of the care team.

Some participants, like Aspen, are lucky to have found a care provider with whom such an active and affective approach to care is possible. Aspen has a very cooperative relationship with her doctor, whom she describes as 'the endocrinologist of her dreams'[30]. She can rely on her bodily awareness, try things out and suggest treatment options, while the endocrinologist takes on a guiding role rather than strictly prescribing pre-defined treatments. There is no 'one-size fits all' treatment, especially in the case of such an uncertain bodily state as PCOS. Likewise, every patient has their individual needs that might change over time. Rather than trying to forcefully keep up a linear path from diagnosis to treatment to cure, doctors should use their knowledge to find what works for the individual, while the patient should be given the chance to actively engage in this. Thus, both should be actively involved in this collective tinkering.

Sometimes, such exchange of knowledge does not require many ressources. With health care being distributed over different spaces and departments (Mol, 2002) providing the patients with the right communicative tools for a moment when they are needed also is a form of care, as presented by Ash's story. The first time Ash experienced cyst bursts, it was a sudden unbearable pain. However, at that moment, they did not know what might have caused it. And even as they got to the emergency room, no one of the medical staff could really tell what was going on. At some point, they simply assumed that it was a UTI. While for Ash, this enactment of the pain they experienced was not coinciding with an UTI, it could not be clarified, since, as Ash points out, no ultrasound has been done. After a while, Ash went to a gynecologist, where the pain they experienced came up in their conversation. From listening to this explanation the gynecologist assumed that it might be a cyst burst. However, this enactment was not complete, as it was not really confirmed for ten years and an ultrasound had to be taken at the moment the pain occurred. That gynecologist that Ash saw told them how to talk to medical practitioners when another cyst burst happens and how to get an ultrasound to confirm it. Before that visit, the ontology of this pain was ambiguous and unclear; the medical practitioners simply did not know what to do. After that encounter with the gynecologist, Ash was provided with vocabulary which enacts this pain as a (potential) cyst burst and led to further practices (ultrasound exam) that finally could 'confirm' that enactment. Here,

[30]"die Endokrinologin meiner Träume" (Interview 3)

care was provided not through material means, but through the sharing of communicative 'tools' that facilitated the needed material resources in different contexts, illustrating how exchange of knowledge, too, is a form of care.

6.7. Transforming from ambiguous singular to tangible multiples: Queering PCOS

Looking back to the first section of this chapter, I described how PCOS-care is enacted in a singularizing way that perpetuates binary notions of gender and bodily states, and implies an approach of curing. This enactment, however, clashes with many different enactments of bodies, gender, and identities that participants employ. How, then, should practices of PCOS-care look like so that they can account for its multiple nature? Which enactments should 'win' over others in which situations?

> "*This is what I find so problematic that you always want to cure everything [...]*"[31] (Interview 1)

As Rimu suggests in this quote, the medical enactment of PCOS should move away from curing. To him, PCOS is not merely a disease in need of eradication. After one year, Rimu had to terminate HRT because it turned out that he is intolerant to both testosterone shots and gel, the two HRT forms that are covered by insurance. However, while not being on testosterone, he describes his body to 'run' on his PCOS[32] and giving him the appearance he is content with. PCOS, thus, is a part of his corporeality. Therefore, for Rimu the focus should not be on curing his body from PCOS, but rather caring for the symptoms that are experienced as troubling while leaving others alone:

> "*[...] and that it is accepted that I don't have a problem with having it, but that this one symptom is treated but the others are left okay.*"[33] (Interview 1)

Similarly, Spruce differentiates between PCOS symptoms that qualify it as 'disease' and those that do not:

> "*So the other (pauses) things were also not necessarily ideal uhm (pauses) but all that was something where I actually uhm (pauses) did not have the feeling*

[31] "Das finde ich halt so problematisch dass man immer alles heilen will [...]" (Interview 1)
[32] "[...] und laufe sogesehen nur auf meinem PCOS was mein Barthaarwuchs und so weiter angeht"(Interview 1)
[33] "[...] und dass das halt aber auch akzeptiert wird dass ich halt kein Problem damit habe dass ich's habe, sondern dieses eine Symptom halt behandelt wird aber die andern' ok gelassen werden." (Interview 1)

> *that I'm sick and in terms of abdominal pain and psychological things, there I really had the feeling I am sick and I need help with this.*"[34] (Interview 5)

One the one hand, aesthetic aspects of PCOS, although not always pleasant, were never a reason for Spruce to consider themselves 'sick'; on the other hand, the menstruation and mental health issues were symptoms that, for Spruce, were in need of caring. Through such enactments, PCOS becomes a spectrum onto which different symptoms are assigned different meanings, rather than being marked as 'disease' or 'syndrome'.

Elm goes a step further and questions whether PCOS should be regarded as a syndrome or a disease at all:

> "*[...] because I also look at this rather critically that it's just seen as a syndrome and sometimes I think huh, isn't that actually, am I not a living example that the [...] binary gender system simply does not work and that so many people do not abide to this, do not abide to this in many different ways [...]*"[35] (Interview 6)

Since, as described in the very first section of this chapter, PCOS is perceived as a relatively vague and ambiguous term and can look differently in different people, Elm questions whether there is even a need for such syndromification of PCOS. Rather than settle on a pathologizing enactment of PCOS, in which Elm's body is an anomaly, a defect, Elm takes Elm's own body as proof that bodies are diverse and dissimilar and cannot be fully grasped by binary categories. Through this narrative reconstruction Elm, thus, subverts the medical narrative on the 'natural' state of sex-gender:

> "*[...] especially if I look at the results and the arrows go up and down and so on that makes something to your mind and there I would, when you asked [...] how I imagine a successful treatment or a good treatment [...] that it's less depicted as something deviating from the norm and instead depicted more neutrally and not like with arrows up and down and in the middle if it's perfect or that one is not constantly told that is too high that is too low but rather uhm that one tries (laughs) maybe like me, [...] to find formulations in a more*

[34] "Also die anderen (pausiert) Sachen sind jetzt auch nicht unbedingt ideal gewesen ähm (pausiert) aber das war alles irgendwie was wo ich eigentlich nicht das (pausiert) ähm das Gefühl hatte ich bin krank und was so Unterleibsschmerzen und psychische Sachen anging, da hatt ich wirklich das Gefühl ich bin krank und ich brauch da Hilfe mit." (Interview 5)

[35] "[...] weil ich halt auch dem so kritisch gegenübersteh' dass das einfach als 'n Syndrom gesehen wird und denk manchmal so hä, eigentlich ist es nicht 'n-, bin ich nicht so wie so'n wandelndes Beispiel dafür dass [...] das binäre Geschlechtersystem halt einfach nicht funktioniert und dass so viele Leute die dem nicht entsprechen, auf verschiedene Weise nicht entsprechen [...]" (Interview 6)

> *neutral language, that people don't say this is sick and this is healthy and this is uhm uhm because of this you are male and because of this you are female.*"[36] (Interview 6)

Elm's reflection on the visualisation of blood test results highlights the ontological consequences of diagnostic technology. "Through its technology — X-rays, MRIs, blood draws, EKGs, CAT scans — diagnosis transforms our three-dimensional body-minds into two-dimensional graphs and charts, images on light boards, symptoms in databases, words on paper. It holds history and creates baselines. It predicts the future and shapes all sorts of decisions. It unleashes political and cultural forces." – diagnosis, thus, comes in different incarnations (Clare, 2017, p. 41). In this example, hormonal thresholds are entangled with norms for sex, which, in turn, are entnagled with notions of sick/ healthy. Arrows indicating that something in Elm's body is 'too high' or 'too low' enact it as sick, as deviating from a normal that needs to be (re-)established, while thus causing distress for the participant. For Elm, good care would mean dissolving these entanglements, breaking away from the binaries and seeing more than just exceedance or undercut or a certain threshold.

Oleander's enactment of PCOS, however, is different. To him, PCOS is clearly a disease that needs to be treated and taken seriously. Unlike Rimu, Oleander does not receive any benefits from it. In his narrative, PCOS is clearly confined to specific body parts and thus can be treated through a straight-forward intervention:

> "*[...] so I have nothing positive [...] in terms of my ovaries and my uterus because I have PCOS plus endometriosis of course.*"[37] (Interview 2)

Also, while he, too, experienced increased testosterone levels and, thus, increased bodily hair growth, at no point during the interview does he enact PCOS as part of himself that validates his gender. Contrasting the accounts above, PCOS is ejected from Oleander's embodiment. It is merely a syndrome that he suffers from. This contrast points to a notable tension that is also discussed in Wendell's (1993) critique of common feminist

[36] "[...] vor allem wenn ich diese Auswertung mir anguck und da sind die Pfeile nach oben und nach unten und so das macht halt alles was mit der Psyche und da würd ich mir wo du gefragt hast [...] wie stell ich mir erfolgreiche Behandlung oder 'ne gute Behandlung vor [...] das ist weniger ähm so als was [...] von der Norm abweichend ist dargestellt wird sondern einfach neutraler ähm dargestellt und nicht mit irgendwie Pfeilen nach oben nach unten und in die Mitte wenn's perfekt ist oder nicht immer gesagt wird das das ist zu hoch das ist niedrig sondern das ähm eben so mehr (lacht) so wie ich vielleicht versuch Dinge zu formulieren [...] aber mehr versucht wird da 'ne 'ne ähm neutralere Sprache zu zu finden die nicht ähm sagt das ist krank und das ist ähm gesund und das ist ähm ähm deswegen sind Sie männlich und deswegen sind Sie weiblich." (Interview 6)

[37] "[...] also ich hab nichts Positives [...] an meinen Eierstöcken und an meiner Gebärmutter weil ich PCOS hab plus noch Endometriose natürlich."(Interview 2)

narratives on the body. Narratives, which commonly emphasize pride and acceptance of one's body, disregard, as Wendell argues, experiences of the *negative body*, in which the body is "a source of frustration, suffering, and even torment" (p. 117). If your body brings you pain, it is difficult to find joy in and identify yourself with it. Therefore, in line with Wendell's argument, it is important to highlight for my own inquiries into PCOS, that silencing these experiences in novel queer-feminist PCOS ideas of the bodies leads to further exclusion of those who already do not fit into the normative understandings of bodily experience. I will come back to this point with regard to the materiality of embodiment and care in my discussion in **section 7.2**.

