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TALKING ABOUT A TABOO

Health providers' attitudes towards people with
nedonphilia

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Abstract

Background and aim

Pedophilia is a taboo-laden topic, and there are many controversies and unanswered questions, such as questions concerning the prevalence, etiology and changeability of pedophilia, and the possibilities for treatment for people with pedophilia. In addition, pedophilia is often confused to be synonymous with child sexual abuse. Thus, individuals who experience sexual attraction to children find it difficult to seek help within the health care system, and it is not known how health providers relate to people with pedophilia. This study aimed to explore health providers' experience with and attitudes towards people with pedophilia.

Method

A qualitative study using individual semi-structured interviews with nine health providers with treatment responsibility in Central Norway was conducted in the fall of 2016. The informants were asked about their experience with people with pedophilia and their emotions, thoughts and actions towards people with pedophilia. The data was analyzed according to the method of systematic text condensation.

Results

Most of the informants had limited experience with people with pedophilia, and there were expressed a lack of knowledge on the subject. There were expressed surprise over the estimated prevalence of persons with sexual attraction towards children, which was higher than expected. Some saw dealing with patients with pedophilia as unproblematic, while others found even talking about it provoking with a lot of negative feelings. It was said that many aspects of dealing with people with pedophilia was problematic, such as communication, the patient-health provider relationship and the responsibility of assessing dangerousness. Most were unsure about the etiology of pedophilia and hence had different thoughts on what can be offered to people with pedophilia in the health care system.

Conclusion

The finding in this study indicate that health care professionals need more knowledge regarding communication and the patient-health provider relationship when dealing with people with pedophilia. The lacking consensus both among experts and regular mental health providers on the etiology and definition of pedophilia indicates that a continued questioning of the appropriateness of this diagnosis should be encouraged. The health providers showed a willingness to accept people with pedophilia for treatment, but the lack of consensus on what can be achieved through therapy makes it necessary with further research on this area.

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1. Introduction

This study tackles the taboo-laden topic pedophilia, and as a background of this study, the topics child sexual abuse and its link to pedophilia, and the controversies concerning definition of and possible treatment for pedophilia are elaborated. Some of the available research on stigma towards people with pedophilia and its consequences is also briefly presented before moving on to the aim of this study.

1.1. Child sexual abuse

Children being sexually victimized by adults is a serious public health problem in modern-day society. Child sexual abuse can cause both immediate and long-lasting, often multiple negative consequences, both physical, psychological and social, for the affected children (1). Not only are the consequences severe, but also the number of children affected daunting. In the latest report from 2011, the Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS) presents different studies estimating that between 8 and 19 % of girls and between 1 and 14 % of boys in Norway have experienced sexual assault (2). Internationally there is a wide variation in prevalence estimates depending on how sexual abuse is defined, and a meta-analysis from 2013 found prevalence estimates of 17 % for males and 31 % of females below 18 years of age for non-contact abuse, and 6 % of males and 13 % of females for contact abuse (3). The general tendency that girls have a two-to threefold risk of being sexually abused during childhood compared to boys seems to be a persistent finding (2, 3).

1.2. Pedophilia and child sexual abuse – how is it connected?

Child sexual abuse is a legal term while pedophilia is a medical term. These terms are often used interchangeably, but a person with pedophilia is not necessarily an abuser, and a person who sexually offended a child does not necessarily have pedophilic sexual preference (4). Studies have found that perhaps as many as 40 – 50 % of child sexual abusers are not pedophiles based on their sexual arousal pattern (5).

Even though the distinction between the terms child sexual abuse and pedophilia is important, the two phenomena are however related, as there is strong evidence that deviant sexual preference is one of the major risk factors for child sexual offence and for recidivism among identified sex offenders (6, 7).

1.3. Defining pedophilia

Pedophilia, commonly understood as the adult sexual attraction to children, may not be as easy to define as one may think. The diagnosis «Pedophilic disorder» is included in both the *International Classification of Diseases* (10th ed.; ICD-10) and the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5) (8, 9). The most elaborate diagnostic criteria can be found in the DSM-5, according to which an individual must for at least 6 months have recurrent, intense sexually arousing fantasies, sexual urges, or behaviors involving sexual activity with a prepubescent child or children to fulfill the criteria. In addition to this, the individual must have either acted on these sexual urges or fantasies, or experience marked distress or interpersonal difficulties (8).

There are two important controversies when it comes to the diagnosis of pedophilia. Some years ago there was a discussion on whether or not pedophilia should even be a diagnosis (10). According to the DSM-5 it is possible to experience pedophilic thoughts, fantasies or urges without fulfilling the diagnostic criteria if the person doesn't act on these urges nor experience any distress or impairment (8). Similarly, it is possible to not have pedophilic feelings but commit sexual offence against children and thus fulfilling the diagnostic criteria (8, 10). This has been problematized, and Studer and Aylawin argued that a diagnosis of pedophilia is problematic because it seems to “medicalize” an illegal behavior and “criminalize” fantasy (11). Green supported the argument, saying that discussing whether or not pedophilia should be a diagnosis is not the same as discussing whether or not pedophilic actions should be deemed criminal (12). He further put forward several historic and cross-cultural examples of acceptance of pedophilia, and stated that including pedophilia in the diagnostic manual leads to pathologization of a substantial minority of the “normal” population (12).

The second controversy, which has implications for possible therapy and how to handle adult sexual attraction to children in society, is on the etiology of pedophilia and whether or not pedophilia is changeable or stable over time. In other words: Can it be defined as a sexual orientation or as a mental disorder? Both the ICD-10 and the DSM-5 (after being corrected) use the term “pedophilic disorder” when describing adult sexual attraction to children (8, 9). Pedophilia has been conceptualized as a disorder of impulse control related to hypersexuality (13, 14), and another theory supported by empirical findings is the “abused abuser theory”, which suggests that a history of sexual abuse predisposes individuals to pedophilic tendencies (13). If seen as a mental disorder, a full understanding of etiology, risk factors and treatment

is however still lacking (13), and Langfeldt argues that defining pedophilia as a mental disorder has important implications for further research on these areas (15). On the other hand, Seto conceptualized pedophilia as a sexual age orientation because of its similarities with gender based orientations (hetero-, bi- and homosexuality) when it comes to early age of onset, correlations with sexual and romantic behavior, and stability over time (16). Grundmann et al recently found in a study of a clinical sample of 494 non-prosecuted self-identified pedophiles and hebephiles (individuals with a sexual attraction to pubertal individuals) that the self-reported arousal to sexual fantasies involving children showed early onset and stability over time, which supports Seto's views on pedophilia (16, 17).

The two controversies – whether pedophilia should be a diagnosis or not, and whether pedophilia is changeable or stable over time – makes it a complex matter, which is also further complicated by the confusion of pedophilia with child sexual abuse. It is therefore not clear how health providers relate to pedophilia in their clinical practice.

1.4. How common is pedophilia?

Most studies on pedophilia are on sex offenders with child victims, and research on self-identified pedophiles is rare (18). Prevalence of pedophilia in the general population is unknown, but is estimated by Seto to be maximally 5 % in men (5). Because large-scale epidemiological surveys were lacking, this number was based on small surveys who found that 3-9% of male respondents acknowledged sexual fantasies or sexual contact involving prepubescent children (5). Wurtele et al found that 4 % of women and 10 % of men asked online reported some likelihood of either watching child pornography or having sex with a child if they were guaranteed of not being caught or punished (19). A Finnish population-based sample consisting of 1310 male twin individuals found that 0,4 % reported sexual interest in individuals below 12 years old, and 2,7 % reported sexual interest in individuals between 12 and 15 years old, with 2,4 % reported having masturbated to thoughts about individuals between 13 and 15 years of age (20). An unknown number of people with pedophilia are probably living undetected by the justice system, and are either afraid of committing sexual offence or have already offended – either way they have no contact with preventive services, and little is known about this group (21). Even though they are undetected by the justice system, they might try to seek help in the health care system, and it is unknown how they would be met.

1.5. Stigma towards people with pedophilia

Public stigma can be understood through the three aspects of stereotype, prejudice and discrimination (22). Stereotype may also be understood as the cognitive knowledge structure, a negative belief about a group, which leads to prejudice, which is an emotional reaction such as fear, anger or pity. This finally leads to the discrimination, behavioral consequence of prejudice, such as social distance (22).

