Who is sensitising whom? A participatory interview guide development as an awareness tool within a health care research project

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1. Introduction

1.1. The interview guide in semi-structured, guided interviews

In the methodological discourse on the qualitative, guided interview, well-composed interview guides are considered suitable instruments for collecting data and generating complex narratives on specific topics. In addition to deciding on an interview form, reflection on how and which questions to ask is described as the most important preliminary work for a qualitative interview [1] and the semi-structured interview guide is the most frequently used tool in qualitative research [2,3]. However, the interview guide is considered to play a tricky, ambivalent role: The guide can reinforce or mitigate interviewing errors, pretend too much or too little, and perpetuate the problematic attitude of the questioner to evoke only their own knowledge and viewpoints from the interviewee [1,4,5]. In short, the interview guide is involved in power relations in the interview situation and is a central actor in their reinforcement, exercise, or mitigation.

Yet, the research literature has so far questioned the powerful process of interview guide composition mainly unidirectionally from the interviewers to the interviewees [1,2,6]: while interview types such as biographical interviews certainly do set different emphases in openness and closedness of questions and some theoretical conceptions of qualitative interviewing suggest to not use a guide at all, methodological reflections on the interview guide within guided interviews focus mainly on the researchers, who actively construct the interview guide. Semi-structured, guided interviews are illuminated in terms of how they would more or less legitimately direct and control the researched and what is said in the interview situation. In this setting, the respondents may refuse, hesitate, dither, or even keep silent, but the researchers remain the actual actors as they and their accomplice – the interview guide – specify and significantly shape the research situation. According to Thompson (2021), through the design of the interview guide, the researchers specify "what a dialogue is and what is to be represented" [7].

Without negating structural hierarchies in the interview situation, we here take a different perspective that has so far been less illuminated in theoretical and methodological discussions about interview guide production. We explore how a collaborative process, following the criteria of participatory research, can weaken the power effects of the interview guide and mitigate a paternalistic

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attitude of the interviewers towards the interviewees. We are interested in how the collaborative design of the interview guide initiates negotiation processes between the researchers, the interviewees – hereafter referred to as co-researchers – and within a research team. We start by exploring theories on interview guide development, then describe our aims, purposes and research questions, depict our findings as four epiphanies and finally departing from theories of interview guides give recommendations for other researchers.

1.2. Theories on interview guide development

To date there are many manuals, guidelines, and practical instructions on how to design an interview guide. For example, systematic methodological reviews such as Kallio et al. "provide a practical tool for researchers developing a semi-structured interview guide as a data collection method" [2]. However, there is no specific theory that focuses exclusively on the use of guides in qualitative interviews, let alone on a theory of the semi-structured guide. Rather, guides are part of various theoretical approaches and methods used in qualitative research. Guides themselves often do not strictly follow a particular theoretical approach, but in turn are considered to serve as a tool to support a broader theoretical perspective.

What *does* exist is a considerable body of work on theorizing the interview, the interviewer and the interview situation [8]. These contributions do tackle theoretical conceptions of how to construct research instruments such as the semi-structured interview guide – but rather implicitly. In her comprehensive guide to the theory and practice of reflective inquiry, Kathryn Roulston (2010) refers to a wide variety of theoretical conceptions of the qualitative interview [8]. We first introduce theories of interviewing which are most relevant for us and delineate the enclosed conceptions of the interview guide. We secondly justify our chosen theoretical markers for constructing the interview guide.

Neo-positivist assumptions are still evident in much qualitative research [8]. Neo-positivism is an approach in the philosophy of science that presumes that scientific knowledge can be obtained through the use of justified methods. In neo-positivistic conceptions of the interview, the interviewer appears as a rather detached, neutral figure which keeps "bias" and "researcher influences" as small as possible. The interviewer generates "quality" data and produces "valid" findings [8]. In neo-positivistic approaches to interviewing, a guide appears a neutral tool to support objective and systematic research methods, constructed by the researcher, who should gather as much knowledge as possible in advance about the live worlds of the researched. The interview guide ought to be composed of "good questions", arranged in a skillful manner. The guide suggests a high degree of structure in the interview situation and the interviewees' answers are deemed to be more valid if they do not know why the interviewer has asked the question [8]. Collaborative design of the guide is not envisioned in a neo-positivist approach.

A further influential conception of the interview is the constructivist approach [9] which sees the interviewer and interviewee as collaborators in constructing data. Both generate situated accountings and possible ways of talking about research topics. The researcher produces analyses of how the interviewer and interviewee made sense of the research topic and of constructed narratives [8]. In a constructivist approach, the interview guide does not play a prominent role. For example Kathy Charmaz even "seldom takes an interview guide with her to the interview, as she prefers to keep the interview informal and conversational" [9]. The guide is more a possible point of departure than a skillfully drafted, nevertheless rigid directive. The interview guide or single questions help the researcher to provide understandings of possible ways of discussing topics and does not strongly pre-structure the interview situation.