Evidently, participants, and, looking back on the previous sections, even single individuals, enact PCOS in multiple, even contrasting, ways. So, how to account for this multiplicity?

> "*[...] a broader view, so in every domain both [...] in society itself and the medical practitioners, that it's more than this one problem [...]*"[38] (Interview 1)

PCOS, as Rimu remarks, is more than facial hair growth or potential infertility. Caring for PCOS means much more than merely caring for these symptoms. Instead, speaking through Puig de la Bellacasa's (2017) lens, caring for PCOS means caring for the entire relational web the person and their PCOS body are entangled in. Instead of enacting PCOS in a singularizing way, and putting this monolithic dome over every person experiencing a certain set of symptoms, instead of describing their bodies through some vague, ambiguous singular, the diagnosis should be considered in regard to the individual and their unique experiences, wishes, needs, and relationalities. Rather than holding on to some form of presumed scientific objectivity – or put in Ingraham's (2005) words, *thinking straight* – this case calls for different modes of knowing – for *queering* (Light, 2011) PCOS.

As expressed by Light (2011, p. 432), "to queer something, taking the Greek root of the word, is to treat it obliquely, to cross it, to go in an adverse or opposite direction. It has movement and flex in it. Queering is problematizing apparently structural and foundational relationships with critical intent, and it may involve mischief and clowning as much as serious critique". Going astray from this straight path, seeing the person and their body intertwined in a knot of multiform lines clears the way for different enactments that can capture their lived experiences in much more accurate ways, it gives space to tangible multiples.

[38] "[...] 'n breiteren Blick, also halt in jedem Bereich sowohl [...] in der Gesellschaft an sich als auch bei den Medizinern, dass es halt mehr als dieses eine Problem ist [...]" (Interview 1)

Participants already employ a variety of queering practices in their own care repertoire, be it challenging normative descriptors, weaving counternarratives to the framework of cure, regarding their PCOS bodies not as defects but as proof that bodies are diverse and can come in multiple forms, or forming queer assemblages with others. A significant role in such queering practices is played by language:

> "*And I think these categories, it's not like, like I think we should actually have sixteen genders, you know like in terms of meaningful categories to describe major shared experiences.*" (Interview 4)

This quote is a fragment from Ash's reflection on the power of queer terminology. Using terms like 'transmasculine' to describe their gender identity, or 'euphoria'/'dysphoria' to express one's relation to one's PCOS body, can capture lived experiences in a more nuanced and multiple way. It offers forms of verbalizing body-mind states that go beyond confining medical boxes, and thus provides words to connect and bond over with others:

> "*[...] so it's important for us to have these identifiers that express our life experience that allow us to relate to other groups and like share those experiences [...]*" (Interview 4)

Rather than employing one single label (such as 'PCOS') queer(ing) terminology can direct care at other things than merely blood levels and ulrasound exams, or whether one is or is not able to have children. It can grasp the multiplicity of experiences that people, whether or not they are queer/ trans, have while living with PCOS, affect them on different levels, and thus, bring them closer together and encourage care for each other. Multiplying, nuancing, and ultimately, queering PCOS, focusing on how individual people would like their bodies to be beyond rigid binaries of male/female or sick/healthy, has the potential to offer care for different, even contradictory, enactments of PCOS, since the aim would be to find what 'works' for the individual. "*Because*", as Aspen concludes our interview, "*the trans experience is just simply entirely heterogeneous for all people, right, so it's always about the right thing for oneself.*"[39] (Interview 3).

6.8. Anticipating the unanticipatable – imagining queer utopias: The future of (trans) PCOS care

Throughout this chapter, I have illustrated how telling different stories about the body, and how tracing and weaving different lines and relationalities is itself a crucial practice

[39] "Weil [...] the trans experience ist ja einfach komplett heterogen bei allen Leuten, ne, also es geht ja immer um das Richtige für eins selbst." (Interview 3)

of care. In this last section, I would like to shed light on two forms of how the future plays a role in my interlocutors' meaning-making of PCOS.

Since PCOS and the way it influences the body throughout the years is very uncertain, thinking about the future means coordinating the things one can and can not anticipate:

> "*I think in the future I'll just be very curious what happens with like period regularity if I'm not having any external hormonal influence like I'm very excited to not have any hormonal influence, that would be very cool, you know, like no birth control, no nothing, just just me and my cycle, man (laughs) out in the woods uhm I don't know what menopause might look like. Like that seems, but like I also kind of, I could kind of look it up, but I also am very sceptical that there's any really extensive information about it so I feel like I don't wanna freak myself out uhm and I'm (pauses) I think as I'm getting older, I would wanna be like I've also been considering when I go off testosterone to look into various like hormone regulation things like Maca root or whatever uhm if that would be helpful uhm if I do end up having some sort of distress about my period. So I've had, I've said like done minimal amount of research about it but honestly it's like, I'll cross that bridge when I have to and I would much rather have like a trusted health care practitioner uhm rather than read a bunch of shit on the internet.*" (Interview 4)

HRT and PCOS: Precaution

Before starting HRT, Rimu's blood work results he had to obtain prior to the intervention were explained to him to exhibit 'testosterone levels of a sixty year old man'. For his endocrinologist this was a reason for precaution. As Rimu was told, undergoing HRT with PCOS came with the risk of exacerbating the testosterone levels even further, which could eventually lead to anemia. Therefore, the HRT was approached under precautionary measures. Rimu's endocrinologist started with a lower dosage and gradually increased it, while closely monitoring his blood work to be able to adapt the testosterone if necessary.

Ash's stance towards the future, particularly the aspects that are indeterminate, is mixed. They anticipate the time after terminating HRT with excitement and curiosity. While uncertain, it poses a new kind of embodied experience for Ash, a body that, connecting to **section 6.3**, *acts* without any type of hormones. While this form of embodiment lies in the near future, because Ash plans to go off testosterone in a couple of years, this quote also features a more concerning aspect located in a much distant point in time, namely

menopause. Strikingly, in the fact that they bring up menopause as an uncertain and potentially concerning stage in life with PCOS, an active process of thinking about and anticipating the future can be witnessed. The first time this concern came up was at an earlier stage in the interview, when Ash spoke about their mother aging and being told to prepare for menopause:

> "*[...] so yeah uhm no idea, and yeah I have no idea whether this affects menopause in any particular way, this literally did not occur to me until I just said it now with respect to my mum [...]*" (Interview 4)

Now, towards the end of the interview, it comes up again with regard to Ash's own future in their body, illustrating how this certain form of risk anticipation is both conveyed to them through the relationship with their mother, as well as a broader social context, since having to prepare for menopause is something their mother is being told by her social environment.

HRT and PCOS: Testosterone as an artifact

When I asked Aspen whether her doctor mentioned any risks or any specific measures that need to be considered in regard to PCOS and HRT, she said that while this actually is an interesting question, she was never really told anything about that topic. As she described to me, the bodily testosterone is like an artifact which is overwritten by the external testosterone that you get through HRT. Therefore, her endocrinologist also did not take any particular precautions and just started with the regular testosterone dosage.

Further, not only is this something they apparently have never thought about before, but also, as they point out, they do not hope to find this information on the internet. It is clearly something that, at this point in time, can not be known, and thus comes with potential distress. To deal with the indeterminate and coordinate this potential distress, Ash, in their following sentences, engages in a practice of distribution which is done along two lines. First, while in Mol's (2002) case, different enactments are distributed throughout different hospital departments in order to keep them from clashing, distribution here is done along different moments in time. To avoid potential tensions, certain practices belong to a different point in time, in a different constellation of actors and elements. And this is where the second form of distribution comes in. By, again, voicing their wish for a health care practitioner they can trust, Ash also distributes a part of the responsibility to handle this uncertainty to someone within an expert position. Although the process of aging with PCOS is uncertain, Ash, in this scenario, does not have to go about it alone. Like in **section 6.4** this reflects

the importance of an attentive and caring relationship with medical practitioners. Even if times are uncertain, attentiveness and commitment to find practices that work (Mol, 2008) can function as a safety net.

HRT and PCOS: PCOS treatment?
While not mentioning any particular risks or measures, Oleander's doctor congratulated him on soon being over with the 'whole PCOS topic', implying that his main PCOS issues, which are cyst bursts and severe menstruation cramps will stop after starting HRT – an effect that would enact HRT as a PCOS treatment for Oleander. However, after starting HRT, he experienced an unwanted side effect that exacerbated his problems. Since Oleander's period started to become regular, he had to endure these severe PCOS symptoms every month. Considering the conventional PCOS treatments that aim at period regularity, HRT, in this case, acts as a PCOS treatment in a medical sense. Since Oleander, however, does not want that for his body, it is a negative side effect of HRT that he wishes to take care of.

The second form of dealing with the future is utilizing it as a tool in order to speculate on how things could be otherwise and imagine what alternative values and practices could be to the fore (Dunne & Raby, 2013). I would like to close this chapter with this snippet from Elm's interview imagining a world of affective and inclusive PCOS care, as I think it vividly summarizes a multitude of things discussed in this chapter. It, too, contains ideas of how care practices could be distributed to make them more diverse and viable. It, too, designates PCOS care to a collective domain. And it, too, entails a particular notion of queering in regard to the future, which will be of particular attention in these final paragraphs.

