INTRODUCTION

The Critical Methodologies Collective

In qualitative research, the research process is often filled with moments of discomfort. These discomforts can appear at any stage of the research: when choosing the subject of research, during fieldwork, in the process of analysis and when presenting research findings to different audiences. In this edited volume, we take these moments of discomfort seriously and use them as sites of knowledge production for reflecting on the politics and ethics of the qualitative research process. By locating our experiences in implementing nine different PhD projects carried out in different disciplines and research contexts in social sciences, we argue that these moments of discomfort help us to gain important insights into the methodological, theoretical, ethical and political issues that are crucial for the fields we engage with. Drawing on feminist and other critical discussions (Mulinari and Sandell 1999, Gunaratnam 2003, Back 2007, Gunaratnam and Hamilton 2017), we deal with questions such as: What does it mean to write about the lives of others? What are the ethical modes and conundrums of producing representations? In research projects that are located in the tradition of critical or engaged scholarship, how are ethics and politics of representation intertwined, and when are they distinct? How are politics of representation linked to the practice of solidarity in research? What are the im/possibilities of hope and care in research?

Representation, solidarity and accountability in qualitative research

Qualitative research is a representational practice, in the sense that it is concerned with making sense of the world, by understanding and interpreting the meanings of different practices, phenomena and processes. This is done by constructing representations of those who are being analyzed. Representational practices in research, like any other representational practices, always involve a process of translation (Hall 1997). Such a process carries in it an inherent violence of transformation, reduction or obliteration (cf. Hastrup 1992). In this sense, it opens up space for dilemmas of ethics of representation. Such general questions of research ethics should, however, not be divorced from questions concerning research politics. As we have learned from conceptualizations of, as well as debates on, the working of representation in feminist, critical and post-colonial fields (Foucault 1970[2002], Said 1978[2003], Hall 1997, hooks 1999, Ahmed 2000), these processes are not innocent, but deeply implicated in power relations of societies that the research concerns. In this sense, to create a representation is always a political endeavour. It is also the case in critical research that aims at producing knowledge that is concerned with issues of justice. While structuralist and semiotic traditions teach us how representational practices operate, critical, feminist and post-colonial traditions encourage us to contextualize these practices in particular historical moments in order to explore their implications for imposing and maintaining, but also resisting, unjust social structures.

A basic condition in qualitative research is that it is impossible as a researcher to fully understand every aspect of people or communities we conduct research with, with the resultant conundrum in representation. It is impossible to acquire 'full representation on the one hand, and full comprehension on the other', which

can be seen as an inherent failure (Visweswaran 1994, p. 100). This inherent failure should be recognized by the researcher, something that would allow to 'question the authority of the investigating subject without paralyzing him' (Spivak 1998, p. 276). This means carefully reflecting on the practice of creating representations of other people, while not letting these critical reflections lead to a state of not being able to do any representations at all.
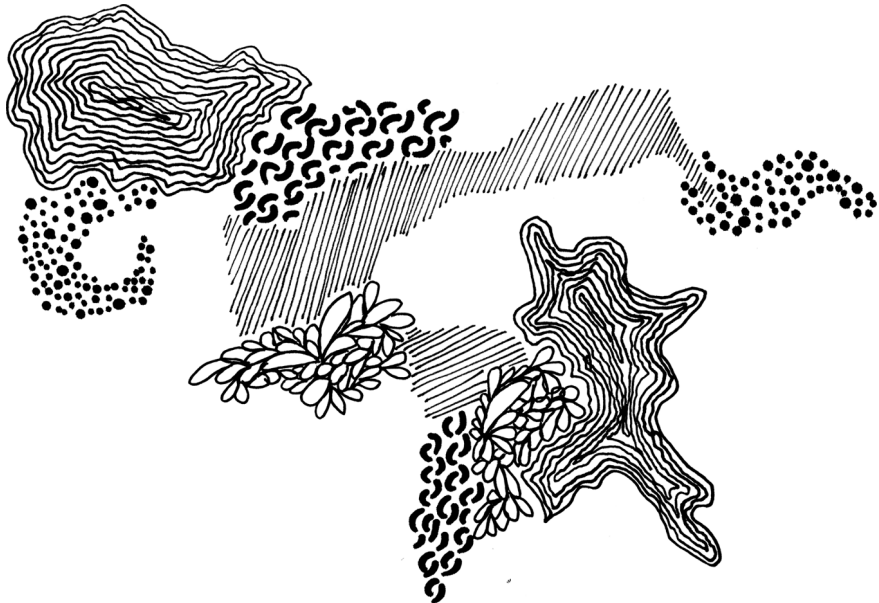
In this volume, politics and ethics of representational practices in research are considered in relation to the question of accountability. Based on Haraway's discussions of accountability as part of feminist objectivity, Bhavnani (1993) holds that anyone who claims to undertake feminist research must carefully avoid reproducing dominant representations which reinforce inequality. Accountability, then, she argues, is both about being accountable towards individuals (research subjects) as well as being accountable to the 'overall project of feminism' (1993, p. 98). In many of the research projects discussed in this book, this question is complicated by the fact that researchers often face competing or even conflicting accountabilities. Most importantly, tensions might occur between accountability towards the research participants and accountability towards political struggles in which the research project is situated (see the chapter by Tove Lundberg and the chapter by Vanna Nordling in this volume). Some key questions that we pose to ourselves in this context are: What modes of representation are both ethically accountable to those represented in the study *and* politically accountable in the context of contentious justice struggles? And what if these two types of accountabilities not only diverge, but even remain in tension? It is when asking these questions that we might find it productive to distinguish between the ethics and the politics of research. All our studies are politically committed to different struggles of social justice: from queer recognition of non-binary sex characteristics, through asylum rights and migrants' rights, to antiracist critique, we recognize and adhere to a particular ideal of knowledge production in academia – one that understands the role and significance of social science in reproducing, supporting and opposing power structures.

This type of critical research often builds on an epistemology where partial perspectives coming from 'below' are seen to have the potential of creating more valid situated knowledges, as these positions will render visible the structures of power in our society, as well as structures present in the production of knowledge (Haraway 1988; also see Harding 2004, p. 128). Importantly, these positions at the margin, creating partial perspectives from below, are not static or universal. Oppression is produced through social relations and played out differently in regard to time and context (Mohanty 1988). The positions of social movements with which researchers claim to stand in solidarity, as well as the positions of researchers, need to be subjected to a thorough reflexive engagement (Harding 2004). Simultaneously, the knowledge produced by and in collaboration with social movements should be acknowledged as creating relevant and grounded analyses (Mulinari and Sandell 1999). Striving to research in solidarity brings to the fore a range of ethical as well as political challenges. Scholars who have worked in sensitive and precarious

settings often emphasize the importance of recognizing challenges of asymmetric power relations, representation, trust and suspicion, risks, agency and human rights (Mackenzie *et al.* 2007). An important aspect of this is that the precarious situation for people and/or communities who have been subject to research has led researchers to conclude that we must formulate research projects that contribute something back to the communities and individuals, and that research participants need to be involved in the production of research (Huisman 2008, Düvell *et al.* 2010). These are examples where the ethical dilemmas related to power asymmetries also led to researchers formulating and carrying out their research in modified ways. Although these are honourable ambitions of handling power asymmetries in a constructive way, it does diminish the fact that researchers gain academically from the interaction, whilst the benefits for the participants might be less clear (Sinha and Back 2014; see discussion in Pankhuri Agarwal's chapter in this volume).

Solidarity in a context of critical research can hence be actualized in the meeting between the researchers and the subjects of the enquiry: what can a solidary position as a researcher entail within a relation many times characterized by power asymmetries? What stories are we to tell, how do we tell them, and how to 'get hold of them'? Matters of accountability and representation are hence brought (back) to the fore. We do not claim to 'solve' these issues – doing research in solidarity with movements and struggles will always bring about tensions and ambivalence – but we find it crucial to address and scrutinize them to bring to light how to address, engage with and embrace the discomforts in each case of research.