In a transformative conception of the interview the interviewer dialogues with the interviewee and may work in collaboration to design, conduct and present the research project [10–13]. The interviewer and interviewee develop "transformed" or "enlightened" understandings as an outcome of dialogical interaction. Interpretations of data produce critical readings of cultural practices that challenge normative discourses. Data produced changes both interviewer and interviewee as each engage in dialogue that question how they approach their worlds. According to Roulston, the *main* purpose of transformative interviewing is "fostering social change for social justice" [8]. Analytic methods and representations draw on critical, emancipatory, and psychoanalytic theoretical perspectives (for example, critical theory, feminist theory, critical race theory, hermeneutics, and psychoanalysis) [8].

Transformative interviews do not necessarily use interview-guides in every interview but similar to constructionist conceptions favour initiating, open questions. These questions shall help that the interview situation becomes a *purposefully* structured talk. The thoroughly selected questions shall assist the researchers to "provide a space for people to engage critically and reflectively with issues that affect them daily" [8]. When the conversation evolves the interviewer does not stick to a structured interview guide but listens carefully and might call upon participants to "think more deeply about the issues they bring to the discussion," [8] and might request examples of what participants mean. Instead of questions, transformative conceptions might prefer alternative elicitation strategies such as drawing, writing, or poetic transcriptions derived from prior data collection [14].

We found ourselves identifying with each theory of the interview, however, in varying degrees concerning the level of structure and participation suggested by the theories. With a neo-positivist approach towards interviewing we share the believe that the interview guide ought to be composed of "good" questions, that means precise questions which come as close as possible to the life worlds of the interviewees, arranged in a skillfull manner. The subjective perspective regarding expectations and experience of participation in the interdisciplinary training concept should be inquired about and not, for example, primarily comprehensive biographical aspects, work environment, or general attitudes toward care.

So the importance we give to an interview guide as a data generation tool differs from the other theories of the interview. In a constructionist version the guide has not such a relevance. As noted above Kathy Charmaz often does not use an interview guide at all. And different to the transformative approach which uses more experimental techniques to produce data, we stick to a rather traditional instrument.

In accordance with transformative approaches, our interview guide might but not has to produce critical readings of social phenomenon that challenge norms. For example, the main purpose of the interview was not to fiercely critique a binary gender system. It

was not our first concern to change the interviewees understandings, world views or self conceptions The construction of our interview guide indeed was somehow oriented towards social change but only to a certain extend – and transformation was not our main concern, so we only adopted a very light version of transformation.

However, we agree with the critique on neo-positivist conceptions of the interview for omitting the experiences of both researcher and researched and not considering that data always is complexly co-produced [15,16]. We sympathize with constructivist, and transformative requirement that the interviewer dialogues with the interviewee and may work in collaboration to design and conduct the research project. That is the reason why we also draw on theoretical fragments of the other theories. They are more suitable for a participatory approach towards constructing the guide. All enable a process in which the topics and questions of the interview guide are co-constructed, co-designed or co-developed. Especially a constructivist approach seems suitable for our paper because it "places priority on the studied phenomenon and sees both data and analysis as created from shared experiences and relationships with participants" [9]. It also relies on the following assumptions: "multiple realities exist, (b) data reflect researchers' and research participants' mutual constructions, and (c) the researcher enters however incompletely, the participant's world and is affected by it." [9] The interviewee is invited to engage in developing the interview guide. The interview guide is not a neutral tool but part of the live worlds of the interviewees. The interview guide enables situated accounts on research topics.

Indeed, in exchanging ideas about the interview guide and considering the interventions of our project partners we have encountered transformational moments for ourselves. However the term "transformative" interview denotes "work in which the researcher intentionally aims to challenge and change the understandings of participants, rather than "transformation" that may be associated with new understandings on the part of either interviewer or interviewee." [9]

In sum in terms of structure we tend more towards a neo-positivist attitude as we use a semi-structured interview guide. In terms of participation we tend towards the collaborative orientations of the other conceptions. Or to put it differently we put constructionist and transformative elements in constructing a partly neo-positivist semi-structured interview guide.

1.3. Objectives, rationale, aim

The aim of this paper is to show how an interview guide designed according to the criteria of participatory research can positively influence the attitude of the interviewers and weaken the power effects of the interview guide.