Jahnke and Hoyer found indications that stigma against people with pedophilia is highly prevalent, but that research on the area is scarce (23). Jahnke et al. conducted two surveys about stigmatization towards pedophilia in the general population, where they found that stereotypes, affective reaction and social distance all were stronger towards people with pedophilia than towards people with alcohol abuse, sexual sadism and antisocial tendencies (24). The most important predictors of social distance were perceived dangerousness for children and adolescents, greater anger and less pity (24). They also found that about one third considered pedophilia to be controllable, i.e. that the person could choose to control the sexual attraction itself, but that the level of controllability of pedophilia was perceived to be lower than the controllability of alcohol abuse, sexual sadism and anti-social tendencies (24). Demographic characteristics in the sample associated with greater social distance towards people with pedophilia were more right wing authoritarianism, younger age, less education, and having children younger than 14 (24). Gender did not affect social distance towards people with pedophilia, but women showed higher levels of fear, anger and perceived dangerousness (24).

B4U-ACT (“before you act”), a US-based NGO working to promote competent and effective professional services for people with a sexual attraction to children or adolescents (25), conducted two online surveys of self-identified people with pedophilia in 2011. In B4U-ACT’s first survey, “youth, suicidality and seeking care”, 59 % of the 193 respondents said they would not seek help for an issue related to their pedophilic sexual attraction (26). The reasons they submitted for this were largely related to a fear of stigma or because of an expected lack of understanding of pedophilia among health providers (26). In the second survey, “Mental health care & professional literature”, it was found that half of the 209 respondents who had actually seen a mental health professional had experienced that the health provider had made incorrect or unjustified assumptions about them consistent with stereotypes (27). 63 % said these incorrect or unjustified assumptions made it less likely they

would return for further therapy, and 67 % responded these assumptions interfered with reaching any of their own or their therapist's goals (27).

Based on the English abstract from a German study by Stiels-Glenn, where it was found that only 4,7 % of psychotherapists would treat patients with pedophilia (28), it can seem that health providers aren't immune to stigma. About half of the therapists who would not treat patients with pedophilia justified their refusal, some of them by reasons non-related to stigma, such as not practicing psychotherapy, or a lack of knowledge, others by negative feelings or experiences towards people with pedophilia, or because of doubts regarding the patient's motivation for therapy or regarding the appropriateness of the therapeutic setting (28). Jahnke et al. conducted a randomized controlled trial examining the effect of an intervention on attitudes towards people with pedophilia. The intervention group watched a 10-minute anti-stigma video, and afterwards these participants showed significant changes in their attitude towards people with pedophilia (29). The intervention group reported to be less likely to agree with stereotypes, have a more favorable affective response and less social distance than the control group (29). However, willingness to work with people with pedophilia showed no significant change (29).

1.6. Offering treatment to people with pedophilia – preventing child sexual abuse?

The use of the term “pedophilic disorder” in the ICD-10 and the DSM-5 implies it is a condition available to treatment. According to Seto, therapy can only help to increase voluntary control on sexual arousal (5), whereas Langfeldt argues that pedophilia can be cured in some individuals through therapy helping develop a mature homosexual identity (30). The Berlin Prevention Project Dunkelfeld (PPD) found in a pilot study of a sample of self-identified help-seeking pedophiles and hebephiles that a 1-year treatment program resulted in multiple changes in the treated group's dynamic risk factors for offending, such as emotional loneliness and offense-supportive attitudes (21). However, no statistically significant changes in child sexual abuse or child abuse images offence behavior were found, and no changes in the dynamic risk factors in the non-offenders in the treated group were found (21).

Both a Cochrane review from 2012 and a meta-analysis from 2015 found that the available research on psychological treatment of sexual offenders against children does not show that treatment reduces recidivism (31, 32). It could be tempting to look to pharmacological agents to find treatment for pedophilia, but a Cochrane review evaluating the effect of such treatment

found that the available research is too sparse to be concluded on (33). Only a small part of the available research on psychological treatment of pedophilia shows an acceptable quality, and Grønnerød et al. calls for more high-quality research on the area, but as the process of conducting enough high-quality research is both time- and resource-consuming, they suggest a shift of focus (31). They suggest joining efforts to prevent sexual offences against children several areas, such as through community integration programs for released offenders and low-threshold mental health services for persons at risk of becoming offenders (31). The Prevention Project Dunkelfeld has shown that pedophiles can be reached for primary prevention of child sexual abuse, and thus implies the feasibility, at least in a German context, of preventive treatment efforts offered to self-identified and help-seeking pedophilic and hebephilic in the community (4, 21).

1.7. Health care use among people with pedophilia

B4U-ACT's first online survey found that 45 % of respondents had seriously considered suicide for a reason related to their sexual interest in children, and most found that they could not talk about this to anyone (26). In the second survey, 58 % said that they had wanted to see a mental health professional for an issue related to their attraction to minors, but did not do so (27). Only 33 % responded that they did see a mental health professional, either voluntarily or involuntarily (27). They did so primarily to address a large number of problems other than just controlling sexual feelings, such as to improve their self-concept, deal with society's negative response to the attraction to minors and figure out how to live in society with this attraction (27). In not all cases the professional's goals were compatible with the patient's goals, as health professionals put more emphasis on learning to control sexual feelings and extinguishing or reducing the attraction to minors (27)

Houtepen et al. found in their qualitative study of self-identified pedophiles that 6 out of the 15 participants had sought help from professionals either to get help with coping with their pedophilic interest or because of symptoms such as depression that seemed partly to be caused by the pedophilic interest (34). Three of these found the help useful, but the other three argued that the help was not sufficient due to lack of clinical knowledge about pedophilia in general. Two participants reported not seeking help because of fear of stigma (34). Goode argues that to be able to prevent child sexual abuse and keep children safe one must allow for open communication regarding the subject of pedophilia (35). Houtepen et al. suggest that

more attention should be given to pedophilia to better educate mental health professionals and to reduce stigma (34).

2. Aim for the current study

It has been estimated that between 3 and 9 % of the population have pedophilic thoughts (5). Most studies are done on convicted molesters (18), and little is known about the possibly large group of people with pedophilia living undetected. Grønnerød et al. suggest low-threshold mental health services for persons at risk of becoming offenders, such as self-identified pedophiles as a measure to prevent child sexual abuse (31). Studies have shown that this kind of preventive therapy offered to self-identified help-seeking people with pedophilia and hebephilia is both feasible and can change some important dynamic risk factors for offending (4, 21). Such preventive measures are currently lacking in Norway, and some of these might try to seek help within the health care system (27, 34). However, it is unknown how common it is for self-identified pedophiles to seek help in the health care system. Reluctance to seek help for pedophilic thoughts might arise from the public stigma towards pedophilia in the general population which has been shown to be very high (24). Similar stigma also seems to be present among many health care workers (27, 28), something which further adds to a person with pedophilia feeling alienated by health care workers (26, 27). The many controversies concerning the etiology, definition, changeability and possibilities for treatment for people with pedophilia further complicate the matter. The result can be that persons with sexual attraction to children feel that they cannot get help for this from health care professionals, and this may have further negative consequences for children's safety. Thus, one area where more knowledge is needed is how health providers relate to people with pedophilia.

The aim of this study was therefore to investigate the following question:

What is the experience of health care workers with people with pedophilia, and what are their own thoughts, emotional reactions and actions towards these patients?

3. Method

3.1. Design

The study was a qualitative study with semi-structured interviews of health providers with treatment responsibility. It was conducted in Central Norway in the autumn 2016.

The qualitative design was chosen because there is little available knowledge on this area (23). Studies have shown that psychotherapists may not want to receive people with pedophilia as their patients (28), but the understanding of the background for this attitude is only limited. Because the subject is complex, and I assumed that health providers' relationship with the subject is complicated, it was hard to know exactly what I was looking for. A qualitative method with interviews was therefore considered useful, because it allows for participants to speak freely about the subjects, and I didn't need to have a clear hypothesis about the answers or formulate alternatives, as in a questionnaire.