Overview of the book

The chapters that make up this volume draw on experiences from research processes in nine projects. They all engage with issues of ethics and politics of representation in different ways. In some chapters, ethical and political dilemmas related to representational practices are analyzed as experienced in the fieldwork. In others, the focus is on production of representation at the stage of writing the text. Still others draw parallels between these stages. While the moments of discomfort that open up for different dilemmas are specific to the particular research process, we hope that they will resonate with similar dilemmas in other fields and contexts as well as disciplines.

In a dialogical piece opening this volume, Tove Lundberg captures how the choice of terms and definitions – both in conversations with the research participants and in the text produced by the researcher – might entail politically infected dilemmas that go beyond conceptualization of the object of her study. She articulates how, in the research project on variations in sex characteristics, usually referred to as 'intersex' or 'disorders of sex development', she was struggling when choosing how to talk about her research and address her participants. Lundberg shows how this choice had to do with particular politics of representation and how using certain terminology not only entailed a commitment to a particular scientific explanation of the phenomenon she was studying, but also situated her work politically in relation to different justice struggles. Lundberg shows how this dilemma reflected something at the very core of her study: the ways in which sex characteristics are constructed in a binary system where there are clear options and no in-betweens allowed, and explores whether it is possible to navigate in less categorical ways the conceptual, theoretical and political choices she has been confronted with.

The issue of ethics of representation arises at the very beginning of the fieldwork, by being related to living up to such central ethical requirements as informed consent. When we engage with other people's lives with an aim of producing a representation of them, how can we be sure that those represented consent to this? Johanna Sixtensson describes in her chapter how giving consent or 'saying no' to being represented in a research project is a complicated practice that should not be reduced to a single act or signature on an official consent form. Her account of an exchange with one of her young research participants, both at the time of the fieldwork and after her thesis had been published, discloses complexities and ambivalences of asking for and giving consent.

In another way, the issues of representation are at the heart of Emma Söderman's chapter. Söderman explores the work around the *No Border Musical*, in which she herself performed. In her thesis, she analyzes not only the ways in which a representation of the experience of borders was created in the musical by a group of activists that included irregular migrants, but also how working on the musical opened up for practices of commoning. There are two levels of representational practice in her work: the theatrical representation of the musical and the representation produced

as a result of research. In her chapter, Söderman explores what we as researchers can learn about representation from the method of community theatre, in which people with and without the experience of irregular migration work together. She shows how on the stage irregular migrants are confronted by what she conceptualizes as *faceness* – an expectation of embodying the representation of the other. Söderman's chapter illustrates how issues of aesthetic representation – be it through performative arts or in text – are closely related to issues of representation in the political sense of the term. The question thus is not only where the source of frames of reference for representation is located, but also who is expected to represent or stand for the other.

A commonality of experiences in the field – and more exactly of the experience of waiting – is used as a point of departure in the chapter by Pankhuri Agarwal. Describing her fieldwork in the research on internal migrant workers in Delhi, who are struggling for their rights through legal proceedings, she shows how her waiting in the field became a site of knowledge in itself. By waiting for some research participants and waiting together with others, she learns not only about the workings of legal institutions in India, but also about how particular hierarchies and power relations are produced through temporal and spatial aspects of waiting. While experiencing waiting, with all its frustration and discomfort, which becomes for Agarwal a methodological tool in itself and a way of connecting with her research participants, she also shows how her experience of waiting is fundamentally different from that of the workers'. In a way, the very act of representing the experience of waiting transforms this experience and thereby creates a distance from the participants, suggesting the limits of commonality in the field.

In yet another way, the issues of representation – both in the field and in text – are present in the chapter by Katrine Scott. In ethnographic work, being in the field also involves a self-representational practice, when the ethnographer represents themselves to the research participants. Scott describes her search for finding a common ground with university students in Iraqi Kurdistan. She explores her performance of middle-class respectability in the field using concepts of 'studying sideways' and 'matching' and shows how these strategies open up for certain possibilities, while at the same time they bear risks of obliterating differences and power relations in the research process. In the second part of her chapter, Scott illustrates how the question of self-representation is not limited to the fieldwork, but continues in the process of writing: she explains how she used auto-ethnographic accounts as entry points to analysis, and discusses what such a stylistic choice means for representational practice of the other in relation to the ethnographic self.

Another contribution, written by Vanna Nordling, deals with the politics of representation in relation to expectations of inscribing one's research into a particular field. In her chapter, Nordling analyzes the dilemma of representing her research on social workers supporting migrants whose application for asylum has been rejected. She writes about how her framing of the topic would shift when presenting to different audiences, in different research fields and in a changing political climate: making visible diverse, often conflicting, expectations of how social workers should

be portrayed and their practices understood. In a way, the chapter illustrates how representation created in the research is always a product of available frames co-created by other scholars, disciplines, institutions and political contexts in which the research is produced. Nordling's chapter, in a somewhat similar way to Söderman's, touches upon the issue of visibility of representation and its use for the political struggles, when such visibility might actually transpire to carry very concrete risks.

Another chapter addressing issues of representation in relation to the writing process is by Marta Kolankiewicz. It describes the process of anonymization in research on anti-Muslim racism in courts of law in Sweden. Kolankiewicz explores representational practices in relation to the significance of proper names of those depicted in the research. She analyzes the working of different anonymization procedures – from erasing original names, through substituting them by numbers or symbols, to giving pseudonyms – in order to ask questions about the politics and ethics of such operations. By situating these practices in the context of research on racism, Kolankiewicz shows how names are significant markers of difference in racist discourses and practices, but at the same time meaningful signs that carry with them diverse histories of racialization that should not be obliterated if we want to understand different experiences of racism. Finally, she poses the question of the role of the proper name for the possibility of attending to the singularity of the stories represented in the research.

The final chapter builds on a conversation between Pouran Djampour and Eda Hatice Farsakoglu and deals with the practice of care in the field and in research more broadly. Djampour and Farsakoglu set out from their observations from doing research with young people with experience of migrating to Sweden and with Iranian LGBTQ refugees in Turkey waiting for resettlement to a third country, respectively. They analyze caring encounters in the field through a reflexive lens. They argue that creating knowledge together with, and learning from, research participants involves making oneself vulnerable. They also show how caring encounters and relationships between researcher and research participants may alter both the research process and the content of ethnographic material, with an awareness of the challenges, limitations, multiplicities and contradictions inherent in ethnographic research. Djampour and Farsakoglu close the chapter by addressing the reader and proposing that the practice of *sharing* – a practice that started through the given encounters with the research participants – instantiates the practice of *care* itself. In a way, this final point relates to all the chapters of this volume, which have been written with the intention of sharing moments of discomfort.

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1

BECOMING 'UNSTUCK' AMONG POSITIONALITIES, TERMS AND DISCIPLINES VIA CONVERSATION (WITH MYSELF)

Exploring Potentials for Affective Reflexivity in Critical Intersex Studies

Tove Lundberg

> In memory […] there's no ahead and no behind really, is there? Memory wells up in the now, in vertical time. And remembered time, as you know, is shot through with imagination.
>
> (Hustvedt, 2019)

RESEARCHER TOVE: So, where do I start to write reflexively?

CLINICAL PSYCHOLOGIST TOVE: Well, I guess I am stating the obvious now, but I think you just did.

RESEARCHER: I guess I did. By conversing with an externalized part of myself, which is you. Just as if I were doing a Gestalt therapy exercise?

CLINICAL PSYCHOLOGIST: Yes, you have split off a part of yourself in order to experience yourself more clearly from different perspectives, just like in Gestalt therapy.

RESEARCHER: Great. I guess the next reasonable question to answer is why we are here.