This aim shall be achieved by exactly contouring the processes of co-constructing the interview guide conjointly with the interviewees. To put it differently, the objectives of this paper encompass describing, contouring and analyzing the interactions that happen when giving back the interview guide to the interviewees, the changes made in the questions and reflections in the attitudes of the interviewers.

The rationale of this paper is to further fill a variously identified research gap "on how to develop a semi-structured interview guide" [2]. The process how to develop a semi-structured interview guide has rarely been systematically researched from a participatory perspective and there is a scarcity of studies that focus on the development of semi-structured guide by both the researchers and the co-researchers. The purpose of this paper especially is to discuss how such development can be conducted in a participatory way.

Our research questions are: How can the semi-structured interview guide be designed participatively? Whether and how can the process of designing the interview guide also have an impact on the interviewers? How exactly can that be enriched participatory? What insights does the development process of the interview guide provide to the researchers?

1.4. The health care project Empower-DSD

The semi-structured interview guide was developed for the qualitative evaluation of the Empower-DSD study. Its focus is on the development and evaluation of interdisciplinary, diagnosis-specific training for children, youths and young adults with a difference of sexual development (DSD) and their relatives. The term DSD encompasses a variety of diagnoses that can be divided according to the chromosomes in chromosomal DSD, 46,XY-DSD, and 46,XX-DSD and include differences in gonadal development, sex hormone synthesis, or sex hormone action. Some examples of DSD diagnoses are the Turner and Klinefelter syndrome, congenital adrenal hyperplasia (CAH), or complete androgen insensitivity syndrome (CAIS). Clinical characteristics, e.g., development of the external genitalia or pubertal development, as well as the time of diagnosis, vary individually.

1.5. Participation in Empower-DSD and the development of the interview guide

The participatory involvement of co-researchers in the interview guide development is part of the broader participatory orientation of the Empower-DSD study: the entire research process is conducted together with those whose lives and bodies are affected – people with DSD. Relatives, peers, and the self-help groups (SHGs) are actively involved during the whole study.

The ideal core principle of participatory research is *with and for and not about* people. Experiences, insights, and expertise of involved persons should be systematically, symmetrically, and equally considered for knowledge production [17,18]. 'The affected' are to become co-researchers.

Because of the project's core topic – differences of sex development – it makes particular sense to base Empower-DSD on a participatory approach: medical paternalism has determined the medical history of sex for a long time. A diagnosis of variant sex development often resulted in the 'adjustment' of external genital structures to one sex [19–21]. Families have often been left out of these decisions. Surgeries, often performed during infancy or early childhood, were done without comprehensive information or consent of the children due to their young age. This approach was also referred to as "optimal gender policy". It followed the general

presumption that to know and openly live with a difference in sex development most likely would lead to an unhappy life. In recent years, persons with DSD have fiercely criticised this policy [22], and the health care situation of intersex people has increasingly become a public issue. The German Ethics Council [23] and the German Medical Association [24] call for surgery to be performed only in "medically necessary" cases. The guideline "Variants of Sex Development" of the Scientific Medical Societies (AWMF), which has been valid since 2016, includes this demand in its recommendations and emphasizes the child's right to physical integrity and co-decision in therapeutic measures [25]. Finally, in May 2020, the "Law for the Protection of Children with Differences in Sexual Development" was enacted, declaring surgeries permissible only in life-threatening cases or cases that cannot be postponed to an age where the child can decide on its own. Further operations are possible in selected cases after prior approval by the family court. Thus, the guide development for qualitative evaluation of Empower-DSD is part of a shift in gender policies towards the standpoint that an open engagement with a diagnosis and/or ambiguous sex forms a necessary condition for a successful and happy life, and that this openness to its differences in sex development must be carefully developed with the 'affected' person and its close ones.

1.5.1. Participation in guide development

The semi-structured interview method is considered as enabling reciprocity between the interviewer and participant [2,26] and the benefit of participatory research is described to improve the quality of survey instruments (e.g. questionnaires, interview guides) [27]. Yet, there has not been much systematic exploring on how exactly the co-researchers can be involved in the designing process of an interview guide, let alone a semi-structured interview guide. The participatory aspect is often only introduced only after the guide has already been developed.

Following common insights of participatory research [27], we think that data delivered through participant answers become better through the involvement of participants in designing as precise questions as possible. And we first and foremost believe that inserting participatory elements in a structuring tool can assymetrate the interview situation.

2. Materials and methods

This paper focuses on the interactions and negotiations that took place during the development of a semi-structured interview guide for a qualitative interview study. These processes fashioned into the interview guide were not surveyed by a rigid, encompassing method but contoured by log books and memos. The interview study was part of the broader mixed-methods Empower-DSD project.