> "*Definitely that the doctors inform you about that, that bodies can function very differently, that there aren't only two genders, that [...] there are places to go for people who are outside of this [...] how can I phrase this in a good way, well uhm that doctors just maybe, yeah uhm simply say (laughs) uhm there is a diversity of uhm genders or they say uhm gender is a social construct and that [...] there is a universe and (laughs) uhm I think that is very very far uhm from how it currently is and I think I would find it good if they just (pauses) yeah you can also formulate utopias if you wish, but uhm I would also find it great if they refer you to places to go to, if they say uhm that is really dangerous, we have to keep an eye on that, that is something where uhm many people in our society have problems with, you can do something about it if [...] that it's just made transparent that these are things they are harmful to the body according*

> *to the current state of research. These are things uhm where you maybe have to be careful in regard to mental health but there are places to go if you want to find out how [...] you actually want to be with your body and so on because (pauses) I think many people do [not] know this, so I definitely, I can say from my perspective that I didn't have an idea of how [...] I want my body to be, or to this day it is really a process [...]*"[40] (Interview 6)

This longer quote, too, illustrates an active process of formulating the future. Particularly the increased number of pauses and turn-offs in this fragment manifests how, incited by my question on how Elm would imagine 'good' PCOS care, Elm in this very moment is engaged in weaving a potential version of reality. It, hence, presents an act of collective futuring, of searching for the right words, and thus, for the significant and the valuable within a range of possibilities. Notably, in this train of thought, particularly in its initial stage, Elm is jumping back and forth between how it currently is and how it should be, very hesitantly approaching an ideal version of the future. Here, the shared affect between me and my interlocutor plays a particularly important role. We both laugh at the idea of doctors dropping gender categories, as we both know that this is far from how reality is. We are aware that, while the future offers a multitude of possibilities, they are constrained by prevailing power relations (Chakkalakal, 2018; as cited by Seeck, 2021). But what resonates with me is Elm's following sentence "you can also formulate utopias if you wish." Here, the queering of PCOS care is the utopian, but the queering is also a form of imagining the utopia of PCOS care. This dynamic between queerness and the future is particularly vividly illustrated in the opening of José Esteban Muñoz' (2009) book *Cruising Utopia*, which is why I would like to cite a longer passage from it:

[40] "Auf jeden Fall [...] dass die Ärzt*innen ähm einen selbst aufklären darüber dass es, dass Körper sehr unterschiedlich funktionieren können, dass es nicht nur zwei Geschlechter gibt, dass es [...] Anlaufstellen gibt für Menschen die sich außerhalb dessen [...] befinden [...] wie kann ich das gut formulieren naja ähm dass die Ärzt*innen halt vielleicht, ja ähm einfach grundlegend sagen (lacht) ähm es gibt einfach 'ne Diversität an ähm Geschlechtern oder die sagen ähm dass ähm Geschlecht 'n soziales Konstrukt ist und dass [...] da ein Universum ist und (lacht) ähm das ist aber halt glaub ich sehr sehr weit ähm ab von dem wie's gerade ist und ich glaube ich fänd schon sehr gut wenn sie einfach (pausiert) ja man kann ja auch Utopien formulieren wenn man sich wünscht, aber ähm ich fänd auch super wenn sie einem Anlaufstellen geben, wenn sie sagen ähm das ist wirklich gefährlich, da müssen wir drauf gucken, das ist das wo ähm viele Leute in der Gesellschaft Probleme haben mit, da können Sie was machen wenn [...] einfach so transparent gemacht wird das sind Sachen die schaden dem Körper nach heutigem Stand der Forschung, das sind Sachen ähm da müssen Sie mit ihrer Psyche vielleicht gucken aber da gibt's Anlaufstellen auch wenn wenn Sie 'rausfinden wollen wie [...] Sie mit Ihrem Körper überhaupt sein wollen und so weil (pausiert) ich glaub dass viele Menschen wissen [nicht] bescheid, also ich auf jeden Fall kann jetzt von mir aus sprechen dass ich nicht so 'nen Bild davon hatte wie [...] ich meinen Körper jetzt haben möchte, oder bis heute das voll der Prozess ist [...]" (Interview 6)

> We may never touch queerness, but we can feel it as the warm illumination of horizon imbued with potentiality. We have never been queer, yet queerness exists for us as an ideality that can be distilled from the past and used to imagine the future. The future is queerness's domain. Queerness is a structuring and educated mode of desiring that allows us to see and feel beyond the quagmire of the present. The here and now is a prison house. We must strive, in the face of the here and now's totalizing rendering of reality, to think and feel a *then and there*. (p. 1, emphasis in original)

This striving towards how things could be otherwise, this imagining in spite of the present's seeming inflexibility embodies so much of what care in Puig de la Bellacasa's (2017) – and, as elaborated in **chapter 2**, others' – sense is about. To care means to stay with the trouble, to be committed and involved and to never take things as 'finished'. It is about the ability to imagine how things could be different, the tracing, drawing, and connecting of lines, being continuously engaged in a game of string figures (Haraway, 2016). For, "SF is storytelling and fact telling; it is the patterning of possible worlds and possible time, material-semiotic worlds, gone, here, and yet to come" (ibid., p. 31).

7. Embedding: Discussion and conclusion

"[I]t matters deeply both how we care and who cares for these assemblages we are."
– Hil Malatino, *Trans Care*

Informed by online articles, Youtube videos, forum discussions, medical guidelines, as well as my personal experiences, I started this thesis off by outlining different potential challenges of seeking medical PCOS care as a trans person. In the subsequent chapter, these challenges were tied to broader discussions on classifications, norms, power relations, exclusions and ignorance, as well as different acts of speaking back, resurrecting subjugated forms of embodied knowledge and approaching them with care. This line of thought ultimately led to the research question: *How do trans people enact PCOS, and what does that tell about care through standardized medical practices?*

As supported by my findings in the previous chapter, seeking medical care confronts participants with a singularizing enactment of PCOS, which imposes a set of pathologizing and gendered norms upon their PCOS bodies, while neglecting, ignoring and de-problematizing their individual needs and concerns. Participants' enactments and their coordination practices, however, are multiple, situated, non-linear and embodied, unfold along different temporal trajectories and are embedded within diverse constellations of human and non-human actors. They highlight how making sense of PCOS and caring for it is inextricably entangled with making sense of one's own body and identity. They illustrate how self-caring for PCOS means being involved in various acts of tinkering with objects, remedies and knowledges, but also how systemic discrepancies create limits to self-care. They, further, show how collectivity both within and beyond the medical context is a crucial and indispensable element of caring for PCOS.

Along these multiple lines, participants embody a range of practices that twist, subvert and reinterpret medical and socio-cultural master narratives on their bodies and identities, ultimately queering PCOS. As demonstrated, queering can be done through adoption and usage of new labels and categories, reconstruction of medical narratives on notions

of 'normal' and 'natural', assembling within queer affective communities, or envisioning queer utopias to speculate about the features of 'good' PCOS care.

In this final chapter, I would like to take up the different strings weaved in the previous chapter and trace their further implications for the broader structures of trans PCOS care. While engaging in bundling up the various strings, I will be guided by the two parts composing my research question. Its first part, the multiple ways PCOS-care is enacted by my participants and how this multiplicity is characterized will be revisited in further detail in the following section. Subsequently, the implications of such enactments for medical PCOS care and the tensions arising from their encounters will be discussed along the lines of their material consequences, as well as the broader infrastructures of care in **section 7.2**. Lastly, in **section 7.3**, I am going to reflect on the limitations of this project and provide an outlook on further avenues for research on this case.

7.1. Multiplying the singularized: Contours of PCOS-care

Approaching a case through the lens of multiplicity "highlights that there are many possible ways of seeing, feeling, doing or being a particular thing. Multiplicity resists reductionism and invites an exploration of the many possibilities of things" (Setchell et al., 2018, p. 166). My empirical findings started off with accounting how participants, when seeking medical PCOS care, are confronted with what I called a singularizing medicine. While classifying, standardizing, and normalizing is an all through human practice (Bowker & Star, 1999) that can yield productive ways of navigating the world, participants' stories highlighted how, structured by relationalities of power and inequality, such practices bear dangerous implications. As shown by their different encounters with the medical, such approaches push participants' bodies into singular, compartmentalized boxes, and, in the course of doing so, disregard and render invisible the multiplicities of their (sex-gender) identities. Combined with normative and transmisic notions on the body, and sometimes even explicit ignorance, this singularizing medicine leads to denial of knowledge, dismissal of autonomy, and, ultimately, uncare.

However, while the PCOS care my participants encountered tends to operate along such singularized notions, nothing about this case is singular – neither in regard to participants' meaning-making practices, nor the medical realm itself. Albeit the research question by which I entered the field was neatly structured into three distinct aspects – focusing, first, on participants' 'own' enactments of PCOS, second, their interactions with 'medical' enactments, and third, participants' ways of living with and managing the syndrome – my narrative representation of my interlocutors' experiences clearly illustrated the difficulty

to tackle these three aspects in a distinct way. As reflected by the term 'PCOS-care', they all are entangled in inextricable ways. Lines that are drawn together, entangled, or suspended between points (Ingold, 2016) give rise to certain shapes – shapes that exhibit different contours. While PCOS-care is multiple, and thus constantly in flux, tracing its contours brings out the different spatio-temporal dimensions, the multiple paths, and the diverse dynamics through and along which practices of making sense and caring for PCOS unfold, assembling into various shapes. These contours can be articulated as follows.