3.2. Participants

The aim was to include participants working as health providers with a treatment responsibility in the primary health care system or in the mental health care system. The reason for this is that I assumed that if anyone with pedophilic thoughts would seek help it would be in these systems. Furthermore, the mental health care system is the place where someone with possible pedophilia would be referred, given that the primary health provider views pedophilia as a mental health problem. I primarily wanted to include informants having experience with working with people with pedophilia, or having encountered people with pedophilic feelings seeking help. However, I had reason to believe that only a minority of people with pedophilia seek help for problems related to their sexual attraction (26, 27). Therefore, I assumed that health workers' experience with this patient group is limited, so I decided to aim for health care workers both with and without direct experience from treating persons with pedophilic thoughts.

In a qualitative study the aim is to get a sample that ensures that informants represents the richness of information and variation needed to enlighten the subject of interest from different positions. I therefore wanted to achieve variation in the sample regarding variables that might affect the participant's attitudes, such as gender, age and working experience. I also wanted to include workers in both the primary health care system and the mental health care system, including different professions, such as medical doctors and therapists with different educational background. Given that attitudes and thoughts about people with pedophilia is

possibly also affected by whether or not the informants have young children (e.g. under the age of 14) (24), I also wanted participants both with and without young children in the sample.

3.3. Recruitment

Several different methods were used to recruit participants to the study. Since there is no organized treatment offered to non-prosecuted people with pedophilia, and therefore no established contact network, the recruitment was done by sending emails inviting medical doctors working in affiliation with the Norwegian University of Science and Technology (NTNU), and psychologist and psychiatrists in central Norway to participate. Their email addresses were retrieved from a contact list belonging to the faculty of medicine at NTNU and from the internal directory at St. Olavs Hospital, Trondheim. For some participants, a snowball method of recruitment was applied, where a participant recommended and gave permission to contact someone of their knowledge to participate in the study. I also personally contacted some general practitioner's offices providing written and oral information about the study. Interested participants were asked to contact the study personnel, and an interview was scheduled.

Over the course of the recruitment I kept a track of the earlier mentioned variables that might affect the participant's attitudes. I was prepared to more directly contact and recruit participants if I would find the variation in the sample unsatisfying, for example if the gender balance in the sample would be uneven, or if I wouldn't have any participants with young children. However, this proved not to be necessary, as the sample that resulted from the recruitment as described was considered satisfactory in terms of variation on the predefined characteristics.

3.4. Interview guide

A semi structured interview guide was used to ensure that all main topics were covered in all interviews. The interview guide contained some detailed possible follow up questions, but not all of these were meant to be asked in every interview, they were intended to be used as help to cover the main themes in the interview guide. Under each main theme follow-up questions were asked according to what the participant brought up. Having open questions and being able to adjust the questions to each participant was considered important. That way it would be possible to discover new understandings based on individual's experience, and not the other way around. At the end of the interview the participants were also asked if they had

something to add, or they felt that there were topics related to the main subjects that had not been addressed.

To describe the informants, they were asked about their age, profession, children and the age of these. These factors were important to continuously evaluate the variation in the sample.

The themes in the interview guide were developed from the research question and thus the relevant literature.

The first part of the research question is about the health care worker's experience with people with pedophilia. I decided to ask "through your profession, have you ever met any patients where it became clear that they had a sexual attraction to children?". As there are many misconceptions about the term "pedophilia" and its link to sexual abuse, I decided to avoid using this term, at least in the beginning of the interview, and rather using the expression "sexual attraction to children", to try to clarify what I was talking about. If the participant did have some sort of experience with this patient group, I asked follow-up questions about this experience, and the further main themes were explored in light of this experience.

The rest of the interview guide was developed on the basis of Rusch et al's presented elements of stigma: Stereotype, prejudice and discrimination (22). These elements are represented in the research question, as stereotype is "translated" to thoughts, prejudice is "translated" to feelings and discrimination is "translated" to actions. However, as the subject is generally linked to a lot of emotions I found it natural to start with questions about the prejudice – e.g. the participant's emotional reaction to the subject. I then moved on to the stereotype, the cognitions or understanding of the subject, and I included questions mostly about the understanding of the phenomenon pedophilia, since this is a matter of great discussion, but also wanted to get a hold of the participant's thoughts about the people experiencing pedophilic thoughts. Finally, I included questions about the actions to be taken towards this group in the health care system.

The complete interview guide (in Norwegian) can be found in the appendix 2.

Main themes and examples of questions are as follows:

- The participant's experience with patients
 - o Have you ever, through your work as a health provider, met any patients where it became clear that the patient felt a sexual attraction towards children?

- The participant's feelings towards pedophilia
 - o How do you feel about having patients with pedophilia?
- Stereotypes/knowledge about pedophilia
 - o How would you define pedophilia?
 - o Do you think people with pedophilia represent some sort of danger in society?
- Behavior towards people with pedophilia
 - o Did you/would you offer any help to someone who presented a sexual attraction to children?
 - o How should we meet them?

During the first interview it became clear that communication was an important subject, and this subject was added to the interview guide through the question “how would you talk to someone about possible sexual attraction to children?”. After the first interview, the question “Are there differences in how you relate to this in your job compared to your personal opinion/feelings?” was also added because the first interviewee put emphasis on the distinction between that participant's personal and professional attitude.

3.5. Data collection

Data was collected using semi-structured individual interviews, which each lasted between 25 and 45 minutes. To ensure that emerging themes were explored in the next interviews, the interviews were transcribed and partially analyzed after each 2-3 interviews. Halfway in the data collection all the data was analyzed before moving on with the next interviews.

3.6. Data analysis

The analysis was done according to the method of systematic text condensation (36).

Systematic text condensation consists of four steps; (1) Total impression – from chaos to themes, (2) Identifying and sorting meaning units – from themes to codes, (3) Condensation – from code to meaning and (4) Synthesizing – from condensation to descriptions and concepts (37). This is an iterative process, where I did certain steps several times, and revised some of the choices made.

I will here give a brief description of how the analytic process was carried through in practice, using the four steps of systematic text condensation:

- 1) Total impression – from chaos to themes

The entire transcript was read to get a general impression of the whole, looking for preliminary themes. During this first stage, I strived to encounter data with an open mind, and tried to find different themes than the ones in my interview guide. The preliminary themes I found at this stage were “feelings towards people with pedophilia”, “understanding of the phenomenon” and “Encountering patients with pedophilia”.

2) Identifying and sorting meaning units – from themes to codes

On this stage, I selected text fragments containing some information about the research question, called “meaning units”. The meaning units were sorted into temporary themes, which were given names that were continuously revised and adjusted. These themes emerged from the preliminary themes from the first step. Some of the themes to be defined first were “communication”, “competing considerations” and “the health care system’s role”. These themes were discussed between researchers, and were changed and elaborated to create themes that would tell a story of the encounter between a patient with pedophilia and a health provider, from before the meeting (“emotions and general attitudes” and “imagining the patient’s perspective”) to the actual meeting (“interactions”, “dangerousness” and “a balanced view”), to contemplations on what can be done (“treatment and prevention”).

3) Condensation – from code to meaning

The meaning units of the code groups were subdivided into a few subgroups, after which I made an artificial quotation captioning the essence of the meaning units in a condensate. For an example, see table 1.

4) Synthesizing – from condensation to descriptions and concepts

The subgroups found in step 3 were put forward as analytic text, which made the analysis of the final product. I regularly returned to the original transcript and compared the analytic text to the original data, to make sure the original meaning was not lost.

All four steps were done after four interviews, and in the last five interviews no completely new themes emerged, but I encountered some new aspects of the themes I had already explored. The code “competence” was added after the last interviews, but the rest of the codes were maintained and further elaborated in the last part of the analytic process. An example of how meaning units were summarized in a condensate and later written as a part of the analytic text can be seen in table 2.

To maintain participant confidentiality, there will be no individual description of the participants in the results chapter, and the quotes will not be linked to specific participants. However, in the analytic process emphasis was put on representing each participant's point of view.