Following the suggestion of Elo et al. [28] that the interviewees (or in our case the peers as subgroups of the interviewees) should be included in the development of the interview guides, the peer groups presented by the SHGs were included from the beginning of the interview study in the development of the interview guides. The researchers hope that in this way the interview guide would represent a precise knowledge of the various diagnoses that is as contextually accurate, as complex as possible, and gender-inclusive.

Yet qualitative methods do not strive for strict replicability and reproducibility in a quantitative sense and cannot produce generalizable results.

2.1. Data generators: methodical memos and logbooks

The empirical material of this contribution consists of methodical memos and entries from the logbooks of the two qualitative researchers. Methodical memos are short notes for which the researcher briefly interrupts the research process and writes down reflections and ideas on the methodical procedure, on the use of research instruments, or on its design. The literature mainly engages with theoretical memos, code, and category memos [29,30]. Following the spirit of participatory research, we in turn argue here that methodical memos are also very important for fixing and specifying what is elusive, to facilitate collaboration and exchange with co-researchers. Here, we refer to memos of a methodical nature that were produced before and during the process of interview guide development. These memos go beyond the mere description and planning of methodical steps, as we will show below.

The logbook, in turn, represents a version of a research diary and is one of the self-reporting instruments for data collection [31]. The logbook is a writing and reflection method in which the researcher documents situations and at the same time analyses and interprets them. During writing, impressions, events, thoughts, and emotions should be recorded. We paid special attention to so-called epiphanies – to moments in the research process that were retrospectively and selectively perceived as particularly significant, disruptive, striking, or of essential nature [32].

2.2. Data generations

We began the interview guide development with research on the four diagnoses. They formed the context of the interdisciplinary training concept to be evaluated and thus also the context of the interview guide. We drew on practical knowledge and experiences from the bi-weekly team meetings, monthly project meetings, consensus meetings to agree on the content of the training concepts, and various project working groups. In addition, we participated in meetings in which representatives of the stakeholder associations contributed to the training materials. We further took part in training sessions lasting several days, performed to educate the future trainers, the so-called trainer academies. Furthermore, expert articles, daily newspapers, talk shows, online readings, and forums and blogs of persons with DSD and their relatives were considered.

This resulted in 22 different interview guides for the respective target and age groups and diagnoses in this project. These topic guides were given to nearly 50 project participants, i.e., professionals and representatives of the SHGs. They discussed the research instruments and sent them back to us along with their thoughts, recommendations, and critique. The construction process of the

interview guide – the time from the first formulations to its first use in an interview – took a total of almost one year and occurred in parallel with the development of the training programmes.

There was no inclusion or exclusion criteria: The topic guides were given to all professionals and representatives of the SHGs being involved in the project. Because the "intervention" was manageable, no criteria was used and all participants responses were considered.

These participatory preliminary processes of creating the guidelines were challenging in the sense that they required emotional engagement, resources of staff and time. The responses had to be collected, sifted, discussed and thoughtfully woven into the guide. Some responses were harsh, some made fun of the qualitative researchers, some were witty. Every answer from the participants had to be treated respectfully and answered carefully. The interactions were precious to the researchers as we hoped they would not only improve the quality of the guide but also might be the foundation for building solid partnerships over time – partnerships of trust and understanding.

3. Findings and discussion

3.1. Participatory interview guide in Empower-DSD: four epiphanies

We now discuss this collaborative process on the basis of four epiphanies that we recorded in our logbook and methodological memos during the construction process of the interview guide.

3.1.1. First epiphany: deconstructive (self)reassurance

"Empower-DSD is pretty progressive", Author 1 writes in her logbook. She has been a staff member at Empower-DSD only for a few weeks and she associates the adjective "progressive" with a deconstructive understanding of the sex/gender binary which is dominant in the discipline she studied for years – gender studies. AUTHOR 1 understands gender as the social or cultural dimension of sex, which is neither determined nor caused by biological sex. Moreover, sex and gender are interwoven, and the sex/gender distinction is socially constituted, contested, and changeable [33]. Inherent in such an approach to the sex/gender distinction is the call for deconstruction and flexibilisation of rigid binary notions of sex and gender. This deconstructive view is directed outward: the individual person is to be strengthened in rejecting externally determining, social notions of sex and gender. People should be empowered in their own understanding of sex and gender [34].