CLINICAL PSYCHOLOGIST: Well, yes, I was just about to ask.

RESEARCHER: Sure. Okay, let's see how to articulate that. {*Thinking*} Well, before I became a researcher, I worked as a clinical psychologist for several years.

CLINICAL PSYCHOLOGIST: Mm-hmm.

RESEARCHER: As a clinical psychologist, you are such an important part of me and inform my thinking. However, you are never explicitly acknowledged in my academic work. I often feel like I have to choose a certain role or positionality in representing myself in academia, which usually excludes you. I was wondering if this kind of conversation would help me acknowledge the 'in-betweenness' of us that I feel that I embody.

CLINICAL PSYCHOLOGIST: Okay.

RESEARCHER: And as a PhD candidate, I didn't really explicitly talk to others about how to navigate the complexity of positions, roles, stakes, interests, feelings and so on that I guess most researchers experience.

CLINICAL PSYCHOLOGIST: So, instead you converse with yourself.

RESEARCHER: Yes, I guess so. {Laughs}

CLINICAL PSYCHOLOGIST: Well, as a clinical psychologist, I think that talking about things, even with yourself, is usually better than being silent about it. So what will be the topic for our current conversation?

RESEARCHER: You know my doctoral research on variations in sex characteristics (see Lundberg 2017).[1]

CLINICAL PSYCHOLOGIST: Yes, I know. What about it?

RESEARCHER: Well, I have this feeling of discomfort, which haunts me. That I wasn't reflexive enough during my doctoral research. I mean, I didn't write anything about reflexivity in my thesis and I just can't let that go. I feel like a bad qualitative researcher.

CLINICAL PSYCHOLOGIST: Okay, so do you mean that not including reflexive sections explicitly in your thesis suggests that you were not reflexive at all during your PhD project?

RESEARCHER: Well, drawing on ideas by scholars such as Skeggs (2002), I think I was doing some kind of reflexivity even though I didn't make my reflexive self explicit in the text? Today, I am quite inspired by Alvesson's and Sköldberg's (2017) idea of reflexivity as happening when 'thinking is confronted with another way of thinking' (p. 384) – that reflexivity can be about challenging our *thinking*. And I think I was doing that. However, the research process just felt like a mess and, by the end of it, I was just so happy to have a thesis to hand in at all.

CLINICAL PSYCHOLOGIST: So, by challenging your thinking, one interpretation is that you actively reflected during your research at least?

RESEARCHER: Maybe. I guess I was doing 'reflection-in-action', to borrow Schön's (1995) words. Schön's thinking informed the way I reflected on my practice as a clinical psychologist. I guess I just used what I had and went with it? However, I feel that this reflexive practice could have been more theoretically informed; that I should have 'grounded' myself in a reflexive perspective earlier.

CLINICAL PSYCHOLOGIST: Yes, well, that is always part of a process, isn't it? That you are where you are and it is hard to be somewhere else, especially to be more knowledgeable than you are?

RESEARCHER: Yes, I guess so. That is also why I chose to be part of writing this book. I want to use this space to look at my 'reflexivity in retrospect', as Doucet and Mauthner (2007) call it, as a form of what Schön (1995) describes as 'reflection-on-action'. In what way did I actually practise reflexivity? What kinds of ideas and theories was I drawing on that were behind the scenes and not really made explicit in my thesis? And did my practices of reflexivity actually make my research any better (Pillow 2003)?

CLINICAL PSYCHOLOGIST: That makes sense. And you want to explore this with me?

RESEARCHER: Yes, I want to explore it with you. Because I understand, now, that your perspectives and ideas were crucial in how the thesis developed. However, I never explicitly acknowledged in the text the expertise you brought to the thesis. Perhaps because it was so subconscious and unarticulated even within myself? And because I didn't utilize your knowing systematically? So, this chapter is a way of making sense of what I was doing as a PhD candidate and trying to make your input more explicit and transparent.

CLINICAL PSYCHOLOGIST: That sounds reasonable.

RESEARCHER: I also think that this has more general implications as well, because I am starting to understand how a dialogue between qualitative methodology and clinical psychology, in a broad perspective, can be very constructive. I think we need more texts that acknowledge these kinds of conversations. And maybe this text can contribute to the small body of literature that does exactly that as well as open up for other collective and interdisciplinary conversations where research positionalities and perspectives can be highlighted in constructive ways (see e.g. Hollway and Jefferson 2011)?

CLINICAL PSYCHOLOGIST: That sounds reasonable. So, how do we move on in this conversation to be able to attend to what is important?

RESEARCHER: Well, I thought that in the next section we would try to reconstruct some of our conversations from 2012 and onwards.[2] I was really struggling with terminology during my PhD project, and your input helped me move forward when I felt stuck. I thought we could focus on that. And then, I thought, we could end this chapter with a reflection on what happened during my PhD project.

CLINICAL PSYCHOLOGIST: Sounds like an interesting exploration. Let's travel back in time, then, to 2012 when you'd just started your PhD position.

Reconstructing my discomfort with terminology[3] as a PhD candidate in 2012 and onwards

RESEARCHER TOVE: {*Clearly frustrated*} Okay, so here's the thing. What should I even write in the material I use to recruit participants? Should I use, or should I avoid, terms such as 'intersex' and 'disorders of sex development' (DSD)? I just feel so frustrated. And whatever term I use, I will position myself in the topic area as either from the human rights or the medical perspective, in a way that I

feel uncomfortable with. I also feel that whatever term I use I will offend some people. I really feel stuck!

CLINICAL PSYCHOLOGIST TOVE: Well, what did you write in the things you sent to the ethical review boards in Sweden and the UK before you started your project?

RESEARCHER: That this is research {*reads from information sheet*} 'about young people whose sex development has been different from others: they may have been different from birth, or they may have become different at some time in their development'.

CLINICAL PSYCHOLOGIST: Well, perhaps use that?

RESEARCHER: {*Stirred up*} Sure, but how do I WRITE about it? I can't write that in every sentence in my thesis! I need a noun, a term, something to represent the phenomena I am supposed to explore! Should I perhaps find language that works irrespective of perspective, that would be as descriptive as possible? 'Atypical sex development'?

CLINICAL PSYCHOLOGIST: Hmm… Just thinking critically here… Do you really think that 'atypical sex development' is *more descriptive* than 'intersex' or 'disorders of sex development'?

RESEARCHER: No, I guess not. That's actually also kind of normative. And also, if I use yet another term, I will perhaps neither be able to stay in conversations with those communities who use 'intersex', nor those who use 'DSD'. So what should I do?

CLINICAL PSYCHOLOGIST: {*Thinking*} Well, do you really need to figure it out now? And are you sure that you, of all people, are the one who should be sitting here in your room and trying to figure this out on your own? You are more than one year into your PhD project and you really need to start doing interviews as soon as you have ethical permissions. Perhaps you just have to throw yourself out there and see what happens? Perhaps the answers you are looking for are not in your head but could be articulated in conversations with the people who live these experiences in their everyday lives?

RESEARCHER: Good point. That feels like the first thing you learn on any course in critical methodology. {*Pause*} So, should I just ask people what they think about this? However, this wasn't part of the original project, and isn't really part of the interview guide, is it? Doesn't that make me a bad researcher?

CLINICAL PSYCHOLOGIST: Well, it is part of the interview guide to ask people what terms they feel comfortable with and what terms they want to use during the interview. In other words, you need to ask them what terms they use, or prefer to use, and how they feel about different umbrella terms such as 'intersex' and 'DSD', right?

RESEARCHER: That's true.

CLINICAL PSYCHOLOGIST: And no, you didn't really understand the importance of this question before coming to this point of your PhD process. But isn't that the whole idea of research – of really learning things and understanding that you might not know what the most important things are when you design the research?