3.6.1. Table 1: Step 3 and 4 of the analyzing process

Meaning units	Condensate	Analytic text
<p>“I think it would be quite strange, yes. I would probably feel disgust towards someone who did something like that”</p> <p>“It is in a way the most hideous thing that exists”</p> <p>“He was very sweet, yes he was. (...) and we sat and talked a bit about how it was to find little girls sexy, and I remember trying to normalize it a bit”</p> <p>“Then the patient showed up, and was a lot more sympathetic and nice than the monster I created the person into in my head”</p>	<p>“I feel disgusted by the action, because one of the worst ways to hurt children is through sexual assault. But it can probably be quite normal to have such fantasies, and if a patient doesn't act on them, the person can be likeable”</p>	<p>When asked about how to deal with people with pedophilia as patients, some participants said they would react with disgust, anger, despair or be repelled by the actions and the harm that these people might cause children. (...) Others said that even though they felt negative feelings linked to pedophilic thoughts or actions, they had still experienced having positive feelings towards a person having such thoughts or committing sexual assault or watching child abuse images.</p>

3.7. Ethical considerations

3.7.1. Views on pedophilia

It has been shown that stigma towards people with pedophilia is highly prevalent (23), also among health providers (28), and that stigma can be relatively easily reduced amongst psychotherapists (29). This study builds on the belief that reducing stigma towards people

with pedophilia would be advantageous. Problematizing stigma towards pedophilia may rise some ethical questions, for example concerning signaling acceptance of child sexual abuse. It is therefore important to emphasize that I do not under any circumstances think child sexual abuse is acceptable, on the contrary I believe that better understanding and more knowledge about different aspects of the subject of pedophilia, can open up for more ways to prevent child sexual abuse.

3.7.2. Possible adverse effects for participants

A research project can be considered unethical if it evokes symptoms of psychological nuisance and the participants are left with unanswered questions, which can cause worrying, unease, insecurity, fear and anger, which in its worst form might affect social functioning (38).

The study touched a sensitive topic which is not often addressed, and which might have caused emotional distress for the interview subjects. Pedophilia is a modern day taboo, and as Jahnke, Imhoff et al. found, just the thought of pedophilia evokes strong emotions such as anger and fear (24). I wanted to include participants both with and without young children, while knowing that the participants with children who might be considered to be in a vulnerable age, also might cause intensified the emotions. As the prevalence of child sexual offence in the general population is high (2), there was a possibility that some of the interview subjects might have been subjected to sexually offence, which might also have evoked stronger emotional distress.

However, individuals with a known tendency to have a strong emotional reaction to sensitive subjects would probably be more likely to refuse to participate. Since the participants were health care workers in the primary or mental health care system, I assumed that they relate to sensitive and emotional subjects through their work. In total, the risk of negative effects in the interview subjects was considered to be relatively low, or the negative effects to be mild. The participants were therefore not offered any follow-up after the interview within the context of the study, because it was expected that the informants, due to being health professionals, would know where to seek help if they would experience any negative effects.

3.7.3. Informed consent and confidentiality

An application was sent to the Norwegian Social Science Data Services (NSD) on the 15.08.2016, and the application was approved on the 14.09.2016 (see appendix 3).

Participation in this study was voluntary, and written consent was collected from all participants (see appendix 1). There was given no compensation to the participants. The participants were not asked to submit any details making it possible to identify any patients that were mentioned. The interviews were recorded, and the sound files were stored on an encrypted and password-protected USB storage unit. The interviews were transcribed, and any possible link between the participant name and the interview was erased. No possible identifying details were included in the transcription. The recorded files were also deleted after the analyzing process was completed.

4. Results

4.1. Informants' characteristics

The sample was comprised of nine participants; two doctors working as general practitioners, two psychiatrists, three psychologists, one psychiatric department manager and one group psychotherapist (table 1). Four were males and five females, with a median age of 51 (range from 29 to 71). Seven of the participants had children, two of whom had children under the age of 14.

Three of the participants had encountered or worked with patients with an open sexual attraction to children, while four participants had met patients who had watched or were watching child abuse images and two had met patients accused of sexual abuse. One participant had met a patient who admitted having committed an act of sexual assault, but did not reveal any sexual interest in children. Two of the participants had no such experience.

4.1.1. Table 2: Characteristics of the participants

Variable	Number of participants
Gender	
Male	4
Female	5
Occupation	
General practitioner	2
Psychologist	3
Psychiatrist	2
Therapist with other background	2
Children	
Yes, over the age of 14	5
Yes, under the age of 14	2
No	2
Relevant experience (more than one experience for some participants)	
None	2
Having had patient(s) with a sexual attraction to children	2
Having had patient(s) who watched child abuse images	4
Having had patient(s) accused of or admitted sexual abuse/child abuse images	3

Throughout the interviews it was not always clear whether the informants were talking about pedophilia or sexual assault, or people with pedophilia or molesters. Some of the findings are probably rather about health providers' attitudes towards sexual assault/molesters, but where

they were specifically talking about pedophilia or people with pedophilia it has been made clear.

4.3. Emotions and general attitudes

4.3.1. Thinking it is not the same as doing it

Some participants immediately connected pedophilia to sexual assault, and described very strong negative emotional reactions, using words such as disgust, anger, despair or repulsion. One participant described some degree of physical unwellness when talking about the subject, such as a bad taste in the mouth. One participant emphasized the importance of signaling to the patient both personal and societal disapproval of these actions. When it was made clear that we were talking about people with pedophilia, not necessarily individuals committing sexual assault, some participants moderated their wording, and one participant completely changed the description, and said it would be unproblematic to meet an individual with just pedophilic thoughts. Others spontaneously said that there would be a great difference in their emotional reaction towards someone just having pedophilic thoughts and fantasies as compared to someone actually having committed sexual assault.

“The sexual attraction towards children is one thing, perhaps that wouldn’t be as difficult to meet, but if I had met a person who assaulted a child, I would find it tougher.”

One participant emphasized the importance of being non-judgmental and accepting the legitimacy of the patient’s emotions. Another participant had encountered an elderly patient with pedophilic thoughts where the participant had found it natural to tone down the deviance of these thoughts, normalize the situation and reassure the patient that the patient shouldn’t think of these thoughts as a sign of craziness. This participant said it was probably quite normal to have these kind of thoughts, as long as they were just “innocent” thoughts.

“When it comes to pedophilia it is so obviously problematic and deviant that I think health providers in general would understand that they need to be accepting of the patient’s emotions and thoughts. I believe health care workers to be that mature.”

4.3.2. People with pedophilia can also be likeable

Informants who had talked to persons with sexual attraction towards children said that even though they had negative feelings linked to pedophilic thoughts or actions, they had experienced having positive feelings towards a person having such thoughts or committing

sexual assault or watching child abuse images. Other participants without this experience also stated they could imagine the same scenario.

“Before I met the patient, while I knew about this, I was terribly anxious, I experienced feelings of repulsion and things like that. Then the patient showed up, and was a lot more sympathetic and nice than the monster I created the person into in my head.”

One participant had encountered numerous convicted perpetrators in prison and two patients with pedophilia seeking help in the health care system. The participant described anger towards some of the convicted perpetrators, while the participant felt mostly pity towards the patients with pedophilia seeking help.

“In the outpatient clinic it was easier to see their suffering, because it was extremely difficult for the patients to realize this fact about themselves, it was such a heavy burden, which it made it easy for me not to be angry. And I just felt terribly sorry for the person experiencing this”

4.3.3. People with pedophilia vs other stigmatized groups

Some said that we are somehow taught that pedophilia is the worst there is, or the worst you can be. Some said they felt stronger negative feelings towards pedophilia because of the seriousness and directness of the damage sexual assault causes children as compared to other illegal or stigmatized behavior, such as drug abuse. Another participant said that dealing with a pedophile would be exactly the same as dealing with other criminals as patients.

“It’s quite often these [pedophiles] we hear about, or that we’ve learned to think have the lowest status in society. In prison or elsewhere, these are the least liked people.”

4.3.4. Professional vs personal attitude

One participant said that realizing one’s own dark and primitive sides and potential to perform actions of aggression or other norm-breaking actions made it easier to accept people with pedophilia. This participant emphasized meeting the patient with acceptance and understanding, recognizing the need for help, and also recognizing that there are many nuances of pedophilia, and it can be a good thing to see the beauty in children. The participant stated,

“There are a lot of nice and soft transitions, and I think it’s a great ability to be able to love children”

Some participants said that there was a big difference in how they related to the subject in their private sphere and as professionals. One participant said that privately this participant felt anger, but that this feeling had no place in a professional setting, and as a health provider you should be able to put your own emotions to the side to be able to treat any patients.

“The people here are ill and need help. Pedophiles are one thing, but there are also murderers and rapists, and many who did many stupid things through the course of their disease. So you can’t have that anger here, if you do, you can’t be here. When you’re here you have to put to the side what’s private, and act as a professional. But privately, I would be furious if I met someone, I probably would.”