For AUTHOR 1, medical terms such as gender dysphoria, gender identity disorder, or pathology seem problematic, as they carry a latent devaluation, stigmatise persons, and tend to blank out the social aspect of sex and gender. From a deconstructive gender perspective, for AUTHOR 1, no sex or gender is disordered, diseased, or pathological. Any variations in sex/gender development are to be accepted as equal. A unifying 'we' is questioned. Rigid notions of sex/gender dichotomies of man and woman are rejected, the fluidity of sex/gender is emphasised, and pathologising foreign attributions for people who cannot be clearly and directly assigned to the two sexes man and woman – or who do not assign themselves – are questioned [35]. Empower-DSD is progressive for AUTHOR 1 because a deconstructive understanding of sex and gender is manifested at many points in the project. For example, the research proposal clearly states that it does not favour an understanding of gender that is determined by biological sex. Genital surgery is viewed critically with reference to the UN Convention on the Rights of the Child. SHGs participate in the project's working groups to determine which training materials are created for the respective diagnoses or what the wording should look like. The working group on inclusive language deals with the question of which words, concepts, and notions the project should use – patient, affected person, variation, speciality, or DSD? The researchers read the project proposal and attend the events which was important preliminary work for formulating questions. AUTHOR 1 also participates in a training academy with all the exercises conducted to educate the professional trainers for working with people with DSD. These activities convey an understanding of gender as a continuum. They encourage trainers to reflect on their own understanding of gender and sex development, and to engage with their own inner attitude towards variants of sex development. The training weekend also includes a lecture on the legal option of not entering first name and gender on the birth certificate and strategies for dealing with bureaucracy.

The logbook entry "Empower-DSD is pretty progressive" is consistent with AUTHOR 1's academic socialisation, which understands the sex/gender relation as changeable and transcending a binary understanding of male and female. Also, the encounters in Empower-DSD take away her own fears that Empower-DSD would follow a medical understanding of gender that still understands gender as determined by sex and classifies everything else as deviant or pathological. The encounters lead to a deconstructive self-reassurance of AUTHOR 1.

Attending the events and reflecting and their own feelings and attitudes represented important preliminary work for formulating questions. With these activities the authors entered the life worlds of their partners. They were affected and sensitized. Especially the working group on inclusive language led to the first question to co-researchers which asks how the variant should be named during the interview. This initiating question in turn should establish trust with the interviewees that the questioners would handle the topic of DSD respectfully in the course of the interview. Although a questionnaire in the spirit of neo-positivism was used, a constructivist element was introduced at the outset. In the sense of the constructivist approach, the comfort level of the co-researchers "should have higher priority than obtaining juicy data [9]"

3.1.2. Second epiphany: irritation

However, these deconstructive certainties soon are irritated. Another logbook entry reports the intervention of a professional after we have sent the first draft interview guides to the stakeholders and ask for feedback. The paediatrician writes that she found it

fundamentally difficult that the CAH interview guide refers to gender variation in the opening question. The term gender variation would probably not mean anything to a child with CAH or to his or her parents. The parents would not perceive their child's gender identity as ambiguous, and neither would the child. The physician suggests that the interview guide should instead ask whether they see any connection at all between CAH and intersex and whether they would see any impact on identity development, perception of gender, or sexuality. Also, the guide on CAH should instead focus the survey on "chronic illness." The guide should ask about the experience associated with the need to take medication on a daily basis. How would respondents feel about having to take medication twice a day in the morning and in the evening for the rest of their lives?

Illness, chronic illness, and pathologies are terms towards which AUTHOR 1 feels discomfort or at least distance. She has learned to use them with the utmost caution because they would medicalise, pathologise, and individualise persons with a variant of sex development. They would turn these persons into a case of illness that is to be cared for medically and for whose management the individual alone is responsible. Why should a social, genderfluid view be a problem? Why should the interview guide suggest that gender variations are a medical problem, indeed an individual physical disorder that should be addressed through medication?

The resistance of the paediatrician stems from the fact that AUTHOR 1 has denied persons with CAH a stable gender identity. UK has just taken the flip side to pathologisation, i.e., she has argued in a social, yet similarly radical way. Both interrogations make clear that even well-intentioned criticism can exert symbolic discursive violence and be encroaching. Nonetheless, it becomes clear that many people with a DSD diagnosis do not perceive themselves as intersex at all, that a gap between the two genders is not relevant to them, and that deconstructive gender fluidity is a norm imposed on them from the outside. Inclusion researcher Mai-Anh Boger refers to this virulence as "destructive deconstruction" and thus suggests keeping in mind that, like the discourse of pathologisation, the discourse of depathologisation can also have negative effects [33].