RESEARCHER: Yes, that also feels like a take-home message from any course in qualitative methodologies. Okay. I'll talk to people and see what happens.
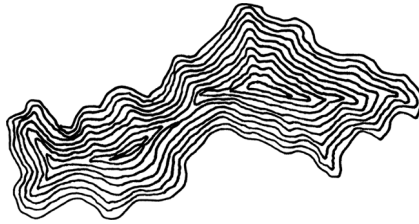
Still struggling as a PhD candidate in 2015

RESEARCHER TOVE: Okay, so I have done 22 interviews with young people and 33 interviews with parents.

CLINICAL PSYCHOLOGIST TOVE: Great! You were really struggling with terminology. What did people say?

RESEARCHER: Well, I am still struggling with terminology. I thought that I could talk to people about what terms they use and what they think about 'intersex' and 'DSD' so I would know what terms I should use in my thesis.

CLINICAL PSYCHOLOGIST: Well, how did it go?

RESEARCHER: Well, the conversations went well. It was quite easy to tune in to the specific thoughts and preferences of each participant. However, I'm still stuck, in a way. I still don't know what term, or terms, to use to write my thesis. And talking to these participants gave me a sense that none of the existing terms works for everyone and every occasion. So, I am still stuck.

CLINICAL PSYCHOLOGIST: Well, you have already submitted two articles. What did you write in them?

RESEARCHER: I tried to avoid the issue.

CLINICAL PSYCHOLOGIST: {*Sounding tired*} But, Tove, come on, you are trained as a clinical psychologist! You know that avoidance typically only helps you from a short-term perspective and that it often ends up not serving you in the longer run.

RESEARCHER: {*Frustrated*} I know! But what am I supposed to do? I don't have time to just sit and wait for some kind of eureka moment! I have 55 interviews to analyze! I need to publish my papers in order to finish my thesis! I only have like 18 months to go before I need to finish!

CLINICAL PSYCHOLOGIST: Okay. So I understand that you are under pressure and that you are very frustrated. And from what you are telling me, you have too much data and too little time. And I understand that this puts you in a position where you need to make choices as to what to focus on and not to focus on.

RESEARCHER: {Upset} EXACTLY!

CLINICAL PSYCHOLOGIST: But, I guess, you must have used some kind of terminology in those two submitted manuscripts. So could you tell me what you did?

RESEARCHER: {*Sighs*} Okay. In one paper (Lundberg *et al.* 2017), I focused only on a specific medical diagnosis, congenital adrenal hyperplasia (CAH). I said in the paper just that this diagnosis is usually covered under the umbrella term 'disorders of sex development' in medicine, but that terms such as 'intersex' and 'diverse sex development' are also used outside medicine. And then I just used the specific diagnostic term.

CLINICAL PSYCHOLOGIST: Well, it sounds like you were trying to be transparent and show the diversity here. So maybe not really 'avoiding the issue', but highlighting it and then not focusing on it in the paper? And in the other manuscript?

RESEARCHER: Well, in that paper (Lundberg *et al.* 2016) I stated that 'disorders of sex development' is used in medicine but that in psychology 'diverse sex development' is increasingly being used – which it was at the time. And then I used 'DSD', as meaning 'diverse sex development', in the article. I wrote this paper with two medical professionals and we had different opinions on what to use. They thought that using the formal medical language of 'disorders of sex development' was the best thing to do. But I just couldn't do that. My whole body just protested. It was just physically impossible! However, while I really appreciate the non-pathologizing sound of 'diverse sex development', I just think it doesn't do the job. It is perhaps the least-bad term, though.

CLINICAL PSYCHOLOGIST: Why do you think that 'diverse sex development' 'doesn't do the job'?

RESEARCHER: Well, this is complex. But, okay, this paper was a narrative analysis of the process of receiving a diagnosis. And 'diverse sex development' is not a diagnostic or medical term. Basically, all people with sex characteristics are covered by that term. So the title says 'a diagnosis related to diverse sex development', which is kind of a compromise. But I don't think that 'diverse sex development' will be able to replace 'disorders of sex development' because it is not referring to what medics want to refer to.

CLINICAL PSYCHOLOGIST: Okay, so what do medics want to refer to?

RESEARCHER: Well, in a medical consensus statement where 'disorders of sex development' is introduced as an umbrella term, it is to cover 'congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical' (Lee *et al.* 2006, p. e488).

CLINICAL PSYCHOLOGIST: Okay, so do you think that 'disorder' is used as a synonym for 'congenital conditions'?

RESEARCHER: Well, I guess so. That this term was to point to conditions that might involve what medics would call pathological processes that 'abnormally affect physiology' (Pasterski *et al.* 2010, p. 189). I just feel that I have a different understanding of how words such as 'disorder' and 'abnormality' function than the people writing these things seem to have. I think these terms are really problematic. And at the same time I kind of get it. The whole healthcare system is built upon medical classifications. At least in Sweden,

as soon as a doctor sees a patient, they need to report a diagnosis in the administrative system to be able to provide the patient with treatment and prescriptions, and also to get the correct funding to the relevant health centre or department.

CLINICAL PSYCHOLOGIST: Yes, this is how it works for us clinical psychologists as well in the healthcare system in Sweden.

RESEARCHER: Exactly. And it is so strange because, you know, the diagnosis can both be based on mutations in a gene, like the cause of a certain medical 'condition', *or* just the reason why someone sought healthcare. Diagnostic terminology is, in other words, formed on very different kinds of bases and the diagnostic system is philosophically very inconsistent.

CLINICAL PSYCHOLOGIST: Sure, causes for a condition and reasons why people seek help are very different.

RESEARCHER: Yes. However, I can't change that system, even though I think that 'disorders of sex development' is a bad term. But then again, if a medical umbrella term is really, really needed, I just think that they – we? – could have done some more work on the term. Like consulted someone who is a public relations specialist or something.

CLINICAL PSYCHOLOGIST: Okay. So what would be a better medical term, do you think, if you do the work?

RESEARCHER: Well, I don't know. But if they want to group diagnoses or conditions together in a classification, why not say just that? 'Conditions classified as affecting sex development'. I don't know. Or 'diagnoses classified as affecting sex development', and then they could keep the acronym DSD –

CLINICAL PSYCHOLOGIST: Sorry for interrupting your thoughts here, Tove. But have you written these things down?

RESEARCHER: What do you mean? No. Why?

CLINICAL PSYCHOLOGIST: Well, I am just thinking as your clinical part here again. You said that you avoided these issues. And I said to you that avoidance doesn't help you in the long term. If avoidance of something doesn't work, what should we do then?

RESEARCHER: What do you mean? Like generally? {*Thinking*} Well, the opposite of avoidance is exposure.

CLINICAL PSYCHOLOGIST: Yes. So, instead of trying to avoid this issue, should you engage in it? Should part of your argument in your thesis be about terminology? I mean, you did talk to people about their thoughts on terminology.

RESEARCHER: Yes, I did. But what do you mean – that this part of the data should be a specific paper?

CLINICAL PSYCHOLOGIST: Yes, for example. Why not?

RESEARCHER: {*Upset*} But I don't even know what to say?!

CLINICAL PSYCHOLOGIST: Well, you have already articulated several important points above. All of that could go into the introduction to the article. And then perhaps you need to engage with the data you have. I mean, what did people say?

RESEARCHER: I can't remember. Everyone just had very different thoughts and opinions. I need to go back and look at the data more systematically. Perhaps I can write a paper on people's preferences when it comes to terminology?

A couple of months later in 2015

RESEARCHER TOVE: Okay, I have some data for you.

CLINICAL PSYCHOLOGIST TOVE: Exciting! Tell me, what did they say?