One participant had personally experienced sexual assault as a minor and said that while this participant was still struggling with forgiving that participant’s own perpetrator, forgiveness is not a relevant emotion when meeting with a patient. The participant further stated,

“As a health provider I feel no need to condemn any patients. These people are deemed to meet condemnation anywhere they go, so they should not meet condemnation when meeting with the health care system.”

Most participants however said that they related to the subject in similar ways both as professionals and in their private spheres. Still, most had little experience and did not know how they would have reacted in their private sphere, and some said it was something they did not really think about it in neither setting.

“I have never encountered the subject in my private sphere. None of my friends have told me that they’ve been subjected to sexual assault as children, or that they have had such thoughts or... so it’s completely coinciding, both at work and private, that I don’t think about it.”

4.4. Imagining the patient’s perspective in encounters with health providers

Most participants agreed that it would most likely be very difficult for any patient to reveal pedophilic thoughts, fantasies or impulses to a health care provider. Possible reasons for the patient not bringing the subject to the table that were mentioned in different ways by several participants were feelings of shame and guilt, fear of being rejected, condemned or even reported to the police, and fear of ruining the client-professional relationship. One informant said that if a patient brought this subject to the table the patient could probably risk actually

being rejected, but the informant could also imagine that a patient experiencing pedophilic feelings would be very sensitive and easily interpret rejection.

“I can understand that someone who seeks help for this is terrified of being categorized and terrified of being rejected. So I can understand that very few dare to seek help for this.”

One of the participants reflected upon the patient’s need to find a health provider that he or she feels can be trusted, and will probably test the health provider as a conversation partner before approaching more difficult subjects. According to this participant, the patient probably wants to decrease the chances of being condemned and increase the chances of being met with understanding and acceptance, and will therefore search a health provider with good communicative skills.

“They need to test their conversation partner; they need to find someone they can trust. They’re terrified of rejection, and they need to find someone who’s listening and accepting before they will dare to say it.”

One participant also mentioned the possible lack of optimism when it comes to the changeability of these pedophilic thoughts or impulses, and therefore the patient would probably think that there’s very little to gain from addressing the subject with one’s health provider. Some also said the patients might be in a sort of denial, and when even admitting these kind of feelings to oneself is difficult, admitting them to a health provider becomes impossible. One participant had received a referral from a primary doctor where pedophilic thoughts were a part of the description in the referral, and emphasized the courage of this patient, who actually sought help.

“(…) who was actually brave enough to recognize it and have the courage to tell a health provider.”

4.5. Interactions with patients with pedophilia

4.5.1. How could I possibly ask questions about pedophilia?

Most of the participants had little experience with patients with pedophilia, and some reflected on the contradiction in the big number of sexual assault victims they had met and the fact that they had met very few or none who experienced pedophilic thoughts or impulses. All participants somehow mentioned communication and the client-professional relationship as an

important aspect of this. One participant emphasized that the health provider should be able to recognize subtle hinting to be able to identify these kind of underlying thoughts.

Some participant said that they would be able to ask questions about sexual attraction to children if they suspected this to be an issue for the patient, but admitted not asking on a regular basis, mostly due to pragmatic prioritizing. One participant who had not asked any patients about sexual attraction to children, saw it as unproblematic asking questions about this. Others said they had never asked any patients about these kind of thoughts or emotions, and could not imagine how they could possibly do so, because of the delicacy of the subject. One participant stated:

“I don’t mind talking about subjects with a lot of shame linked to them, and I prefer talking about it in a direct manner, but pedophilia... there’s a line there. It would be very difficult to address.”

The reasons the participants gave for not asking questions about the subject were fear of ruining the client-professional relationship, fear of offending the patient and also the preconception that any patient with these kind of thoughts would meet such questions with denial or other kind of psychological defense.

“When I say it’s impossible to ask, it’s because I am afraid of offending the person, not because of myself, but because I am afraid of offending and really hurting someone by asking such questions”

Some of the participants said they did not ask questions about it because they did not think about it. They further explained that this might be because pedophilia had not received a lot of attention, neither in general nor in their education. One participant said that this participant believed that there are probably very few people in the health care system with a lot of knowledge on the subject. One participant said that up until a recent meeting with a patient who was watching a lot of child abuse images the participant had not been sufficiently aware of the subject to ask any questions:

“There’s way too little focus on this subject. My meeting with this person is relatively new, so I think this is something I will carry with me into new encounters and be more aware of. It’s like I’ve gotten a new pair of glasses that I didn’t have before.”

4.5.2. Dangerousness

All the participants emphasized the importance of protecting children from sexual assault, and some said they would feel the specific need to inform possible patients with pedophilic thoughts or impulses about the harm that putting these impulses into actions would cause children, and how severely these actions are being judged by society. They all considered people with pedophilia to represent some sort of danger in society.

“When I hear how many people are victimized by sexual assault, how many times I’ve heard stories about it from my own patients, then it becomes very clear that it has huge consequences for their lives, and it is definitely a big problem in today’s society.”

Some of the participants reflected upon how to assess the dangerousness of people with such thoughts, where one said that it would be difficult to assess, and probably depend on the cognitive level of the patient and the ability to exert self-control. If the patient should show little ability to exert self-control the participant would advise that person to avoid «dangerous» situations, such as places with many children. A few of the participants spontaneously compared the assessment of dangerousness in this group with the assessment of suicidal risk in patients with suicidal thoughts. Just as when it comes to suicidal risk, this participant would evaluate the dangerousness to be low if the patient presented only pedophilic thoughts, but no specific plans. Another participant said that, just like when assessing suicidal risk, there is always a chance that the patient will put their thoughts into life even when health providers have assessed the risk as low, but emphasized the importance of addressing the subject.

“(…) in that conversation the patient was carefully trying to say that he could also find young girls sexy, so I had to address this quite directly with the patient; was it only fantasies, what thoughts was the patient having, would he ever do anything about it etc.”

Some of the participants said that as health providers they had to learn to live with the risk and an uncertainty of not knowing what will happen in the future.

“We try our best to predict a future event, and it’s not easy, but what we can do is ask. And then you have to choose whether to trust the patient or not. Other than that there’s not much you can do. We can’t predict the future.”

4.5.3. Colleagues' view on pedophilia

One participant said that one should discuss cases of patients with pedophilia with colleagues. The participants expressed different levels of perceived dangerousness, and some had experienced reactions from colleagues different from their own point of view. One participant said that on one occasion the participant had discussed a patient accused of sexual assault with colleagues, where the participant felt certain that the patient was falsely accused. One of this participant's colleagues, a person with younger children, had not trusted the participant's evaluation that the patient was probably falsely accused. The participant said that probably this colleague's opinion was that one can never be sure enough that someone isn't guilty, and when dealing with this matter the children's safety is more important than the possible mistake of falsely accusing someone. This participant said that the colleague put more emphasis on the possible dangerousness of this patient and therefore the participant felt that the colleague overreacted, while the participant evaluated the situation differently, and felt certain the patient could be trusted. The participant stated,

"There's a dilemma all the way here. The patient can have his career ruined, and for me that's also brutal to watch (...) but maybe that's the way it need to be to protect children, I don't know. (...) When you have small children there's more focus on protecting them than innocent, defenseless men being accused."

One participant who had worked with self-identified pedophiles as patients said that some of the colleagues had reacted negatively, and said that maybe they would be able to see these patients while starting their career, but that they would not have been able to see these patients after having children of their own.

"Several of my colleagues told me that, I remember it very well, that having children changed them, in their view on pedophilia."

4.5.4. When to report

When providing health care to a patient with sexual attraction to children, one informant said that the health provider has a big responsibility. In cases where the health provider isn't sure if the patient can be trusted not to commit an offence, the informant said it can be reassuring if the police is also involved. However, most of the participants said they would only report the patient to the police in the case of a high degree of suspicion that the patient was going to commit assault. One participant emphasized not having enough knowledge on the subject to say when it was necessary to report, and one participant had contacted the work place's

advisor and gotten legal advice saying that the participant did not have legal grounds to report a patient watching child abuse images. This informant expressed great distress with not being able to report behavior that this participant considered a form of assault.

“The legal advice was that the damage has already happened. I get a bad taste in my mouth from that too, but I do understand the principle that if people can’t come to us and be open, trust in treatment is excluded. But at the same time it is terribly difficult for me to accept.”

Another participant stressed the importance of not being too scared and hence scare the patient from seeking help.