That a person with CAH refers to herself or himself as "chronically ill" then does not mean pathologisation, but rather the statement: "I only have a physiological defect and nothing more. I am therefore a completely normal person." The statement is thus also a critical intervention against the implicit normative of the gender studies discourse of depathologisation, which could be formulated as the following appeal: "You situate yourself as gender-variant – as a fluid gender subject." This deconstructive interpretation of identity, while well-meaning, is nonetheless problematic. It insinuates that the other person has a problem with his or her gender identity, and questions, just as the dominant society does, that the person's self-chosen gender identity is normal and unproblematic. Against this background, the attitude of many protagonists in Empower-DSD that a genderfluid view is to be strived for also appears difficult for some. In the research context of Empower-DSD, it levels the specific lifeworlds of the co-researchers instead of strengthening them and perceiving them in their so-being – in their normality. Consequently, we adapted the interview guides to the individual diagnoses in order to cover the needs of the respective diagnosis group and improve conversation with the interviewees.

3.1.3. Third epiphany: the curious cis gaze

In one of the first guide versions for people with XX-DSD and XY-DSD, AUTHOR 1 first poses the following question:

"Does …. …. …. …. …. …. … (agreed upon term for diagnosis) form an important issue in your life right now? If so, to what extent? Interaction with friends, any limitations? Partnership? (first love, possible sexual experiences)"

In the logbook, she notes that she was thinking of historical works in gender studies. In such research, Jutta Eming (2015) or Claudia Honneger (1991) use historical material to vividly show that there were societies in which sex and gender were not the most important categories for social ordering [36,37]. In the Middle Ages of today's European societies, for example, the difference between male and female bodies was less significant than between bodies of different stands (*Stände*). Literary scholar Jutta Eming (2015) reconstructs that medieval texts often enact physical desire for courtly bodies – whether male or female [36]. The stand was much more decisive for social structuring than the binary, natural science distinction into the two sexes of man and woman. Desire in the Middle Ages was ignited by class and its aesthetics. The boundary lines, as medieval literature suggests, thus seem to run less between man and woman than between courtly and noncourtly. With this impulses in mind, AUTHOR 1 wants to open up a space for the co-researchers to also talk about a possible insignificance of sex and gender in their everyday life.

After the draft interview guide has been sent to the project participants, the representative of a parent's SHG writes back – politely but firmly – that this question had little to do with the training. The connection between this question and an evaluation of the training is not clear to her. It seems to be rather "a question of curiosity". Moreover, there are "questions of this kind […] on all sheets, by the way, except those of the professionals". She suggests taking another closer look at the questions. AUTHOR 1 writes in her logbook that she feels caught, although her questions are well-intentioned. The situation points to a so-called "focus problem", meaning that a *cis*-heteronormative gaze connects any practice, character trait, or sentiment issues to the gender of a person, in this case to an assumed transgender identity. Such a *cis*-heteronormative reduction becomes especially problematic when it comes to questions of sexual orientation. *Cis*-heteronormative persons in turn usually are not asked about their sexual preferences, or how they would experience their gender identity, when for example they consult a doctor for a middle-ear infection.

Similar to the parents' representative, a female doctor also insists that peers should not be asked about the significance of their sex variant in everyday life, and certainly not in connection with sexuality. That would be encroaching and has nothing to do with their role as counsellors. Such questions would go far beyond the actual subject of the interview guide – the training (Memo Guide XX XY *S*-concept AUTHOR 1).

In fact, there is a disparity between how the interview guide positions the physicians and how it delineates the peers. AUTHOR 1 asks herself: "Don't I, as a researcher, also have to talk about my gender identity including sexual experiences in the interviews? Don't the professionals also have to talk about this in their trainings? Isn't it only then that the interview guide establishes a real symmetry between researchers and co-researchers? But: who wants to hear that? Does the interview then still correspond to scientific criteria? Or is it not rather dodgy if interviewers and professionals tell their child, adolescent, and young adult counterparts about their sexuality?"

(Logbook entry, June 16, 2020, AUTHOR 1). These thoughts are on AUTHOR 1's mind as she revises the guide's topics. In her qualitative team, she suggests revising the guides for professionals as well. Because of this intervention by the co-researchers, the block 'subjective questions' is taken out of all the guides.

It becomes clear that the first drafts of the interview guides perpetuate a social power imbalance. The interview guides address the professionals as disembodied, gender-neutral, and desexualized subjects and thus uphold their supposedly objective, neutral position. However, the interview guide does not completely determine persons with DSD by their diagnosis, but partly denies their subjectivity by positioning them as standing in a permanent relation to their DSD diagnosis. The interview guide focuses on – indeed, fixes – the respondents and unintentionally reduces them to their diagnoses. Co-researchers have an important influence in designing the interview guide. At this stage of the research process, they are not only experiential experts but scientific influencers and designers. In this way, power relations inscribed in the first interview guides can be mitigated before they are used. In addition, discussion and reflection processes are initiated among the interviewers, which sensitises them to the complex lifeworlds of their interviewees and in which they learn to adopt a certain attitude.