RESEARCHER: Well, most participants don't talk about their characteristics. Not at all. And also many don't use certain labels to describe themselves. This young person explains it well {showing the clinical psychologist an excerpt from the transcription, see Box 1.1}:

BOX 1.1 EXCERPT FROM TRANSCRIPTION OF INTER-VIEW WITH A YOUNG PERSON, CODED AS 'TERMINOLOGY'

Interviewer: I just wanted to hear like what words do you use when you talk about your development, or your condition, or…

Participant: I don't really talk about it that much. *{Laughter}* […]

Interviewer: No, no, so you don't really talk about it with other people, or…?

Participant: Um, I – I – no, not really, I think it's not a defining characteristic of myself.

Interviewer: No, no.

Participant: And I – maybe I've got to hide it a bit, but I don't think that actually it changes who I am and I shouldn't have to use these said words that, you know.

Interviewer: Yeah.

Participant: I'm just – you know, I'm just a bit different from other people […]. Sorry, that's probably not a very good answer, but…

Interviewer: It is a really good answer because, I mean, I'm interested in how you feel about things.

Participant: Yeah.

Interviewer: So that's – that's a perfectly fine answer.

Participant: Okay, good, good.

RESEARCHER: So now this is even more complex! I mean, researchers and professionals are kind of discussing {*talks in a silly voice*}, 'Do we need medical terms or not, and what should those be, and how about "intersex", and so on?', and in their everyday life many people don't really talk about it.

CLINICAL PSYCHOLOGIST: Yes. That sounds important.

RESEARCHER: Important? How?

CLINICAL PSYCHOLOGIST: Well, think as a clinician again. If you met a person who didn't talk about things, you would explore if there *is* a need to talk about things and the reasons for not talking about it. And if there is a need, you would try to make the unspoken 'talkable', right? And 'talkable' in different ways in different contexts? I mean, people have to be in many situations where they need to talk about these things.

RESEARCHER: Well, of course, participants said they needed to talk to their doctor or with partners and so on, and they did address how they dealt or didn't deal with that, in the interviews.

CLINICAL PSYCHOLOGIST: I think this part of the data is useful. It opens up something else about terminology.

RESEARCHER: Okay. How do you mean, 'opened up something else'?

CLINICAL PSYCHOLOGIST: Well, this is an interpretation and it might not be correct. But you have said that you feel very stuck when it comes to terminology, and that it is either 'DSD' *OR* 'intersex' and that you feel that choosing one or the other is problematic, but you can kind of see some of the points of both?

RESEARCHER: Yes, well, this is true.

CLINICAL PSYCHOLOGIST: So, first, you know, drawing on classic psychoanalytic thinking by Klein here (for an introduction to Klein, see e.g. Hinshelwood and Fortuna 2018), being stuck in an either/or position is typically problematic for people in the longer run. We need to be able to understand and integrate both aspects of, for example, the good and the bad in ourselves and others in order to function well. So I think that moving on from this either/or perspective to a more flexible one would be useful here. Second, I wonder if this 'stuckness' in terminology is just a parallel process, mirroring something about the phenomenon itself (see e.g. Sachs and Shapiro 1976).

RESEARCHER: Okay, so I think I got your first point. But this parallel process thing is a bit unclear.

CLINICAL PSYCHOLOGIST: Well, isn't the whole problem that binary understandings imply that sex characteristics need to be either male OR female, and so every kind of sense-making is based on that either/or construction?

RESEARCHER: Yes, and that is why it is called '*inter*sex'.

CLINICAL PSYCHOLOGIST: Yes. And so a psychodynamic interpretation of the terminology discussion is that this debate is stuck in the same dynamics, and perhaps also underpinned by the same socio–psychological forces as the understandings of sex characteristics themselves. The processes relevant for how we make sense of characteristics are also being played out in how we describe these characteristics. This is what we call 'parallel processes' in psychodynamic literature.

RESEARCHER: Okay, now it makes more sense. I haven't thought of it that way. But I think that this perspective could open something up. So the 'stuckness' I feel could be interpreted as not being about me only? I might be embodying larger and more fundamental things here?

CLINICAL PSYCHOLOGIST: Well, from a psychodynamic point of view, that could be an interpretation.

RESEARCHER: So maybe I don't need to 'choose' sides but explore if there are other ways of engaging with terminology.

CLINICAL PSYCHOLOGIST: Exactly. See if there are ways to open up conversations about terminology instead of being stuck.

RESEARCHER: This is potentially useful. {*Thinks for a while*} So when it comes to 'intersex' and 'DSD', one way of opening up the either/or dynamic would be to use both, like in 'intersex/DSD'? Instead of trying to find yet another term, like I was trying to do with 'atypical sex development'.

CLINICAL PSYCHOLOGIST: I guess different stakeholders will interpret that strategy in different ways, but yes, that is something else than choosing one term over the other or trying to sit in your room and 'invent yet another term'. Didn't you have a quote by a parent highlighting this?

RESEARCHER: Well, when I asked a parent what he thought about 'DSD' and said that health professionals and researchers use that as a standard term now, he replied {*reads quote*}: 'Fine – in your lab, do what you like. But when you're dealing with people, {*pause*} because you're so scientifically based, there's a whole group of people who can miss the fact that what you say […] can be incredibly hurtful.'

CLINICAL PSYCHOLOGIST: Ah, that's right. So if we think of ourselves as the ones in the 'lab', I really don't think that folks need yet another researcher suggesting a new term to use.

RESEARCHER: Yes, you have a point. Several young people also talked about the effects that terminology, especially 'disorders of sex development', could have on people. One young person said {*reading from transcript*}: 'I don't like the word "disorder", 'cause it suggests there's something wrong with someone. And for like, you know, some of these kids, […] if they hear "disorder of sexual development", they might, be it subconsciously or otherwise, think, "Oh my God", you know, […] "I've got something wrong with me".'

CLINICAL PSYCHOLOGIST: So that participant shared your concerns regarding 'disorder'.

RESEARCHER: Yes, but, at the same time, some also liked or used both 'DSD' and 'intersex'. Or they were very pragmatic. One parent said {*reads again*}: 'It's all jargon and […] recently they stopped saying "intersex" and started saying "DSD" […]. I'm comfortable with sort of all – all of the different terms […] it's whatever you want, so you know it's, if you want to identify as a person with a [DSD], then that's what you are; if you want to identify as intersex, that's what you are. […] ultimately, [our son] can decide […] how he talks about it. I think that's why I do want to almost talk about it in so many different ways.'

CLINICAL PSYCHOLOGIST: Tove, these are all really strong and important quotes. You need to write this terminology paper.

RESEARCHER: You think so? And illustrate the diversity and complexity of terminology instead of just descriptively summarize what terms people prefer?

CLINICAL PSYCHOLOGIST: Yes, definitely. You can also talk about what people prefer, but yes, highlight what people think. And also, I guess, the discrepancy between the formal terminology debate among professionals and the everyday sense-making and the communication needs that people have, which typically require another way of thinking about terminology. Like having a pool of different terms or ways of talking about your body in different contexts and for different purposes.

RESEARCHER: Yes. Another young person actually made that point really clear by saying that, whatever label is used by professionals, she is the one who needs to 'deal with it'. So yes, I guess I won't be able to avoid writing this paper.

Reflecting over reflexivity in retrospect: From 2019 and onwards

CLINICAL PSYCHOLOGIST TOVE: So, Tove, you wrote that paper eventually.

RESEARCHER TOVE: I did (Lundberg *et al.* 2018). And I positioned it as the first paper in my thesis. Like the foundation for the rest of the thesis.

CLINICAL PSYCHOLOGIST: And for the first time you have tried to put the process that led up to that paper into words in order to write about and evaluate your reflexivity in retrospect, as you said at the beginning of this chapter.

RESEARCHER: Yes.

CLINICAL PSYCHOLOGIST: So, the reconstructed section above really tries to make how you practised reflexivity and what theories you drew on transparent to the reader as well as yourself?