First of all, participants' PCOS enactments do not exist in vacuum. Rather, 'their' PCOS is emergent, provisional, and continuously assembled by a multitude of various elements located in different domains: Their embodied perceptions of the syndrome and individual (bodily) needs, goals, and trajectories; shared experiences with, or advice and support from friends, family members, or fellow trans people with PCOS (on the internet); art and media; the wider queer community and related 'repertoires', such as language and aesthetics; but *also* medical enactments. To sum it up by Schillmeier's (2017) words "[b]odies and minds become affected by, relate, interact with and become dependent on others in different ways than they are used to be" (p. 60). Thus, collectivity, both in regard to humans and non-humans, plays, as I have illustrated, a key role in doing PCOS-care.

Second, informants' PCOS-care unfolds along various non-linear paths. Enactments are never predefined or static. They are in a constant state of becoming, being shaped and altered as they move along the course of PCOS treatment, reaching out into and unfolding along other lived trajectories, such as transitioning, moving, or aging. Contrasting the research on women's experiences with PCOS outlined in **section 2.6**, which presents their journey along clearly distinct stages, my thesis emphasizes how the trajectory of PCOS-care is characterized by constant twists and turns, going back and forth between different junctions, and a continuous switching of paths. Nonlinearity and situatedness could be observed both on a temporal level, i.e. the ways how past, present, and future played a role and made a difference in terms of narrative PCOS enactments, as well as, connecting to my argument above, on a material level, i.e. within the constant re-assembling of different relational webs shaping participants' meaning-making of their bodies and selves. Thus, rigidly distinguishing 'their' enactments from 'other' enactments or assuming that one temporally or spatially precedes the other is not compatible with these observations.

Third, as symbolized by the hyphen between the terms, enactments of PCOS are inextricably intertwined with participants' (visions of) care. In line with Mol's ontological framework, (self-)care practices, be it the type of medication or life-style measures one

takes, what kind of intervention is desired, or what risks one is concerned with and what provisions one takes in regard to them, inevitably lead to a particular enactment of PCOS, and vice versa. Further, participants' vision of how PCOS ideally should be tackled by medical care, and what things to be attentive to along this speculative commitment (Puig de la Bellacasa, 2017) of caring for PCOS, are direct consequences of their enactments of the syndrome. Here, even the body itself plays an active part in enacting PCOS-care. Continuous attentiveness to bodily functions and reactions, such as processing hormones, experiencing pain, or cramps, developing a corporeal awareness, and learning how to communicate it to others, result in a hybridization between knowing the body and inhabiting it. As Schillmeier (2017) argues, "[t]o look at caring relations as shifting and situated reveals that caring about one's body is to learn to have a body through embodied and material relations in multiple ways" (p. 60). PCOS-care is, thus, a deeply embodied practice. And since bodies are not spatially confined, but have leaky and fluid boundaries (Mol, 2008; Mol & Law, 2004), caring for PCOS is closely entangled with caring for other things in one's life. A particularly distinctive example of this dynamic, in this case, is the intermingling of the PCOS body with sex-gender. The ways one's identity is performed, explored, and made sense of, merges with participants' corporeal experiences, including and shaping each other. Labels and descriptors, like inter* serve to account for the experiences one makes when living in a certain body, a body that is looked at and judged in a particular way, and in turn, through enacting empowerment and validation in regard to one's own identity, shape one's embodiment of PCOS.

In sum, enactments of PCOS-care are highly contingent, emergent, and provisional. They involve a constantly changing assemblage of other elements, are non-linear, situated, and deeply embodied. What, then, does this entangled assemblage of PCOS-care imply for the material world structured by standards and classifications?

7.2. Structuring, re-structuring, subverting: The materiality of enactments and infrastructures of care

To answer the above-mentioned question, it is crucial to revisit the world-making effects of care. As Latimer and Puig de la Bellacasa (2013) summarize: "If to care is to be attracted, to be lured by the recipients of (our) care in a relationship that not only extends us but obliges us to take care, then a world is being made in that encounter that rather than determining (us), shifts (us) and (our) priorities. There is nothing before care that comes to be determined by it: rather ontology has care hardwired in it" (p.

161). To whom and what our care is directed at has material consequences. It forms a web of specific relations, while disregarding and dropping others. Conversely, classifying, standardizing, normalizing, making, and doing, in sum, enacting the body in a certain way is also simultaneously a judgement of what to do (Mol, 2002), i.e. how to care for that body. Hence, the ways we see and do the world determine the direction our care is headed, and vice versa.

While, in this thesis, my attention was drawn towards the micropractices that give rise to this relation between knowing and caring, the broader political implications of this intermingling of material and discursive can be observed when tending to the broader infrastructures trans PCOS care is situated in. For, if a set of classifications, standards, forms of knowing, values and practices become deeply embedded into other socio-cultural and technological structures and arrangements, if they become stabilized and last beyond a single point in space and time, and if they are taken for granted, seen as evident, and shape the communities of practice relying on them, then these sets of repertoires can be understood as infrastructures (Star, 1999). Infrastructures are not merely physical objects, but can be regarded as "emergent systems that produce variable practical ontologies—novel configurations of the world and its elements" (Jensen & Morita, 2015, p. 84). Because infrastructures are both ecological and relational (Star, 1999), and are a complex, heterogeneous process of relating and redefining actors (Jensen & Morita, 2015), they are inherently political (McFarlane & Rutherford, 2008), and their politics is experienced on a deeply embodied level (Lancione & McFarlane, 2016).

Thinking my results through an attentiveness to infrastructures, thus, renders the materiality of enactmens more evident. This lens highlights how the observed tensions between the dis-order of participants' bodies that was enacted and imposed on them by their medical practitioners and the consequent de-problematization of the issues participants were seeking care for is rooted in and gives rise to material worlds.

How enactments of PCOS-care materialize in different constellations, and how this material world affects and infra-structures participants' lives can be observed when revisiting the interplay of participants' forms of enacting and inhabiting their bodies. In the previous chapter I emphasized how participants understand and experience PCOS in a very fluid manner. In a simplified view, PCOS can be considered a spectrum – some parts of it are perceived as disease, they have painful and burdensome fringes, other parts are not considered an issue, and instead, are seen as characteristics of one's body, and sometimes are even included into one's identity.

Starting with the enactments of PCOS as part of one's gender-diverse body gathers insights into the tensions they bring along. Elm's embodied identity, for instance, is torn

between differently enacted realities. As an answer to pathologizing and concern-inducing enactments, Elm sees the own body as a 'living example' that constructs of sex-gender do not reflect nature in an adequate way. Taking the matter of Elm's body as 'proof' for its naturalness, thus, works as a reclaiming of this body's *trans* natures* (Barad, 2015). However, moving through the world in this body, Elm is constantly experiencing how it does not fit into this material world. Medicine enacts Elm's body as deficient, as in need of cure and correction; it needs to be molded, re-shaped in order to align with what is considered to be natural. In turn, this also structures Elm's life inside this body, as Elm has to be constantly engaged in taming this 'unruly matter', push it into the prescribed framework and avoid its transgression.

Through these entanglements of matter and norms, participants' queer ontologies are constantly under attack (Hayward, 2017) by medical care. This, in tun, also affects the ways one feels about/in one's body, and which of its aspects are included into one's enactments of self. Further, it also denies the material means necessary for the survival and flourishing of queer bodies. If queer ontologies are under attack, so are the infrastructures that sustain them, and vice versa.

Other ends of this PCOS spectrum reach towards the realm of disease, namely when participants' material bodies are disconnecting them from the world. Such enactments manifested in accounts like Rimu's experiences with stomach pains, Oleander's struggle and complications with cyst bursts, or the syndrome's effects on Spruce's mental health. Again, as I have touched upon in **section 6.7**, it is crucial not to ignore the pain that comes with certain body-mind states in the name of empowerment. Wendell's (1993) critique that I briefly outlined above, is particularly targeted at feminist theories' stances against the idea of transcendence and their advocacy for embracement of the body instead. "Yet", as she argues "feminist theory has so far failed to appreciate the strength of another motive for wanting to transcend the body. We need to recognize that much of the appeal of philosophies of life which recommend some form of transcendence of the body lies, not in elevation of the mind and denigration of the body, but in the desire to make one's happiness, or at least one's sense of self, independent of illness, pain, weakness, exhaustion, and accident." (p. 116). While I agree, that feminist theories of embodiment need to be more nuanced and attentive to the lived realities of those inhabiting certain bodies, my argument for this particular case is not in favor of the body's transcendence. Instead, in accordance with Mol (2008), I argue for giving the body space to actively partake in the process of care. While transcendence implicates immateriality, care is done in and through our material world, and acknowledging the body as an active part can grant insight into the material means necessary for its care.

Here, however, lies the paradoxical nature of medical PCOS care. While participants, on the one hand, are constantly made aware that their bodies, as they are, do not fit into the world and that they need to be 'cured' from this visible difference, PCOS as a category is on the other hand, relatively ambiguous and impalpable. Consequently, this ambiguity leads to the absence of caring infrastructures. Despite life-threatening complications Oleander does not receive the surgical procedure he wishes because his symptoms are considered not 'severe enough'. Rimu, although having tried out his doctors' recommendations several times, is not offered an alternative to weight loss. As Danholt and Langstrup (2012) argue, infrastructures "are never simply there or not there, they are potentially existing and emergent" (p. 518). In this case, accessibility to certain infrastructures of care depends on the category one is put in and the connected expectations and norms attached to that classificatory label. Particularly the double standards set for trans and assumingly cis people as identified in **section 6.1**, reveal how this dynamic, again, is related to norms on what is considered 'normal' and expected, and what is not. As soon as Oleander's access to transition-related interventions are approved and the regulatory process of 'assessing' his body as trans is finished, he obtains access to the oophorectomy and hysterectomy, i.e. the interventions he needs to care for his PCOS symptoms. Forasmuch as the German federal court declared that the mandatory sterilization trans people had to undergo in order to obtain legal recognition of their gender is against the constitution only in 2011 (Giese, 2019; Karsay, 2018), and the structures of the German legal system to this day contribute to active prevention of trans pregnancies (Spahn, 2019), and generally, rigid regulations of their bodies (Appenroth & Castro Varela, 2019), it is discernible how such care infrastructures are aimed at diminishing trans and queer bodily autonomy and existence, and ultimately, are rooted in endeavours of eradication (Clare, 2017).