3.1.4. Fourth epiphany: who participates and who doesn't?

A problem with scientific studies is often that data are collected only from people who participate – and unfortunately not from those who don't. This generates statements about a research question that refer to the recruited persons, but might not represent all facets of a social phenomenon. Sometimes it can be interesting to find out why people do not participate in a study, even though the topic concerns them. Are there reasons for this? And if so, what kind of reasons? It is not possible to get information from these persons, which can be seen as a limitation or even a dilemma in research in general. Especially in this project, AUTHOR 2 asks herself such questions repeatedly. There are SHGs of people with DSD that participate in this project, but also SHGs that don't. Why? Empower-DSD is part of broad societal transformations in the perception, treatment, and management of DSD. As stated in section 1.4.1, there has been a shift in gender policies. While recent decades have seen less open engagement with DSD, today a belief has emerged that a transparent and collaborative handling of a diagnosis and/or one's ambiguous sex leads to a happier life. However, medical care and healthcare research still often remain in a binary, *cis*-normative framework, in which the lifeworlds of children and adults with DSD and their families are not identifiable. In some spheres of society, the issues of variations of sex development and intersex today still are a taboo. AUTHOR 2 repeatedly wonders if individuals with variants of sexual development may not feel well represented in Empower-DSD because university hospitals are involved, the history of which is problematic. "Are they suspicious and cannot imagine that these institutions now want to "empower" them? Do they think that university hospitals may not be able to do that either?"

What does this have to do with our interview guide development? How do we know why people are not participating in this project? Is this even relevant to our research question about the experience of the trainings? Not directly, but indirectly it is. Because the context, including the historical one, has an impact on the actual reality of life. How can open and at the same time sensitive research take place in a field that moves between taboos and openness about ambiguous sex and diagnoses of DSD? How does having no expertise on the topic of gender variations and no points of contact before the project began affect me as a qualitative researcher? Does it make me feel insecure? Do I take on mistrust?" In the numerous meetings that took place over the course of the training programme and interview guide development, AUTHOR 2 listened carefully to experts from a variety of perspectives (professional workers and peers) and asks every now and then "What is treatment like today, what was it like in the past? Since when has it changed?" (Logbook entry, April 20, 2020, AUTHOR 2). Her questions are always answered, but she is often left with a feeling of uncertainty and a desire to know more. She collects information, reads up, also looks for information in non-medical and non-scientific areas, e.g., film documentaries, newspapers, internet.

In order not to be *cis*-curious, as presented in the third epiphany, during the process of interview guide development, we decide against asking further concrete questions related to the contextualization of the project. The concept of care for people with DSD has changed during the last 10–15 years. Many professionals working in the Empower-DSD project are part of a younger generation and did not experience former treatment strategies themselves. Thus, we do not actively address social taboos or, for example, the experience of the institution of university hospitals in relation to medical-historical treatments. Instead, we frame an open-ended question in our guides for peer counsellors and professionals about how they came to do their respective jobs. By doing so, we hope to create a space to also report on contexts if this seems important to the interviewees. Nevertheless, the unsaid of some people seem to be particularly loud in this project.

While the first and third epiphany resulted in a direct reformulation of questions in the guideline, the second and fourth epiphanies were not directly reflected in questions or non-questions. Nevertheless, the epiphanies certainly had an influence on interview guide development. The fact that we are researching in a taboo field, embedded the guideline questions. The effect of the epiphanies is more an attitude that we have in the development.

4. Limitations

This article focuses on research anecdotes that two qualitative researchers recorded in their logbooks and methodical memos [31]. Anecdotes and logbooks carry the risk of limited, subjective-cognitive access. In other words, the insights, observations, and critical self-reflections underlying this article are not the result of a comparison of different data collected through many self-reports, but are based on the 'limited' perceptions of the two authors. On the other hand, this approach can also be seen as an advantage. For Kunz (2015), a positive aspect of the logbook method is that the outlined inner processes can hardly be observed as external behaviour or are usually not explicitly expressed in formalised interview situations [31]. For the most part, inner, ambiguous dialogues of the interviewer disappear in the interview guide. The research instrument becomes a black box. And in most cases the interview guide becomes

a sleek document, often only attached at the end of a reference book or a research article.

Limitation of a neo-positivist account is that a collaborative design of the guide is not envisioned. We therefore also draw on constructionist and transformative conceptions of interviewing and considered them as theoretical markers during constructing the interview guide. By this we tried to mitigate the limitations of the study.