RESEARCHER: Yes, I hope it has made things more explicit. It is more apparent to me, at least. And, oh my, was that hard to write!

CLINICAL PSYCHOLOGIST: Why?

RESEARCHER: Well, first, it is hard to reconstruct something that happened a while ago. I think Hustvedt's quote at the beginning of the chapter illustrates that eloquently. And second, it was all so emotional and I really didn't know what to do with those feelings.

CLINICAL PSYCHOLOGIST: Yes, as a clinical psychologist, I can really see that you were struggling a lot with your feelings during your doctoral research. And I can see that it must have been emotional to return to those feelings as well. I wonder if you want to explore that a bit?

RESEARCHER: It was emotional! And being educated in a very post-positivist and quantitative discipline as a researcher, I interpret having all of these feelings as being biased and as being a bad researcher.

CLINICAL PSYCHOLOGIST: Okay, I see. So struggling with not only the emotions, but with not living up to a certain idea of how a researcher should be?

RESEARCHER: Yes! Exactly! And as an interdisciplinary scholar, maybe trying to navigate inconsistent and competing ideas of how a researcher should be? On

the one hand, trying to adhere to those more quantitative ideals of my discipline and, on the other hand, trying to live up to ideals of being a critical and feminist scholar with social justice and ethics of care in mind.

CLINICAL PSYCHOLOGIST: I see. Yes, you mentioned feelings of 'in-between-ness' at the beginning of this chapter. It sounds like you were caught with challenging affects in between different epistemological ideals?

RESEARCHER: Yes, that is really how I felt.

CLINICAL PSYCHOLOGIST: Yes. And in the section above, where you reconstruct your experience of your doctoral work, there is also this sense of 'stuckness'. Now, when we talk, I still get an embodied feeling of being stuck.

RESEARCHER: Yes, in my academic work I tend to feel that I am walking on thin ice that might break at any minute. That I don't want to move, but have to, and do that slowly and just hope that the ice won't break.

CLINICAL PSYCHOLOGIST: That sounds daunting and… exhausting?

RESEARCHER: It is.

CLINICAL PSYCHOLOGIST: So, what does the walking-on-thin-ice metaphor symbolize right now?

RESEARCHER: Well, after writing the above section on my discomfort with terminology, it is really clear to me how my emotions kept me back, and how I tried to avoid them. And I am just not really sure what to do with all of these emotions in research? I mean, the main training I have had about emotions in research is that they shouldn't be there!

CLINICAL PSYCHOLOGIST: Sure, but you also mentioned critical and feminist theory. And several scholars in these traditions have, in fact, turned to affect.

RESEARCHER: Well, that is true.

CLINICAL PSYCHOLOGIST: And I know you know some of this literature, and that these scholars present very different ideas on emotions in research. For example, that emotions are not just an inevitable part of research, but perhaps even necessary. As in life in general. You know, as a clinical psychologist, I work a lot with affects because they 'move us to act or spur specific action' (McCullough *et al.* 2003, p. 15). In other words, we need affects to do things, for example to do research.

RESEARCHER: Yes, you are right. Hemmings (2012) refers to different theorists stressing the importance of rage, passion and other emotions, and highlights 'that in order to know differently, we have to feel differently' (p. 150). Similarly, Whitson (2017) points out that our emotional reactions to research say something about our 'dreams and desires' about ourselves and our 'research participants' (p. 305).

CLINICAL PSYCHOLOGIST: Exactly. However, I still feel that you are not really convinced that the emotions you experienced should have been there or even helped you during your PhD research?

RESEARCHER: No, I don't feel that they were really helping me! They were awful, and I wish I hadn't had to feel them!

CLINICAL PSYCHOLOGIST: Okay. I hear you. They weren't pleasant. I understand that not having to experience them at all would have been preferable. However, you also wondered if your practices of reflexivity actually made your research any better. Judging from our reconstruction of the discomfort with terminology, I would say that, yes, addressing this discomfort made the research better.

RESEARCHER: Why?

CLINICAL PSYCHOLOGIST: Because by exposing yourself and addressing this discomfort, instead of running away from it, you were able to know differently, just like Hemmings (2012) suggests.

RESEARCHER: Sure. I admit that addressing this discomfort provided me with a new route for my thesis. However, was it worth all the anguish and all the discomfort? Will I ever get rid of all of these negative feelings in the future? I don't know if I can stand being a researcher in the future if it means I will need to struggle like this in everything I do!

CLINICAL PSYCHOLOGIST: Well, maybe the problem is not that you have all of these feelings, but rather that you spend a lot of time and energy trying to avoid them?

RESEARCHER: Well, what is the alternative?

CLINICAL PSYCHOLOGIST: That you work with them.

RESEARCHER: How?

CLINICAL PSYCHOLOGIST: By acknowledging the fact that negative feelings and suffering are an inevitable part of life, including a part of doing research. And as human beings we tend to do two things in response to these feelings. One is to 'overidentify' with our feelings and perspectives: that how we feel and think *is how the world is* instead of *one* way of experiencing life. The other is to try to control or avoid feelings that make us suffer. However, these approaches can create more suffering because they make us psychologically inflexible. For instance, trying to control or get rid of unwanted aspects typically just creates more unwanted thoughts and feelings. Instead of reflecting, we might obsessively ruminate, for example.

RESEARCHER: That is exactly what I was trying to do. So what could an alternative way of relating to our emotions and thoughts be?

CLINICAL PSYCHOLOGIST: Well, if we draw on the understandings from some third-wave behavioural theories, first, we really need to connect to 'the ongoing flow of experience in the moment' (Hayes and Pierson 2005, p. 3). Instead of control or avoidance, we need to willingly accept that we will experience undesirable and negative situations and feelings. This also means exposing ourselves to discomfort instead of running away from it.

RESEARCHER: Okay. {*Thinking*} So, really we can't escape moments of discomfort in research? And drawing on this idea, this whole book could be understood as a collective exposure of discomfort where all the authors try to highlight it, instead of avoiding it? {*Laughing*}

CLINICAL PSYCHOLOGIST: {*Laughing*} Yes, that could be a constructive way of understanding this book.

RESEARCHER: Great! So what do we do next?

CLINICAL PSYCHOLOGIST: We practise developing a 'decentred stance' to cognitively defuse from our experiences, thoughts and feelings. By being non-judgmental and by not overidentifying with our feelings and thoughts, or trying to control or avoid them, we can develop a more flexible way of reflecting upon them and decide how to respond to our experiences. Instead of reacting automatically, this space gives us opportunities to do things that move us in a direction that is consistent with our values. However, this is a striving, a leaning towards something in life; these values are not specific goals that can be accomplished.

RESEARCHER: Well, it all sounds very clever, but it also sounds easier in theory than in practice?

CLINICAL PSYCHOLOGIST: It is a striving that you need to practise. It won't solve your discomfort, but it could help you deal with it in ways that are more constructive than trying to control or avoid things.