The other side of the coin – e.g. medicine's fixation on upholding one's ability to get pregnant, the rigid correlation of overweight bodies and unhealthiness, or the notion of gender as static, a one-way process at most – issues into neglect and uncare. These situations presented by my participants are rooted in infrastructural violence (Rodgers & O'Neill, 2012) and their consequences are experienced on a deeply embodied level. If, within the medical arena, enactments do not align, your body does not align with the world. So, how to transfigure such material realities?

As infrastructures are constantly in flux, every mundane practice contributes to the enactment of ethics and morality (Latimer & Puig de la Bellacasa, 2013; Puig de la Bellacasa, 2017; Tronto, 1998). Ethics, thus, stems from a collective way of doing – "when we shift collective practice, we reconfigure ethos" (Malatino, 2020, p. 40). Small

practices of care and solidarity based on "a diverse set of actors deploying various forms of (counter-)knowledge and different political, social and spatial registers" (Schillinger, 2020, p. 536) can move us move towards novel, "common ways of reading the world" (Mohanty, 2003; as cited by Schillinger, 2020, p. 535) and thus, assemble attentive and inclusive infrastructures of care.

As illustrated above, in caring for their bodies participants are continuously engaged in such practices. By creating counter-narratives to socio-cultural or medical enactments, by taking their PCOS bodies as proof for the skewed medical gaze on sex-gender, by creating and mobilizing their own classificatory labels, or by uniting in queer affective assemblages they are involved in creating new ways of seeing the world. These practices of queering PCOS provide a source for empowerment and self-actualization (Barad, 2015), they transform the supposedly sole way of knowing their bodies, and instead, embrace the multiple and the situated, subversively challenging prevailing power relations.

However, this systemic transfiguration should not be carried out on trans people's shoulders alone, particularly, since, as I have illustrated, collectivity is a crucial building block of care. As Danholt and Langstrup (2012) argue, "the 'self' in self-care is an actor who is highly dependent on, and intertwined with infrastructures of care, in order to be self-caring. Infrastructures of care are the more or less embedded 'tracks' along which care may 'run', shaping and being shaped by actors and settings along the way" (p. 513). In order for these tracks to run in a direction that actually benefits trans people's (PCOS) bodies, care needs to move along a collective and structural level.

Participants' examples of 'good' medical care involve medical practitioners listening to their needs, giving them space to find what works best for their individual situation, distributing the care along different domains, or providing them with tools to articulate their needs in other health-care contexts. What is acknowledged by such practices is that care never simply goes one way, but is reciprocal (Mol, 2008; Puig de la Bellacasa, 2017; Tronto, 1998). In order to ensure good care the cared-for needs to have a chance to respond to the care they receive (Tronto, 1998), and, at best, be given the ability to actively 'work with' the care-giver (Tronto, 2013). This concept of *caring with*, is taken up by Alam and Houston (2020) as an essential building block of *care as infrastructure*, i.e. an infrastructure that builds upon small practices of maintenance, care, and participation.

Accordingly, listening to and including trans patients' situated knowledges into the process of caring for PCOS can provide meaningful guidelines in light of the uncertainties related to the syndrome, and contribute to novel ways of reading the world beyond a framework of curing. Being attentive to an individual's needs, and acknowledging their agency in enacting and caring for their body can contribute to a transformation from

rigid, ambiguous singulars towards tangible multiples which are flexible, resilient, and tentative.

That being said, it is vital to also take into account that care disparities not only occur between doctor and patient, but are also grounded in overarching structures. Participants accounts featured cases where the shortcomings in care were not due to doctors' unwillingness to help, but because of the ways the medical system is structured, such as in regard to insurance coverage of certain interventions, or the material means available to the medical practitioners. Additionally, participants' limited access to health-care services, be it due to financial aspects or the location they were living in, further impeded the provision of good care. Therefore, it is crucial that such a care-ful lens which is attentive to trans people's knowledge and needs, and allows the existence and thriving of their bodies, rather than being targeted at their confinement and eradication, is implemented into the broader structures of (medical) care. In accordance with participants' visions of good PCOS care, such infra-structural changes also need to take place on a legal, institutional, and educational level.

7.3. Initiating: Limitations and outlook

As reflected in **section 4.3**, this thesis is just a small fragment within a broader discussion on trans PCOS care. In fact, thinking through ontological politics, there are always different angles to a case. We do not live in a *one-world world*, but rather in a *fractiverse* that unfolds in multiple realities (Law, 2015). Therefore, I would like to dedicate the final pages of this thesis to a reflection on what has remained obscure in my research, provide an outlook for further avenues of research, and, in doing so, spark further conversation on this case.

While, as reflected in **subsection 5.2.2**, my sample size was adequate within the framework of a master's thesis, the case study could be enriched and rendered more inclusive through drawing closer attention to intersections with racialization, dis_ability, class, age, or location. While my participants were all differently situated in regard to background, experiences or gender identity, many of the above-mentioned positionalities only marginally manifested in their accounts. However, as insights on related branches to this case suggest, tending to such positionalities can make great difference in regard to the ways one experiences one's own body, how this body is viewed and classified within the medical context, as well as what kind of care is received and accessible.

To name an example, although "Black, indigenous women, trans and gender nonconforming people of color (BIPOC) are often left out of the narrative" (Gallardo, 2017,

para. 1), several personal accounts, articles, and artworks by BIPOC on their PCOS experiences highlight how racialization pervades their life with the syndrome. Sharing the story of her PCOS journey as a Black woman, poet Tiana Clark (2018), for instance, draws attention to her struggles with her body's hypervisibility within White female spaces, her doctors' dismissal of her distress, or the denial of medical services altogether, as well as her strategies of self-care as forms of resistance, self-advocacy, and staying alive. Queer chicana actress Toni-Marie Gallardo (2017), too, describes how the pervasiveness of colonial thought and the focus on White beauty standards in PCOS diagnosis and maganement, renders BIPOC bodies as "antithesis" (para. 6) to White, Eurocentric standards of beauty and health, thus further perpetuating self-hatred, shame and assimilation. Further, Nigerian artist Tonia Nneji's exhibition documenting her meaning-making of PCOS through art, "speak[s] [– among other elements –] of [her] struggles with menstrual cycles, weight, insomnia, depression and the agony of discovering meaningful diagnosis in the collapsed healthcare system in Nigeria" (Angelos, 2020). Furthermore, racialization and trans gender come in complex, often violent, intersections (within the medical realm), making the need for further embodied trans BIPOC knowledge even more dire (see for example Ellison, Green, Richardson, and Snorton, 2017; Gill-Peterson, 2018; Howard et al., 2019).

Another example of how intersecting situatedness could make a difference for the outcome of this study can be found when thinking through the case from the viewpoint of critical dis_ability studies, particularly the field's observations on the complex, interdependent relationship between dis_ability and gender. Characteristics and mannerisms delineating gender, for instance, are commonly grounded on norms of abled-bodiness (Spiel, in press), while in other cases gender is straightforwardly denied and – often violently and nonconsensually – taken away from dis_abled people (Clare, 2017). Further, while in my thesis, I strongly focused on forms of queering PCOS, the lens of *cripping* could provide further angles to this case. Cripping, to cite Sandahl (2003), involves "spin[ning of] mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects [, which] expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity, and both disarm what is painful with wicked humor, including camp" (p. 37). Closer attention to such practices could highlight further visions and approaches to PCOS care, and provide more nuance when speaking about the syndrome's painful and troubling elements.

Furthermore, the risk of creating a cis/trans dualism that I reflect on in **section 4.3**, could be mitigated by diversifying the sample in regard to sex-gender and sexualities. Connecting on my speculation of cis femininity as broad experience that is not always

conforming to standards of PCOS medical care, I would argue that practices of queering – if taking the term in its broadest possible sense with regard to practices aimed at deconstructing and skewing normalized expressions, behaviours, identities, or kinship structures (Ingraham, 2005; Light, 2011) – can also be benefitial when caring for those who do not identify as trans. Broadening the spectrum of genders in studying PCOS can point to further struggles with the syndrome's tight entanglement with gendered norms as well as shed light on further requirements for an inclusive and adaptable PCOS care.

In consideration of the points raised above, different methodological approaches could offer different entryways to the multiplicities of PCOS. An ethnographic study of the doctor-patient interaction in a similar manner to Mol's (2002) research endeavor, for instance, could further enrich the observations on this case, since enactments, coordination practices, and clashes could be observed in vivo, which, thus, would bring complementary details to the arena.

Furthermore, online exchanges on PCOS, as it is for instance being done in forum groups, can illuminate further forms of care within such communities of practice (Akrich, 2009). Online spaces are particularly interesting to study with regard to knowledge on and meaning-making of the body, because the virtual interaction largely renders the presence of the physical body invisibile, while still, the body functions as the centrum around which exchanges of knowledge, experiences, or, as I have briefly touched upon in **section 6.4**, affects take place.

Lastly, following transgender studies' tradition of highlighting and emphasizing trans people's experiences, autoethnohraphic methodologies and the corresponding 'use of the self' (Latham, 2017b) which, in contrast to virtual interactions, includes and foregrounds the own body to a greater extent, bears the potential to highlight further angles of the case with regard to PCOS-care as a deeply embodied practice.