“Do I need to report this at a certain moment? Are there any children at a daily risk of assault? Those are the kind of worries I got, but I had a really good supervisor who said I just had to live with the uncertainty, because we can never really figure these things out, and if we’re too scared when meeting with them, we vaccinate a patient group from seeking help the next time around. So it’s important not to scare the patient from seeking help.”

4.5.5. Trusting both sides

When reflecting upon how to assess dangerousness and when to report some participants mentioned trust as an important factor. They said that you have to choose whether you trust the patient or not, but that sometimes it can be difficult. One participant who dealt with a family where one member of the family accused another member of the family of having committed sexual assault against a child in the family, chose to believe each member of the family when they were presenting their story. This participant did not see it as a health provider’s job to judge who tells the truth or not, but support each patient’s version of the truth.

4.6. Treatment and prevention

4.6.1. Defining pedophilia

Most participants said they did not have enough knowledge about the definition and etiology of pedophilia, and were not sure how to define it, but most still elaborated their own personal point of view. Two participants clearly stated to consider pedophilia to be a sexual orientation, and compared pedophilia to other gender-based sexual orientations, such as homosexuality, and stated that they did not believe that therapy could change or affect pedophilic sexual impulses. Others said that the comparison to homosexuality was completely

off, because in a homosexual relationship both partners can be consenting, which is not possible in the case of pedophilia. One participant compared pedophilia to having a sexual attraction to animals, as they are both sexual attractions that can't necessarily be changed, but they are both quite deviant and can cause many problems.

"I guess it's related to how we talk about it elsewhere, in the media... We talk about homosexuality and pedophilia and all this, that somehow those are sexual orientations. I don't think it's a disease for example, it's something you are for some reason"

One participant did not want to state anything when asked about how pedophilia should be defined, as this participant claimed not to have enough knowledge about the subject, and had also experienced great changes in the medical perspective on sexuality over the years. One participant considered pedophilia to be a disorder, while another participant said that the sexual attraction itself did not necessarily have to be considered a disorder, but that it would depend on whether the person experiencing it found it problematic. If the sexual thoughts about children would cause suffering for the patient, then it would be a disorder.

"I would probably think about it as a disorder. But there's a big difference for me between thoughts and actions. Just having thoughts does not need to be problematic nor disease-like in itself (...) What makes it disease-like is what the person thinks and experiences as problematic and difficult. But I think... quite often, as I've understood without meeting them, but from what I've seen and read, probably a lot of those with such thoughts and with that attraction find it unpleasant. But I think there is still a line between thinking it and doing it. So for someone sexually assaulting a child, it is by no means an excuse to say "I was sick" or "I have a disorder"."

One participant said that it didn't really matter how you define it, as this participant claimed to have a principal belief in the changeability of the human mind, and this participant said it is possible to offer different kinds of therapy.

"Disorder and orientation... Does it really matter? To me it doesn't really matter. What does that tell me, the word orientation? (...) There's something behind these words, and that's important to try to get a hold of. Are there any biological aspects? Yes, so what? It could be, orientation could go in that direction, I am not sure about that, but let's say that. What persists is that principally it is possible to change a

human mind, thoughts and emotions and then also actions by talking (...) The point is how it is acted out, and that's what can become a problem for the weaker part."

4.6.2. Curation or help?

All participants, independently of how they defined pedophilia, agreed that patients with pedophilic thoughts or impulses can receive help from the health care system. One participant stated to believe that pedophilia isn't treatable, but that this shouldn't affect treatment of other psychopathologies. This informant emphasized that no patient should ever be refused for treatment. Some said that help should be offered to increase control over these impulses and thereby decrease dangerousness.

"One used to think one could treat homosexuality, right, and that isn't possible. But I would think that it's possible to live with it in a better way, or prevent it from being something that leads to sexual assault."

One participant said that another health provider had claimed to have cured pedophilia in a patient, and this participant did not believe that curation was possible, and by claiming this, one would underestimate the dangerousness of the patient.

"I would think I could contribute by helping that person to talk about the subject, and how to live with it. It must be very distressing to have those kind of fantasies or sexual preferences. So if a patient comes to me with something like that and hasn't done anything about it, I could help prevent that person from putting the fantasies to life."

One participant said that a patient who watched child abuse images was evaluated for group therapy, but was refused from group because of fear the other patients would reject this person from the group. This participant reflected upon the possibilities of creating group therapy with likeminded, to reduce the feelings of guilt and shame.

Some participants said that even though you can't change your thoughts or sexual impulses, talking about it can make it easier to live and deal with. Some emphasized the therapeutic effect of talking about subjects that are linked with a great deal of shame, one of them stated,

"We all have dark sides in us, and it doesn't get any easier by pretending it's not there. Acknowledging one's own dark sides and talking about it makes it easier to prevent these from taking over control."

4.6.3. Preventing sexual assault

When asked about other possible measures to prevent child sexual assault, one of the participants said that health providers see the consequences of sexual assault, but rarely find themselves in a position where they could be able to prevent such events from taking place.

One of the participants suggested that perhaps one should be able to talk more openly about it amongst leaders of leisure time activities for children, and perhaps try to avoid one adult from being alone with one child. The participant said;

“One can think that it should be discussed in scout groups, in sports groups and so on where leaders quite often are accused of assault... I don’t know if you could say that, but one should try to avoid the high risk situation that it is for an adult to be alone with a child.”

Some participants said it’s difficult to prevent sexual assault, and that it’s mostly about talking to children to help them set boundaries and avoid high-risk situations, such as getting into cars with strangers. Some participants said that offering help to people with pedophilia could possibly help prevent sexual assault, and one participant said that as health personnel it is a duty to try to prevent sexual assault from happening.

“As health providers we must try to chart and prevent something from happening. If we get a hunch, it could be anything, but also sexual assault or pedophilia, we have a responsibility to the society to prevent patients we meet from hurting themselves or others in any way.”

4.7. Competence

Several of the participants made statements concerning their own low level of competence regarding pedophilia, and that they perceive the competence level to be generally low in the health care system. Some said that pedophilia should receive more attention in health care educations, and some emphasized that the health care system should take on a larger role to help people with pedophilia.

“I think it’s like that everywhere, in all health care educations. It’s something that might be mentioned briefly somewhere, but you need to be particularly interested or do something more to know more about it. I think it’s like that for everyone. That’s my impression, because everyone has heard about pedophilia, but not a lot of people know anything about it. And that is kind of strange.”

5. Discussion of method

In this chapter it is discussed how the methodological choices might have affected the validity of the findings in this study. Malterud's book on qualitative methods in medical research is used as base for this discussion (37).

5.1. The researcher's role

I myself, as the researcher, am an active part in the research process, and the choices made along the way are colored by my perspectives and pre-understanding of the subject. This study builds on the pre-understanding that people with pedophilia are greatly stigmatized in modern-day western society, and I expected to find a high level of stigmatizing attitudes. I believed that this stigma might prevent people with pedophilia from seeking help, and challenging this stigma could open up for new possibilities to prevent child sexual abuse.

During the interviews, I strived to maintain a neutral, listening attitude throughout the interviews so participants would feel safe to express any kind of emotions or attitudes. This became easier over the course of the interviews, as I could also feel emotionally affected by the subject during the first one or two interviews. It is still reasonable to assume that my attitudes affected the feed-back the interviewees were getting, and which follow-up questions were asked in all the interviews. Some of the participants asked during the interview why I became interested in the subject, and wanted to know my personal opinion on the subject. I decided to answer these questions briefly based on my pre-understanding. This inevitably affected the interviews, but in the interviews where this happened it was towards the end of the interviews, when most of the questions were already answered by the participant.

5.2. Design

A qualitative method has advantages when the subject of interest is complex and not well understood (37), as is the case here. As the interviews were semi-structured, the interviewees were able to talk freely, while the interview guide was supposed to make sure that all subjects were covered in all the interviews. A questionnaire could have been used, but the situation with limited knowledge on the subject beforehand made it difficult to know which specific questions would be suitable, and a questionnaire would have restricted the possibility of exploring emerging themes.

5.3. Participants

The inclusion criteria for this study were quite open, as I wanted include participants working as health providers with a treatment responsibility in the primary health care system or in the mental health care system. Thus, I did not interview any nurses or health providers without treatment responsibility. By excluding nurses and health providers without treatment responsibility, I might have lost information, but the health providers with treatment responsibility are the ones who have the possibility to implement relevant measures when meeting patients with pedophilia.