RESEARCHER: {*Quiet for a while*} So, let's see if I get what you are trying to say. Drawing on these theories, we, as researchers, need to understand that reflexivity is probably not something that would control or remove the moments of discomfort we experience. It isn't about becoming the perfect researcher with no flaws that will get things 'right' all the time? It is rather about accepting that we will mess up, experience defeat as well as success and sometimes be lucky enough to generate constructive knowledge? And that reflexivity could involve developing a 'decentred stance', from where we notice our experiences of research, and critically evaluate what we have written, our thinking, our practices and our feelings and see if what we do is in accordance with the values that we deeply care about as researchers? Also, in order to be accountable for what we do and our representations?
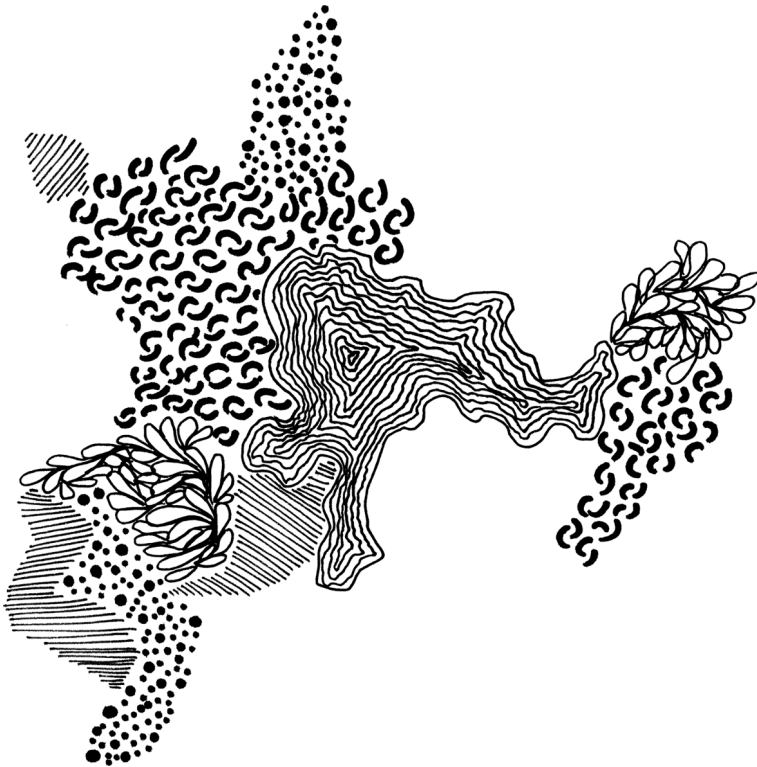
CLINICAL PSYCHOLOGIST: Yes, I think that is a reasonable summary of what I was trying to say.

RESEARCHER: I realize now that my preoccupation with trying to control or avoid my discomfort as well as my feelings of doing things wrong as a researcher actually was a source that led to a centring of myself. This is quite the opposite of what some writers, such as Skeggs (2002), suggest we do as reflexive researchers. If I had had more psychological flexibility via this 'decentred stance', I think I could have focused a lot more of my energy on knowledge production and my participants' concerns and accounts. To use the quote by Hemmings (2012, p. 150) again, 'in order to know differently' I would have had to feel differently about my feelings.

CLINICAL PSYCHOLOGIST: Well, being a researcher is challenging in several different ways. I think that not overidentifying with your discomfort and not interpreting these negative feelings as proof of your being a bad researcher would perhaps have made this work just a bit easier?

RESEARCHER: {Thinking} Perhaps. {Sits quietly for a while}

CLINICAL PSYCHOLOGIST: You are very quiet now.

RESEARCHER: Yes. I am thinking about overidentifying with feelings. And how I felt about the terminology question.

CLINICAL PSYCHOLOGIST: What are you thinking?

RESEARCHER: Well, I think that, as a PhD candidate, I was still emotionally invested in finding 'The Term' that could be used by everyone, everywhere.

CLINICAL PSYCHOLOGIST: Yes, you really desired to 'solve' the terminology debate, didn't you?

RESEARCHER: I think I did, and I was quite disappointed in not being able to do it.

CLINICAL PSYCHOLOGIST: Well, that is a very natural response when people find things hard to contain. That you want something to be solved to escape the unbearable feelings it activates. When staying in the complexity is too over-whelming or when you are doing a lot of unrewarding 'dirty work', as Irvine (2014) calls it.

RESEARCHER: Yeah, that is probably it. I really do find this terminology discussion exhausting in many ways, and I think many others do as well. As soon as I talk to other researchers or health professionals about this, most don't really want to listen to or engage with the terminology discussion. It feels like many just

want to decide on a term and then we can move on to discuss other 'more important' things.

CLINICAL PSYCHOLOGIST: Yes, well, as we discussed in the reconstructed part above, maybe it isn't about terminology *per se*, but about the phenomenon itself.

RESEARCHER: I think that interpretation makes sense. I think that I as a PhD candidate, in an embodied sense, experienced being 'amiss in how [some]one is recognized, feeling an ill fit with social descriptions', as Hemmings (2012, p. 150) calls it. However, it is only really in the last year that I have comprehended the width and depth of what this really means, also affectively.

CLINICAL PSYCHOLOGIST: Well, building on that, terminology sounds even more important to acknowledge in a thesis, then.

RESEARCHER: Yes, I think so. Liao (2015), who is a clinical psychologist and researcher, also talks about the need to start addressing emotions more explicitly in this topic area. She refers to healthcare, but I think we need to focus more on feelings in intersex research as well. If I were to write my thesis now, I would focus a bit more on different affective aspects and also try to utilize an affective reflexivity more explicitly.

CLINICAL PSYCHOLOGIST: Well, then, I understand why you think using your knowing as a clinical psychologist more explicitly would have been useful. Maybe you can do that in the future?

RESEARCHER: Maybe.

CLINICAL PSYCHOLOGIST: So, should that be the concluding remark of this chapter?

RESEARCHER: Ermmm… {*Hesitating*} If I am now supposed to follow your psychotherapeutic technique to connect to 'the ongoing flow of experience', which basically is the focus of this text now, I cannot avoid noticing some hesitations.

CLINICAL PSYCHOLOGIST: Great, let's notice them together.

RESEARCHER: Okay. So, in a way, I feel that the thoughts in this chapter are important. But I also just wonder how 'new' these ideas are, like methodologically? I mean, isn't this just some kind of introspective form of reflexivity, which has been criticized by so many academics (see e.g. Skeggs 2002, Pillow 2003)? Am I not just writing about my 'self' a lot now, which makes me self-centred and narcissistic as well as decentre what is important in my research?

CLINICAL PSYCHOLOGIST: What if it is narcissistic and self-centred?

RESEARCHER: Do you think it IS narcissistic?!

CLINICAL PSYCHOLOGIST: Well, I think that it is possible to interpret it in different ways. And I guess some would say that academia is quite narcissistic. And speaking of that, let's think about your hesitation to write about your 'self'. You are working in a system where the best success indicator of who you are as an academic is the texts you are writing. So, in this system, the impression-management of your 'self' is what you have got to deal with. Is that narcissistic? Then, yes.

RESEARCHER: But being in academia doesn't mean that I have to centre myself in everything I do, does it? And I just wonder if there is too much centring of myself in this text?!

CLINICAL PSYCHOLOGIST: Well, you did make it clear that you wanted to use this chapter to explore your reflexivity during your PhD research. So, one interpretation could be that this is a self-centred and confessional piece. But maybe you and others can still learn from it?

RESEARCHER: Well, I certainly have learned something in writing this chapter. But maybe I should have done this work quietly and privately in my office?

CLINICAL PSYCHOLOGIST: Well, that is what you said you did as a PhD candidate, didn't you? And then you were worried about not being reflexive enough.

RESEARCHER: Fair point.

CLINICAL PSYCHOLOGIST: Or maybe it isn't narcissistic? Another interpretation could be that maybe it is not only your 'self' that is in focus here, but rather your thinking and your knowing? But these are, of course, related to your 'self'. By that I mean, as I think Skeggs (2002) points out, the self is a historically and socially produced 'necessity' nowadays, isn't it? I mean, can you 'escape' your 'self', even though we can clearly see that this is part of a certain discourse? Can you step outside of discourse? As far as how I understand Foucault (1984), you can't. And do you really focus on your 'self' or is it not your 'subjectivity'? And what is really the difference?

RESEARCHER: Okay, I see the complexity here. These are all really hard and important questions. And they are not really new questions, either…

CLINICAL PSYCHOLOGIST: Well, your hesitation about this chapter being 'new': I don't think this is new. Does everything you write have to be 'new'? And what does 'new' even mean? Does it mean ideas, words or meanings that have never been expressed before? Always writing something new seems like a very hopeless and tiring ideal for an academic.