* * *

Despite its limitations and all the further possible avenues it can explore, this project provides the first detailed insight into the, as of yet highly neglected, lived experiences of trans people with PCOS. As such, by specifically tending to trans people's perspectives, this thesis tells a story that challenges the dominant discourse on PCOS, and, in turn, indicates how things could be otherwise. Thus, my results also have interventive character, as they explore and highlight those practices of (medical) PCOS care that are potentially more flexible, inclusive, and tangible for individual needs and forms of embodiment. Furthermore, this thesis gathers insights into the ways (gendered) standards and classifications imminently impact the lives of those not adhering to such notions, and

thus adds to the STS scholarly work on such matters. Last but not least, rooted in my own situatedness and research approach, this project not only contributes to the relatively small number of STS research engaging with trans people, but also connects this field to a radical transgender studies intent of upheaving one's own embodied experiences and seizing agency in producing knowledge about oneself.

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Glossary

assigned female/male at birth The terms highlight "that when we come into the world, somebody else [– judging from our physical characteristics –] tells us who they think we are." (Stryker, 2017, p. 12). 2

binding "Binding is the act of pushing the breast tissue down to create the appearance of a flat chest." (*'Binding'*, n.d.). 65

body-mind Eli Clare (2017) uses this term to resist the dualism of White Western culture that regards the body and mind as two separate entities, and instead, by following the lead of the many communities and spiritual traditions that have done so before, reflect their inextricable linkage. As such thought neatly resonates with my theoretical sensitivities I am, too, using this term when referring to the corporeal and the psychic.. 2

cis Also refered to as cisgender, describes those who identify with the gender they were assigned at birth. The terms are used as adjectives. 3

dis_ability Writing the term in such a way reflects the social model of dis_ability which "locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment" (Marks, 1997, p. 88). Through upholding of barriers, and refusal to provide resources that would allow participation, equality, and autonomy, a person literally becomes dis_abled by society (Murstein, 2018). 15

dyadist The term *dyadic* is used to refer to people who are not intersex (*'Dyadic'*, n.d.). Thus, the adjective *dyadist* comes from *dyadism* which describes a kind of sexism that erases and ignores the existence of intersex people and assumes that human bodies are strictly dyadic, i.e. strictly classifiable into a binary structure of sex (*'Intersex'*, n.d.). 17

gender euphoria Standing in contrast to *gender dysphoria* (literally describing a sense of despair), the term conveys the sense of joy or pleasure over the congruence between

how one subjectively understands one's experience of gender and/or how one's gender is perceived by others (Stryker, 2017). 78

hirsutism Clinical term for facial hair growth. 2

hysterectomy Procedure of surgically removing the uterus. 68

inter* I use this term when writing about participants' enactments of PCOS as intersex, in order to capture the multiplicity and openness conveyed by their usage of different terminology and evocation of different perceptions on why PCOS is (not) intersex. The asterisk is meant to symbolize the in vivo nature of the term – the intersex embodiment and experience is actively enacted in the participants accounts and, thus, is open-ended and contingent. 72

intersex Umbrella term referring to variations in sex characteristics or reproductive anatomy ranging from genitalia, hormones, internal anatomy, or chromosomes (*What is Intersex? Frequently Asked Questions*, 2021). Oftentimes the term is used to invoke community and to unite all people sharing experiences living with variations in their sex traits (ibid.). 17

mastectomy Procedure of surgically removing the breasts. 31

non-binary *Non-binary*, also occurring as *nonbinary*, describes people whose gender does not exclusively fit into the binary model of female/male. It is both used as a label to refer to one's gender identity, and as an umbrella term for genders falling into the above-given definition, such as agender, genderfluid, genderqueer, etc. Notably, not everyone who identifies as non-binary considers themselves trans. While in my thesis I use *trans* in the broadest sense, I try to take this into account by referring to my participants by their self-chosen labels.. 3

oophorectomy Procedure of surgically removing the ovaries. 68

polycystic Exhibiting several cysts. 2

queer I use the term 'queer' as an umbrella term referring to those gender identities and sexual and romantic orientations, behaviours, and self-expressions that are rendered 'other' and 'marginal' within a cis-hetero-normative society (Jackson, 2005). Correspondingly to intellectual thoughts of queer theory, I understand 'to queer' as a

range of practices of implicitly and explicitly subverting, deconstructing, crossing, or moving in adverse or opposite direction (Light, 2011) to those identities, behaviours, expressions, kinship structures, and other forms of cis-hetero-normativity which are considered normal and desirable, and are organizied, ritualized, and institutionalized within our society (Ingraham, 2005). These practices of queering also always bear critique of the stigma, violence, and exclusion brought upon by such structural and foundational relations (Light, 2011; Love, 2014). 28

sex-gender In consideration of the culturally varying and not clearly definable conceptions of what excatly counts as 'sex' (Stryker, 2017), as well as the scholarly work my thesis is built upon which approaches the 'social' and the 'biological' as entangled, I intend to avoid creating a clear-cut dichotomy between sex and gender. Instead, I utilize Latham's (2016; 2017b) approach of viewing *sex-gender* as an assemblage which gets enacted and materializes in different situated ways. 5

trans The term *trans* – also occurring as *trans**, *trans-*, or *transgender* – describes everyone who does not identify with their gender assigned at birth. In this thesis the descriptor is kept as open as possible and used as an umbrella term involving those who identify within the spectrum of both binary and non-binary gender, or something completely beyond these spheres (Stryker, 2017; Stryker et al., 2008). In my usage the term is deliberately held open so it can be combined with other terms indicating individual labels (e.g. transgender, trans non-binary, transfluid etc.) (Appenroth & Castro Varela, 2019). The respective terms are used as adjectives. 3, 136

transition Transition describes the process one goes through in order to reach their desired social role, and/or physicality ('Transition', n.d.). As this process is based on unique requirements of each individual, there is no single definition for it (ibid). To name a few examples, it might entail legal name and gender entry change, but might also be done by means of medical procedures, such as genital, or top surgery, and/or hormone replacement therapy (HRT). Whether or not, and in what ways a person wishes to transition also highly varies from individual to individual. 4

transmisia '-misia' is a word in Ancient Greek meaning 'hatred' or 'disgust'. Hence, transmisia means disgust or hatred towards trans people. It is chosen as an alternative to '-phobia' which describes irrational fear (Troop, 2013). 6

transsexual Coined within the medical sciences, transsexual, while being ambigious in usage, is commonly refered to those trans people who seek medical interventions in order to physically change their bodies, usually within a gender binary (Stryker, 2017). Nowadays, particularly because of its medicalizing and binary subtext, the term is considered old-fashioned, and not everyone who identifies as trans wishes to be referred to as transsexual (ibid.). However, it is important to note that some people use the term as a self-chosen label. 5

Acronyms

AES Androgen Excess Society. 4

afab assigned female at birth. 2

AGS Adrenogenital syndrome. 74

BIPOC Black people, indigenous people, and People of Color. 113

FTS feminist techno-science. 15

GID gender identity disorder. 26

HRT Hormone-replacement therapy. 4

ICD International Classification of Diseases. 5

LBGTQ+ lesbian, bisexual, trans, queer, and other sexual/ romantic orientations, and genders. 28

LGBTQIAP+ lesbian, gay, bisexual, trans, queer, intersex, asexual, pansexual/ polysexual, and other sexual/ romantic orientations, and genders. 54

NIH National Institute of Child Development and Health. 3

PCOS Polycystic ovary syndrome. 2

PCOSA Polycystic Ovarian Syndrome Association. 22

STS Science and technology studies. 9

A. Appendix

A.1. Interview guidelines

A.1.1. English version

- Before we start I will give you a brief overview of my research topic. On the one hand, I am interested in trans people's perspectives on PCOS and their personal experiences with living with it. And on the other hand I would also like to focus on experiences with PCOS treatment, as well as the medical system in general. So my first question is maybe a little broad, **when hearing about my research topic, what are your thoughts?**

- Let's start at the beginning of your story, **could you tell me about the moment when you first came across PCOS?**
  In what context did this come up?
  Why did the topic come up?
  What were your thoughts on this? Do you remember?
  Did you already know about PCOS or did you know someone who had it?
  OR: Did you experience any symptoms before that moment? Did you have any suspicion on what this could be?

- **When was the moment where you started to further engage with PCOS (and how long is this ago)?**
  What did your engagement with PCOS look like? What did you do?

- **Could you tell me about the first time you encountered PCOS within the medical context?**
  In what context did this happen?
  What made you seek a medical practitioner?
  What happened then?

- **Could you describe me the moment when you received the diagnosis?**
  In what context did this happen?

What did your doctor explain about it?
What measures did they suggest?
Do you remember what your thoughts were on this?
What did this diagnosis mean to you?

- **Have you been suspecting this or did you do some further research on your own?**
  Where did you get further information on PCOS?

- **How did you deal with it?**
  What did it mean for you?

- **When talking to others about your diagnosis, how do you explain PCOS to them?** [If no diagnosis was received: When talking to others about PCOS how do you explain it to them?]
  Do you always use the same explanations or do you have different versions depending on whom you speak to? [e.g. friends, family, medical practitioners, ...]
  Could you give me some examples?

- Let's come back to your conversation with the doctor. You told me that [repeat what participant said about diagnosis] **What happened then? Were there any measures taken in terms of treatment?**
  Do you remember what was explained to you about it?
  How did you react?
  What were your thoughts?
  What happened then?

- **Have you tried out different treatment approaches?**
  How did these treatment approaches look like?
  What experiences did you make with trying them out?

- **What did your doctor promise you in regard to the results of the treatment?**

- A particular treatment option can be perceived differently by different people. Hence, I would like to ask **whether you have any thought or an idea on how a successful treatment would look like for you?** What should happen for you to view a treatment as successful?