I consider to have achieved a sample with the intended variation on the variables gender, age, children, working experience, and level of health care system at which the participants worked. This held together with the fact that the participants showed a great variation of both attitudes, experience and points of view in the interviews, leads to a conclusion that the sample has a richness of information and variation enough to make it relevant for our research question.

5.4. Recruitment

The recruitment method that was applied required quite a lot of initiative from the participants, as most of them were only approached through email once. I did not send any reminder emails, and probably could have gotten a bigger sample if more active recruitment methods were applied, or if I would have sent out reminders. Due to the requirement of some sort of initiative from the participants to be interviewed, participants with more radical attitudes or strong emotional reaction to sensitive subjects might have excluded themselves. It has been shown that a minority of the general population might think that people with pedophilia should be incarcerated even though they haven't committed any acts of sexual abuse (24), but this kind of punitive mindset was not found in the participants. Some participants described strong negative emotions when talking about the subject, and therefore it seems that this mindset is represented in the sample.

5.5. Data collection

There is a possibility that the data collection method did not allow for the participants to reveal the entire spectrum of their thoughts and emotions related to the subject. A personal interview is arguably more confronting than submitting thoughts anonymously through for example a questionnaire, which might have revealed more radical attitudes. It is unknown whether the participants presented their honest personal attitudes, or might have modified

them into more open-minded and understanding attitudes. However, the participants showed a variation of both attitudes and points of view in the interviews, and it is therefore assumed that such modification is only limited and does not significantly affect the results of this study.

Most of the interviews were held at the participant's work space, but one interview was held at the participant's home. Both the participants' work space and home are considered acceptable settings, as I assumed them to be safe spaces for the participants, and thus facilitating an open, honest interview. However, as the research subject is something covert, such as emotions, thoughts and attitudes, the interviewees had the possibility to filter their thoughts, and there is no way of knowing what was being let out.

5.6. Transcription

The information from the interviews was transcribed and interpreted continuously. Meaning might be lost in every step on the way from the actual interview to the analytic text. The understanding that was created in the meeting between two people, is only partially conserved in the recorded sound file, and is further distorted in the transcription. The transcription took a lot of time, as I listened and transcribed carefully, and tried to make sure statements did not lose their meaning. Sometimes statements need to be interpreted as being said with irony, exaggeration or humor, depending on the tone of voice or laughter in the recording, and this was noted when found to be necessary.

5.7. Data analysis

The analytic process is taking elements in and out of context, and there is a large risk of misinterpretation or loss of information. To avoid loss of information the same person carried through all the interviews, the transcription and large parts of the analytic process. However, one single researcher analyzing the material alone increases the chances of misinterpretation or missing out on important aspects, so parts of the analyzing process were carefully discussed with my supervisor. Through the analytic process I also tried to stay loyal to the original meaning in what was being said in the interview, by going back to the transcript.

Both the interviews and the transcriptions were held in Norwegian, and most of the analytic process was done in Norwegian, but the writing of the analytic text was done in English. Meaning might have been lost or changed, both in the analytic text and in the quotes, which are also translated. There has been an active use of dictionaries and other supportive tools during the writing to try to minimize this.

6. Discussion of results

In this part, the findings are first summarized and thereafter discussed in light of the available research on the area.

6.1. Summary of findings

Some of the informants in this study said that they had little or no experience with pedophilia, and rarely thought about the subject. There were expressed surprise over the estimated prevalence of persons with sexual attraction towards children, which was higher than expected. Some reflected upon the high number of encounters with patients who had experienced sexual assault in their childhood, and the very low number of encounters with patients with a sexual attraction towards children. On further investigation most informants remembered somehow having encountered the subject in one or more of their patients. Some saw dealing with patients with pedophilia as unproblematic, while others found even talking about it provoking with a lot of negative feelings. Most said that they saw it as difficult for both the patients and themselves to address the subject in a clinical setting, because of a fear of condemnation, fear of offending or a fear of ruining the client-health professional relationship. Some reflected upon how to assess dangerousness, and how to balance health providers' duties to the patients and the public. Some felt their primary responsibility was to understand and help possible victims of assault while others emphasized the importance of understanding and helping people with pedophilia. Most informants were unsure whether pedophilia should be defined as a mental disorder or a sexual orientation.

6.2. Connecting pedophilia to child sexual abuse

It was found that the estimated prevalence of pedophilia, ranging from 3 to 9 % (5), was a surprise to the informants. They had much more experience with patients having experienced sexual assault in their childhood than patients presenting pedophilic thoughts. This indicates that there are health care workers that do not connect the frequency of pedophilia to the frequency of child abuse even though the prevalence of child sexual abuse, ranging from 8 to 19 % of girls and from 1 to 14 % for boys (2) is somewhat comparable to that of pedophilia.

Not making the connection between prevalence of child abuse and pedophilia can be seen as somewhat surprising as there were informants who immediately connected child sexual abuse to pedophilia, and based especially on this, they expressed strong negative emotional reactions towards pedophilia. Although there might be some connections between pedophilia and child sexual abuse, it has been suggested that up until 60 % of the convicted child sexual

abusers are pedophiles (5), and that a person with pedophilia is not necessarily an abuser (4). Given that not all perpetrators are pedophiles, and not all pedophiles are perpetrators, it seems that pedophilia in itself is neither necessary nor sufficient as a cause or an explanation for sexual assault. Thus, it is likely that there must be other factors than pedophilia affecting whether a person commits sexual offence against children or not. There is quite strong evidence for the abused abuser theory, meaning that an individual being subjected to sexual abuse in its youth has greater risk of committing sexual offence against minors later in life (13). The rates of experienced child sexual abuse among child molesters are elevated, although varying (13), and one community sample study found that 7,7 % of the men who had experienced multiple episodes of sexual abuse reported having engaged in sexual activities with children 13 years or younger, while the same number for respondents who reported no experienced child sexual abuse was 0,2 % (39).

Another aspect regarding the connection between pedophilia and child sexual abuse is that most studies on pedophilia are done on convicted molesters (13, 18). This may lead to a limited understanding of pedophilia and the connection to sexual assault, but it has been suggested that abnormalities in motivation or inhibition in general may play a role (13). In one recent study, non-offending pedophiles were found to have superior inhibitory control than offending pedophiles (40). Some health workers explicitly mentioned other risk factors than pedophilia for child sexual abuse, such as limited cognitive abilities. However, the general impression was that pedophilia was seen by the informants as a strong or dominating risk factor for child sexual abuse in a situation where they were talking about pedophilia.

Based on the findings in this study and the literature, it can be suggested that the making an unjust connection between pedophilia and child sexual assault not only leads to negative emotions in the health providers, but may also lead to a lack of awareness of the factors leading to sexual assault, and possibly missing out on opportunities to modify these risk factors.

6.3. Stigma affects patient- health provider communication

Jahnke and Hoyer found indications that stigma against people with pedophilia is highly prevalent, and that it is reasonable to assume that stigma causes reluctance towards admitting pedophilic feelings to health providers (23, 29), which is also confirmed by the findings in B4U-ACT's online survey (26). As Cohen et al points out, because sexual activity between adults and children is illegal and a socially taboo, openly discussing pedophilic inclinations or

behavior implies a considerable legal and social risk for the affected (13). The health providers in the current study also said they thought it would be very difficult for patients to disclose their sexual interest in children to a health provider, and mentioned shame, fear of being rejected, condemned or even reported to the police, and fear of ruining the client-professional relationship as reasons for this reluctance.

Stiels-Glenn found that many psychotherapists in Essen, Germany did not want to receive people with pedophilia as their patients (28), but in the current study most participants either had accepted or said they would accept someone with pedophilia as their patient. This suggests that there are health care workers which at least when asked face to face will not admit to letting negative feelings towards persons with sexual attraction towards children affect the patient-professional relationship. However, it was found that participants found it very difficult for them as health providers to ask questions about a possible sexual attraction to children. Some explained this reluctance to address the matter by a lack of awareness, because of the little attention given to pedophilia in both their education and work space. Both the fact that pedophilia receives little attention in health provider's education and the fact that there is only one clinic in Norway which offers therapy to self-identified pedophiles (41) could be interpreted as signs of structural discrimination. Structural discrimination causes adverse circumstances independently of individual prejudice or discrimination (42), and it can be suggested that stigma and a lack of knowledge are connected, and are affecting both the patient (27) and the professional's ability and willingness to address the subject in clinical encounters.