Finally, this contribution is grounded in perspectives of the two qualitative researchers who are both *cis*-gender researchers. Both strive to do justice to the lifeworlds of their co-researchers and to engage with them respectfully. However, AUTHOR 1 and AUTHOR 2 have grown up in a world where their gender identity "woman" was indeed subject to changes in form – from girl to teenage girl to young and older woman. They assumed an identity position that indeed entailed societal disadvantages. And yet neither AUTHOR 1's nor AUTHOR 2's gender identities were never significantly questioned by others or contested from the outside.

5. Ethical issues

The involvement of participants as co-researches poses particular ethical challenges for researchers and co-researchers. As mentioned above, the involvement of co-researchers in the construction process of a semi-structured guide especially meant dealing respectfully with the various interventions and answers of the co-researchers and to translate them into research questions without changing their content.

6. Discussion

Despite sticking to a traditional research instrument as the interview guide, we assert that neo-positivist development of an interview guide can be enriched by participatory elements. By investing time, staff and emotions. Based on this, we now give further recommendations on the design of neo-positivist research instruments in a participatory and collaborative manner.

6.1. Explication of assumptions on empowerment

We show that participatorily designed neo-positivist interview guides can initiate valuable negotiation processes within and between researchers and co-researchers. In the project Empower-DSD, the negotiation processes involve underlying, often unspoken assumptions about what empowerment means in relation to understandings of sex variation and gender. The participants usually clearly situate themselves as male or female, perhaps because of their young age. Talking to adult intersex people reveals that many do not label their bodies as ill or clearly male or female. This paper therefore recommends investing time, patience, and resources in reflecting on different underlying notions of empowerment and engaging as researchers with such divergent notions, including one's own attitudes towards sex and gender.

6.2. Keep open

Once again, participatory research demands from researchers the basic attitude of critical self-reflection and questioning of their own position of power. The collaborative design of the neo-positivist interview guide shows that beliefs of researchers that at first glance seemed to be progressive do not also have to have an empowering impact on their co-researchers. Thus, not all co-researchers welcome the stance of the genderfluid gaze but reject this perspective as a new normativity. The article recommends that instead of dismissing the co-researchers' critique of these new norms as sensibility, defensiveness, or traditionalism, the researchers should critically reflect on their own viewpoints inscribed in the research instruments and adjust them if necessary.

6.3. Design marginal-seeming research instruments collaboratively

Each research instrument might unintentionally and unconsciously perpetuate power imbalances and presuppositions and impose them on co-researchers. Especially the third epiphany shows that the interview guide once again portrays professionals as neutral, disembodied, universal figures, while it delineates peers and respondents as heavily conditioned by – virtually absorbed by – their diagnosis. We recommend to develop the interview guide in a participatory manner and allow co-researchers to give critical feedback, intervene, and correct the instrument. The interventions then can turn the interview guide into a buffer against a possible curious *cis*-gaze and orient the interview situation more towards topics for the interviewed and not the interviewers, i.e. in our case the education programmes for the children, young adults, and their parents.

6.4. Listen to the interview guide's outside

Finally, the fourth epiphany shows that every guide, no matter how well thought through it is, does have an outside. This insight is nothing entirely new [1]. And yet it is worth reiterating. We can only speculate about this outside, but it is a valuable one that says: stay open, stay sceptical. Every interview guide, no matter how eloquent, produces a silence, and every change of gender order, of patient empowerment, no matter how well-intentioned, produces an outside that is worth listening to.

7. Conclusion

Guidelines in semi-structured interviews are ambivalent neo-positivist instruments that emerge from power-saturated discourses and carry a problematic assumption of the interviewer as a rather neutral, detached figure. Guidelines as much as interviewers are part of social spaces. For Empower-DSD, these social spaces mean the embeddedness in broader social transformations concerning questions of how to deal with differences in sex development. The assumption that ambiguous sex and/or a DSD diagnosis makes a happy life impossible has partly shifted to the position that to openly name the difference and deal with an ambiguous sex development is a prerequisite for good medical care, healthy relationships, and recognition and support organised by friends and relatives. To come out as being diagnosed with DSD is the basis for living a good life. However, the insertion of constructionist, transformative elements the participative development guide development has also shown that how exactly that openness should be lived is not clear at all. The negotiation of topics, language, and labelling between the interviewers and the interviewees has laid the foundation for a good exchange in order to be able to say the unsaid in the first place.

In that sense, interview guides cannot fully resolve power relations and abandon their theoretical legacies. However, a discussion about these neopositivistic tools, the accuracy and appropriateness of their questions, can lead to an attitude of the questioners that is reflective, mindful and responsible, and deals with the difficulty that the interview situation is also a space in which ambivalences must be managed. Finally, the participatory approach and the insertion of transformative, constructionist elements led the two qualitative researchers to become more sensitive to the wording and usage of questions.

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