- **Could you describe how a typical interaction with your doctor looks like?**
  Which specialist do you go to?
  What do you talk about?
  How do you feel about this?
  Do you go there alone?

- **Could you describe to me your last interaction with your doctor?**

- **Do you come across any situations in your life where having PCOS plays a role/ is of significance?**
  Could you give me some examples?
  How do you deal with these situations?

- **How do you deal with PCOS?** [might be already answered above]
  Where do you get information on PCOS? What kind of information?
  Do you search for regular updates? Where?

- After reflecting on your experiences with PCOS **is there something else you would like to add?**

- **If you could change anything in regard to how PCOS is treated or dealt with, be it within the medical system or be it in everyday life, where would you start?** You can speak fictional.

- Imagine I just recently learned that I have PCOS, but I have no idea what to do or where to start. **What would you tell me? What would your advice be to a fellow queer person with PCOS?**

A.1.2. German version

- Ich werde dir zu Beginn einen ganz kurzen Überblick über das Thema meiner Masterarbeit geben. Ich interessiere mich einerseits für die Perspektiven von trans Menschen auf PCOS und ihre persönlichen Erfahrungen damit. Andererseits möchte ich mich auch gerne auf Erfahrungen mit PCOS Behandlung bzw. dem medizinischen System im Allgemeinen fokussieren.
  Vielleicht zu beginn eine etwas allgemeine Frage: **Wenn ich dir so von meinem Forschungsinteresse erzähle, was sind deine Gedanken dazu?**

- Lass' uns mal ganz am Anfang deiner Geschichte beginnen, **wie war das denn für dich als du das erste mal mit PCOS in Berührung gekommen bist (also darüber erfahren, gehört hast)?** Könntest du mir darüber was erzählen?
  In welchem Zusammenhang war das?
  Wieso kam das Thema auf?
  Erinnerst du dich was damals deine Gedanken dazu waren? Bzw. hast du schon etwas darüber gewusst oder kanntest du wen, di*er PCOS hat?
  (Falls zufällig: Was waren deine Vermutungen was es sein könnte? Hast du dich dazu informiert?)

- **Wie war der Moment in dem du begonnen hast dich intensiver damit zu beschäftigen (und wie lange ist das her)?** Wie sah das aus? Inwiefern hast du dich damit beschäftigt?

- Schauen wir uns das mal im Rahmen des medizinischen Systems an, wenn du dich zurück erinnerst, **wann bist du da das erste mal damit in Berührung gekommen?**
  Wie war das erste mal als es im Rahmen einer medizinischen Behandlung vorkam? [hier könnte auch bereits die Diagnose aufkommen]
  In welchem Zusammenhang war das?
  Was hat dich dazu veranlasst zum*r Arzt*Ärztin zu gehen?
  Wie ging es damit weiter?

- **Wie war das für dich als du die Diagnose bekommen hast** (sofern du eine bekommen hast)?
  In welchem Kontext war das?
  Was ist dir von dem*der Arzt*Ärztin erklärt worden?
  Welche Schritte hat dein*e Arzt*Ärztin vorgeschlagen?
  Erinnerst du dich was du darüber gedacht hast?

- **Hattest du bereits einen Verdacht oder hast du noch weiter dazu recherchiert?**
  Wie hast du dir zusätzliche Infos geholt?

- **Wie bist du damit umgegangen?**
  Was hat das für dich bedeutet?

- **Wenn du mit anderen über deine Diagnose redest, wie erklärst du ihnen PCOS?** [wenn es keine offizielle Diagnose gab, dann lautet die Frage: Wenn du mit

anderen über PCOS redest, wie erklärst du es ihnen?]
Erklärst du das allen so oder unterscheidet sich deine Erklärung je nachdem mit wem du gerade redest? (z.B. Freund*innen, Familie, andere Ärzt*innen)
Könntest du Beispiele nennen? (Bei wem gibt es Unterschiede? Wie sehen diese aus?)

- Kommen wir zurück zu deinem Gespräch mit deinem*r Arzt*Ärztin. Du meintest ja [wiederholen was Teilnehmer*in zur Diagnose gesagt hat]. **Was ist dann passiert? Wurden irgendwelche Schritte in Bezug auf Behandlung unternommen?**
  Weißt du noch was dir über die Behandlung erklärt wurde?
  Wie hast du reagiert?
  Was waren deine Gedanken dazu?
  Wie ging es weiter?

- **Hast du mehrere Behandlungsarten ausprobiert?**
  Wie sahen diese aus?
  Welche Erfahrungen hast du damit gemacht?

- **Was hat dir di*er Arzt*Ärztin von den Behandlungen versprochen?**

- Es ist ja so, dass Behandlungen immer ganz unterschiedlich wahrgenommen werden. Deswegen würde ich gerne fragen, ob du schonmal darüber nachgedacht hast oder eine Idee davon hast, **was eine erfolgreiche Behandlung/ Behandlungsart für dich ist?** Wie passt das damit zusammen was dein*e Arzt*Ärztin dir gesagt hat?

- **Könntest du mir beschreiben, wie eine typische Interaktion mit deinem*r Arzt*Ärztin abläuft?** [Nach den Erfahrungen der letzten Interviews wäre eine alternative Formulierung der Frage: Kannst du mir beschreiben wie deine letzte Interaktion mit deinem*r Arzt*Ärztin ablief?]
  Zu wem gehst du (also welches Fachgebiet)?
  Worüber redet ihr da?
  Wie ist das für dich?
  Gehst du alleine hin? Oder hast du Personen die mit dir mitkommen?

- **Gibt es Situationen in deinem Leben in denen die Tatsache dass du PCOS hast bedeutsam geworden ist/ wichtig war/ eine Rolle gespielt hat?**

Könntest du mir Beispiele nennen?
Wie gehst du damit um?

- **Wie gehst du selbst mit PCOS um?** [wird eventuell in der vorherigen Frage beantwortet]
  Woher beziehst du deine Informationen zu PCOS? Welche Art der Information? Holst du dir regelmäßige Updates? Woher?

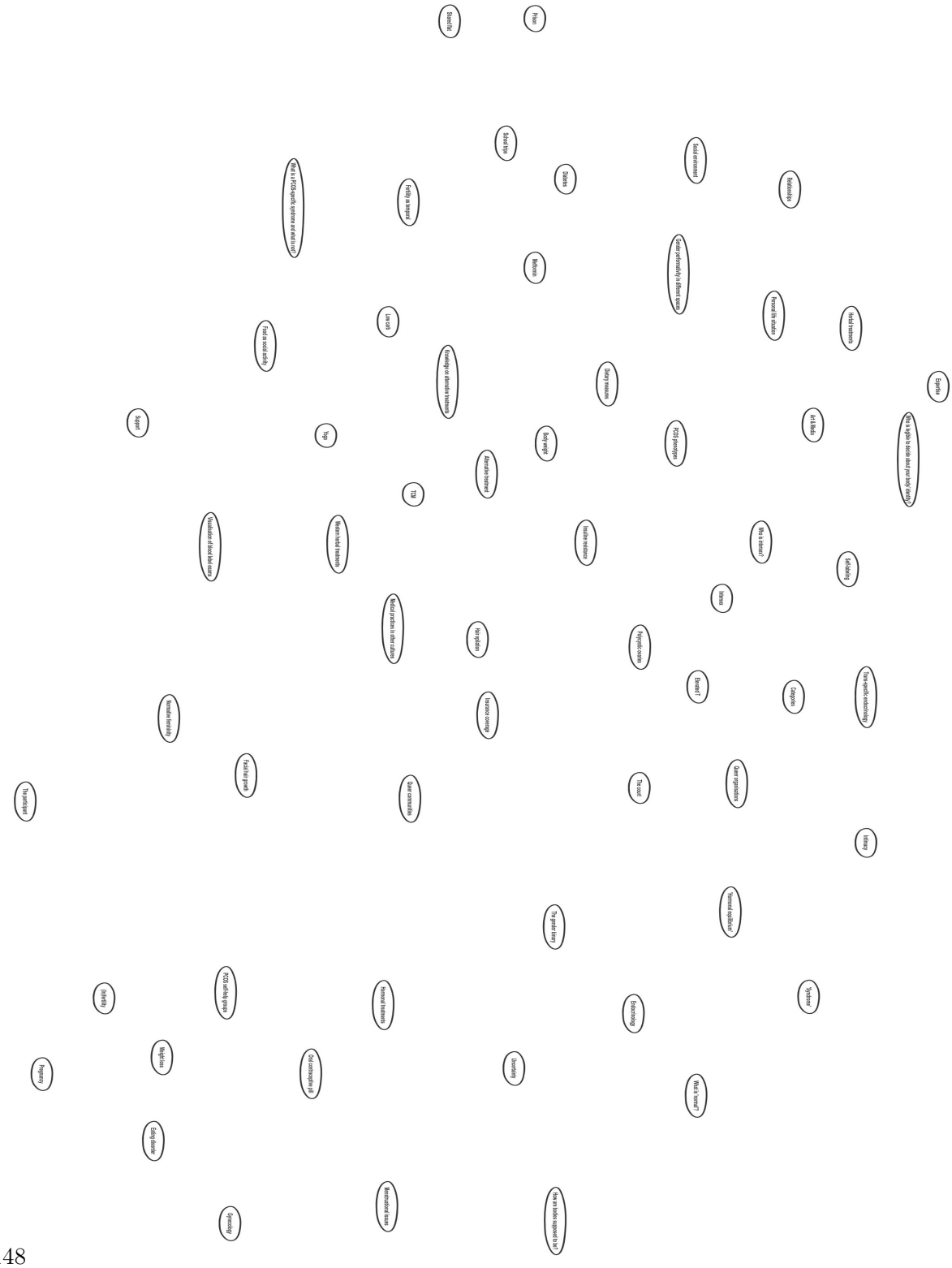
- Nachdem wir jetzt über deine Erfahrungen gesprochen haben, **gibt es etwas, das wir ausgelassen haben?**

- **Wenn du etwas im Bezug auf PCOS Behandlung oder den Umgang mit PCOS sei es im Alltag oder sei es innerhalb des medizinischen Systems ändern könntest, wo würdest du ansetzen?** (Muss auch nicht unbedingt realistisch sein).