RESEARCHER: It is a very hopeless and tiring thing to be an academic!

CLINICAL PSYCHOLOGIST: Then should you perhaps stop overidentifying with these ideals and start to 'decentre' from them a bit?

RESEARCHER: Actually, I'm not sure I will be able to do that. But sure, I'll try.

CLINICAL PSYCHOLOGIST: Well, trying is all we can do. Remember that being in a 'decentred stance' as well as living and researching in your valued direction is a striving, a leaning towards something in life. It isn't a goal that can be reached once and for all time.

RESEARCHER: Okay, sure. So, I will try to decentre from problematic academic ideals but still reflect on and engage with them. And I hope that the readers of this book will too.

CLINICAL PSYCHOLOGIST: Well, social support is one of the most effective coping strategies there are. You all know that from writing this book.

RESEARCHER: That is true.

CLINICAL PSYCHOLOGIST: So, can the clinical psychologist share a final professional tip, then?

RESEARCHER: Sure, go on!

CLINICAL PSYCHOLOGIST: I suggest that you all continue resisting these problematic academic ideals together.

RESEARCHER: Collective resistance via affective reflexivity? {*Pause*} I like that. I'm on!

Notes

1 'Moments of discomfort', which is part of the title of this book, sounds like a good descriptive summary of the feelings of disorientation, frustration and 'stuckness' I experienced as a doctoral researcher in psychology from 2012 to 2017. The discomfort was mostly related to my attempts to position myself in a field of research where at least two very different bodies of knowledge with contrasting views are evident. The topic of my thesis was to explore the lived experiences of people with sex characteristics that do not conform to typical understandings of female or male physical development (Lundberg 2017). Within medicine, such characteristics are typically referred to as 'disorders of sex development' that are understood to be 'congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical' (Lee *et al.* 2006, p. e488). The term 'intersex', however, is used by many people with personal experience of DSD as well as by human rights advocates and researchers within the humanities and the social sciences (Lundberg *et al.* 2018). In these contexts, intersex characteristics are understood as naturally occurring variations of human embodiment that should be recognized and protected by human rights. One main challenge that gave rise to the discomfort was to stay in conversation with both of these perspectives and at the same time try to articulate my own position in an intelligible manner. The different participants whom I interviewed for this project, 22 young people and 33 parents, described very different challenges in their everyday lives, presented diverse ways of making sense of their or their child's variations and preferred different terminology to describe these characteristics (Lundberg *et al.* 2018). Some participants drew on medical discourses and labelled themselves or their child as someone with a specific medical condition. Others articulated thoughts that were more in line with the human rights perspective and some young people also identified as intersex. Only some participants utilized both discourses. A challenge during my research was thus to respect the many different ways that participants made sense of their embodiment, while at the same time critically analyze and discuss the medical *as well as* the human rights perspective. Being caught in a dilemma of respecting research participants while at the same time, on a more general level, problematizing and criticizing the same frameworks of understanding that participants draw on is not a unique or new challenge. Feminist scholars have struggled with these issues for decades (Wilkinson and Kitzinger 1996, Finlay 2002a). However, even though I think I was able to articulate some kind of strategy in dealing with these moments of discomfort, I still feel that my 'solution' was very provisional. Finally, I was also discomforted when I was trying to put all of the above-mentioned discomfort, and the ways I coped with it, into words. As a young clinical psychology student, I was encouraged to do such reflexive work when I saw clients; however, I was never trained to do so when I did research. The formal and expected requirements of the thesis and the lack of time and skills of understanding how I was to 'write about reflexivity' led me to omit the reflexive parts I initially planned to have in the introduction to my thesis. In other words, I retreated from engaging with reflexivity (Finlay 2002b). This chapter starts in the discomfort related to reflexivity and the chapter's main aim is to write about those reflexive parts that were omitted in my thesis.

2 While it looks like all these conversations happened in my head, they did not appear in an academic vacuum. Many of the insights presented in this chapter have been possible because of other people's input. I could never have arrived at these thoughts if it were not for Katrina Roen, Peter Hegarty, Lih-Mei Liao, Margaret Simmonds, Ellie Magritte, Del LaGrace Volcano and many others. I am also deeply thankful for conversations with Catrine Andersson and Elinor Hermansson, which have helped me feel differently about my feelings.

3 Narrating a history of intersex in order to provide a background and a context for the current situation is a complex task. Narrations in current academic texts usually use the paradigm of medical guidelines from the 1950s (the ones suggested by Money, Hampson and Hampson 1955) and describe the growing critique of researchers (such as Fausto-Sterling 1993, Diamond and Sigmundson 1997, Kessler 1998) and activists (such as Chase 1998) during the 1990s as the starting point for the current situation. Narrations also often point out that these developments led many stakeholders to be concerned about medical practices by the beginning of the 2000s (Davis 2015). One main discussion since then has been in regard to whether early surgery should be performed in order to normalize the appearance of children's genitals. Other aspects that are typically narrated as important parts of the changes that have happened since the 1990s include discussions on how to understand these variations, what terminology to use, and if, and in that case how, medical classifications should be constructed. Many authors, for example Dreger (1999), Karkazis (2008), Reis (2012), Davis (2015) and Garland (2016), provide important historical contextualizations. When it comes to terminology, activists reclaimed the term 'intersex' as well as 'hermaphrodite' from medicine in the 1990s (Davis 2015). In 2005, activists, bioethicists and medical practitioners wrote a piece together arguing for a revision in terminology and medical classifications (Dreger *et al.* 2005). Their main point was that the diagnostic taxonomy, including terms such as 'hermaphroditism' and 'pseudo-hermaphroditism', was problematic because the terms were based on the histology of gonads and, thus, scientifically misleading as well as stigmatizing. They suggested a system where specific conditions were recognized and that these could be grouped together with the medical umbrella term 'disorders of sexual differentiation' (DSD). This suggestion was taken up by medical experts. Also in 2005, a consensus meeting with paediatricians and a couple of patient representatives was held in Chicago. A year later, a Consensus statement was published (Lee *et al.* 2006). In this document, the umbrella term 'disorders of sex development' (DSD) was presented as well as a new taxonomy that classified specific conditions on the basis of chromosomes. The authors argued that 'disorders of sex development' was a better term than 'intersex' because it was more descriptive and because it incorporated advances in medicine. It was also understood as less confusing and stigmatizing as well as more meaningful to the people concerned. Since the early 2000s, different groups that organize people with lived experiences of intersex/DSD have appeared and some have changed their format and approach (Davis 2015). Some are organized as support groups and work in close collaboration with health providers and medical researchers in order to improve care. Some of these groups support the current medical terminology and taxonomy as well as the guidelines and practices. While not all groups understand DSD as 'disorders of sex development', but rather as 'diverse' or 'differences of sex development' (Monro *et al.* 2017), some still support the idea that these variations can or should be understood from a medical model. Other organizations have continued to criticize medical practices. Some of these latter groups ground their claims in human rights (Ghattas 2015). With the support of international LGBTQ organizations, some groups argue that the still-occurring practices of non-essential surgery violate children's rights to bodily integrity and self-determination (a concern also raised by the United Nations Human Rights Council 2013). Commentators are also critical of the changes in medical terminology and classifications (see e.g. Davis 2014, Monro *et al.* 2017). They argue that this medical reclassification pathologizes variations in embodiment which, in turn, underpins problematic medical practices. Some also argue that the continuous medicalization of these sex characteristics gives medical professionals a disproportionate amount of power in defining how these variations should be understood and also treated. As such, the move towards using the term 'DSD' in medicine can be understood as a form of hermeneutical

injustice, where the right to self-determination in understanding and naming one's body and oneself has been taken away from people with these sex characteristics (Carpenter 2016). It was in the context of these complexities that my doctoral thesis was situated.

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