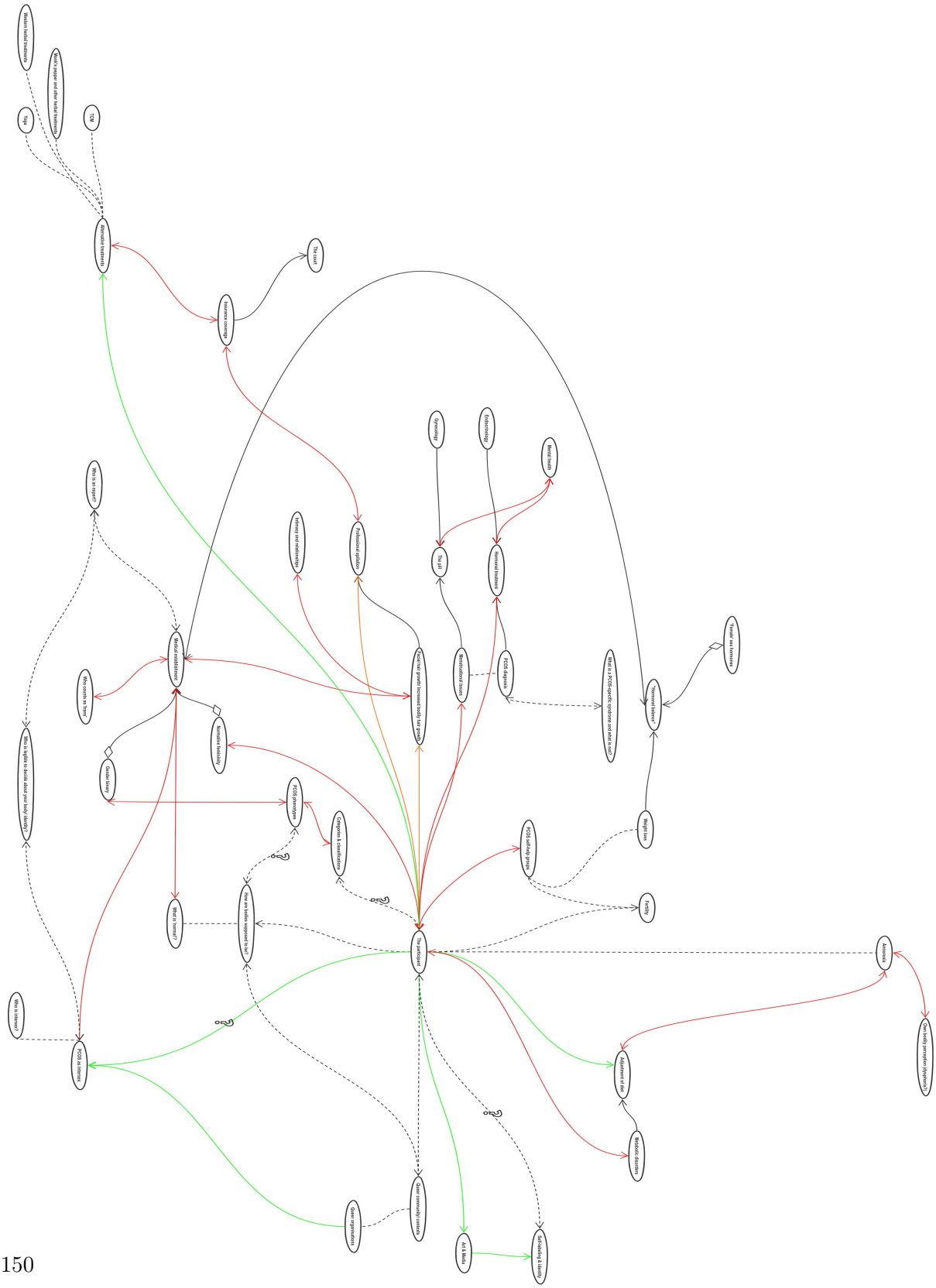
- Stell dir vor ich würde zu dir kommen, und ich hätte gerade erst erfahren dass ich PCOS habe oder ich hätte die Vermutung dass ich PCOS haben könnte, wüsste aber überhaupt nicht wo ich anfangen soll. **Was würdest du mir raten?**

A.2. Examples of situational maps

A.2.1. Example of messy map



A.2.2. Example of relational map



B. Abstract

Within the discourse on and care for polycystic ovary syndrome (PCOS) – an endocrine syndrome most commonly characterized by elevated testosterone levels and plurality of ovarian cysts – trans people with this diagnosis remain relatively invisible. However, due to the yet uncertain and controversial nature of PCOS, this absence can perpetuate the health-disparities resulting from medicine's prevailing pathologizing and objectifying gaze on trans bodies and identities even further.

Through the lens of ontological politics sensitized by a focus on situated knowledge and STS frameworks on care, I conducted six narrative interviews with trans and gender-diverse people based in Germany in order to explore their enactments of PCOS, their needs, wishes, and strategies for the care thereof, as well as their experiences within the medical context, and thereby inquire into the broader implications for PCOS care within standardized medical practices. In so doing, my intention was to shed light on the tensions and discrepancies arising from medical practices that are fundamentally based on binary, normative and rigid standards, while giving my trans participants a voice in the discourse on affective and inclusive trans PCOS care.

As resonates within their stories, when seeking medical care, participants are confronted by a singularizing enactment of PCOS, which imposes a set of pathologizing and gendered norms upon their PCOS bodies, while neglecting, ignoring and de-problematizing their individual needs and concerns. Conversely, participants' enactments of PCOS are multiple, situated, non-linear and embodied, unfold along different temporal trajectories and are embedded within diverse constellations of human and non-human actors. Along these multiple lines, participants embody a range of practices that twist, subvert and reinterpret medical and socio-cultural master narratives on their bodies and identities, ultimately queering PCOS.

Discussing the findings along the broader material infrastructures of care, I argue that tending to trans peoples' embodied knowledge and their queered PCOS enactments bears potential of shifting the focus beyond the ambiguous singulars as produced through standardized medical practices, and, instead create tentative, flexible, and affective multiples that are tangible for the individual and thus offer a more inclusive PCOS care.

C. Kurzfassung

Innerhalb des Diskurses zum polyzystischem Ovar-Syndrom (PCOS) – einem endokrinen Syndrom, welches üblicherweise durch erhöhte Testosteronwerte und eine Vielzahl an ovariellen Zysten charakterisiert wird – bleiben trans Personen mit dieser Diagnose relativ unsichtbar. Aufgrund des ungewissen und kontroversen Charakters von PCOS, kann diese Abwesenheit jedoch die Disparitäten in der medizinischen Versorgung, welche aus einer waltenden Pathologisierung und Objektifizierung von trans Körpern und Identitäten durch die Medizin resultieren, noch weiter verstärken.

Durch eine Herangehensweise der politischen Ontologie sensibilisiert durch einen Fokus auf situiertes Wissen und STS Konzepte zu Care, führte ich sechs narrative Interviews mit trans und geschlechtlich diversen Personen aus Deutschland durch, um ihre Enactments von PCOS, ihre Bedürfnisse, Wünsche und Strategien für deren Versorgung, sowie ihre Erfahrungen innerhalb des medizinischen Kontextes zu erforschen, um dadurch die übergreifenden Implikation für PCOS Care durch standardisierte medizinische Praktiken zu untersuchen. Hierbei war meine Intention, die Spannungen und Diskrepanzen, welche sich aus auf binäre, normative und rigide Standards beruhenden medizinischen Praxen ergeben, aufzuzeigen, sowie meinen trans Teilnehmer*innen eine Stimme im Diskurs über eine affektive und inklusive trans PCOS Fürsorge zu geben.

Ihre Erzählungen weisen ein singularisierendes Enactment von PCOS auf, mit welchem die Teilnehmer*innen beim Aufsuchen medizinischer Versorgung konfrontiert werden und welches sie mit einer Reihe von pathologisierenden und vergeschlechtlichten Normen auferlegt, während dadurch ihre individuellen Bedürfnisse und Anliegen vernachlässigt, ignoriert und ent-problematisiert werden. Hingegen sind die PCOS-Enactments der Teilnehmer*innen multipel, situiert, nichtlinear und verkörpert, entfalten sich entlang verschiedener zeitlicher Trajektorien und sind in vielfältige Konstellation aus menschlichen und nichtmenschlichen Aktanten eingebettet. Entlang dieser mannigfaltigen Linien verkörpern Teilnehmer*innen eine Bandbreite an Praktiken welche die vorherrschenden medizinischen und sozio-kulturellen Narrative über ihre Körper und Identitäten verdrehen, zerrütten, und reinterpretieren und damit letztendlich PCOS queeren.

Während ich die Resultate innerhalb weitreichender, materieller Versorgungsinfrastruk-

turen diskutiere, argumentiere ich dass, ein Hauptaugenmerk auf solche gequeerten PCOS Enactments Potential hat, den Fokus jenseits der ambigen Singularitäten wie sie durch standardisierte medizinische Praktiken hervorgerufen werden zu verschieben und stattdessen, unverbindliche, flexible und affektive Multiplizitäten, die greifbarer für das Individuum sind und daher eine inklusivere PCOS Versorgung bieten zu kreieren.