6.4. Pedophilia – a disorder?

Pedophilia is included in both the main diagnostic manuals, the DSM and the ICD-10, where it is defined as a disorder, classified as one of the paraphilias (sexual arousal to atypical objects, including pedophilia) (8, 9), but there is an ongoing debate on whether sexual attraction towards children is a disorder or not, including if it should be listed as a diagnosis (10). Defining what should be a part of the DSM nosology has been debated for different topics for many years. The inevitable example related to sexual attraction towards children, is the process of removal of homosexuality as a diagnosis from the DSM. When homosexuality was eventually removed from the DSM-II in 1973, it was the result of social and political changes, and ultimately the result of a vote by the Board of Trustees of the American Psychiatric Association (43). It thus becomes evident that the nosology of the DSM can be

highly influenced by culture, politics and values. The continued presence of a diagnosis of paraphilias in the DSM has also been said to be linked to tradition and a lack of real questioning of the appropriateness of these diagnoses (10).

Some authors have been supporting the definition of pedophilia as a mental disorder (15, 44), or even suggesting an expansion of the diagnosis, including hebephilic disorder (in which the individual experiences sexual interest in pubescent individuals) (45). On the other hand, others challenge the presence of pedophilic disorder in the diagnostic manual or conceptualize it as a sexual orientation (12, 16). The informants in this study also had different understandings of the phenomenon, some were unsure about how to define pedophilia, and some said they clearly considered pedophilia to be a sexual orientation. The ongoing debate is thus also reflected among the opinions of health care workers.

The controversy of pedophilia as a disorder can be seen to be rooted in a larger debate, which concerns the very definition of a mental disorder. Since the DSM-III, a mental disorder has been defined based on the consequences of a condition, and not its etiology (46). It has been classified as either a painful symptom (distress) or impairment in one of the more important areas of functioning (disability), and that the disturbance should not only be in the relationship between the individual and the society unless the deviance or conflict is a symptom of a dysfunction in the person (46). Wakefield conceptualized mental disorder as a failure of a person's internal mechanisms to perform their functions as designed by nature and therefore having a harmful effect on the individual's well-being as defined by social values and meanings, so-called "harmful dysfunction" (HD) (47). Whether pedophilia fulfills these criteria has been disputed, and Malon argues that pedophilia's presence in the DSM is based on an evaluation of the danger to others, rather than the harm experienced by the individual, a concept he called "dangerous dysfunction" (DD) (10).

Some of the informants in this study who argued that pedophilia is indeed a disorder mostly based their views on the harm that putting pedophilic impulses to actions would cause. The "dangerous dysfunction" thus resonate with some health care workers, causing them to not question the diagnosis pedophilic disorder. As pointed out in the introduction, sexual assault is a legal term, and it has been said that the diagnoses of paraphilias were included in the DSM because of their forensic history, rather than their pathology and therapeutic need (48). The diagnosis pedophilic disorder has been said to criminalize fantasy and medicalize an illegal behavior (11). From reviewing the available literature, it seems that pedophilia might

still be present in the DSM for reasons of tradition and purposes of social control, rather than scientific reasons and purposes of diagnosing and treating patients.

The overall impression from the current study was that health workers who consider pedophilia to be a disorder also do so because of the deviance from the social norms and possible danger that pedophilia represents. This breaks with the otherwise dominating Hippocratic tradition in medicine (10), and a continued questioning of the appropriateness of this diagnosis is encouraged, especially the question of what should be the purpose of a diagnosis – should it be for social control or help and treatment purposes?

6.5. If not treatment – then what?

Having pedophilia as a diagnosis gives strong indications that it is a condition that should be treated. However, this study found that there are health care workers who do not believe in treating pedophilia in itself. Nevertheless, they saw it as beneficial for a person with pedophilia to see a health professional either for reasons of social control or relieving the shame and guilt that carrying such a diagnosis might imply. Whether it really is beneficial for people with pedophilia to be in contact with mental health services may also be debated, as a meta-analysis found no reduction of recidivism through psychological treatment of sexual offenders against children (31), which is also the findings of a Cochrane review on the subject (32). However, these contain studies predominantly done on convicted sexual offenders against children, and not help-seeking people with pedophilia. A German study did find a reduction of the dynamic risk-factors for offending in a sample of help-seeking self-identified pedophiles (21), and Grønnerød et al. also calls for low-threshold mental health services for persons at risk of becoming offenders (31).

While the goal of such mental health service in the literature seems to be prevention of sexual assault, an online survey among self-identified pedophiles showed that this group mostly wanted to achieve other goals, such as improving their own self-image (27). In the current study it was found that some health workers consider reducing dangerousness as a primary goal, while others spontaneously said that relieving shame and guilt and living with it in a better way would be possible goals for therapy. Some participants in this study said that health providers have a responsibility to prevent sexual assault, and some mentioned providing help to people with pedophilia as a possible way of preventing child sexual assault, while others said that health providers can't really prevent sexual assault. Some said that

prevention of sexual assault can mostly be done by implementing measures directed towards the children at a vulnerable age or leaders of leisure time activities for children.

The reluctance to accept people with pedophilia for treatment reported in other studies was not found in this study. Nevertheless, health service for people with pedophilia is lacking, and communication and therapy in the existing general and mental health care system seem to be complicated by a lack of knowledge and lack of consensus about what should be the goals of treatment for people with pedophilia.

7. Conclusion

The health providers in this study showed variation in their attitudes towards people with pedophilia due to limited experience, lack of knowledge and confusion between the concepts child sexual abuse and pedophilia. This indicates that health care professionals need more knowledge regarding communication and the patient-health provider relationship when dealing with pedophilia.

The debate among experts concerning whether pedophilia is a mental disorder or not, was reflected in the variation in the informants' attitude. The lacking consensus, both among experts and regular mental health providers indicates that a continued questioning of the appropriateness of this diagnosis should be encouraged.

The health providers in this study would accept people with pedophilia for therapy, either to relieve shame and guilt, increase controllability or to treat other psychopathology. Although this indicates a willingness to accept people with pedophilia for treatment, the lack of consensus on what can be achieved through therapy makes it necessary with further research.

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Appendix 1: Written consent (in Norwegian)

Førespurnad om deltaking i det vitenskapelege forskningsprosjektet
«Kva haldningar har helsearbeidarar til å jobbe med menneske med pedofili?»

Bakgrunn og føremål

Dette er eit spørsmål til deg om å delta som informant i ei studentoppgåve i medisin om haldningar til menneske som har pedofile kjensler (har ei seksuell tiltrekking til ungar i før-pubertet eller tidleg pubertet) blant helsearbeidarar. Prevalensen av menneske med pedofile kjensler er uvisst, men har blitt estimert til mellom 3 og 9 %. Slik pedofili er definert i DSM-V og ICD-10 er det mogleg å fylle kriteria utan å ha begått overgrep, og det er uvisst i kor stor grad det finst menneske som lever med slike «forbudte kjensler» og kva strategiar dei nyttar for å halde desse i sjakk. Det finst lite kunnskap om denne gruppa menneske, sidan dei fleste studie på pedofile er gjort på dømte overgripingarar, og ein veit lite om i kor stor grad dei søker hjelp i helsevesenet. Studie viser at stigma mot pedofile er særleg sterkt, og ein kvalitativ nederlandsk studie der ein intervjuar sjølvidentifiserte pedofile viser at nokre av informantane let vere å søke hjelp pga. redsel for stigma medan andre opplevde å møte kunnskapsmangel når dei søkte hjelp. Denne studien søker på dette grunnlaget meir kunnskap om helsearbeidarar sine eventuelle erfaringar i møte med menneske med pedofili og helsearbeidarar sine generelle haldningar til pedofili. Studien vert gjennomført av Nora H. Serigstad, som er 5. års medisinstudent ved NTNU. Rettleiar er professor Aslak Steinsbekk ved Institutt for Samfunnsmedisin, NTNU.

Kva inneber studien for deg?

Du vil bli bedd om å setje av om lag ein halvtime til å bli intervjuar av medisinstudenten. Du vil bli spurt om bakgrunnsopplysningar (alder, yrke, familiestatus) og om dine haldningar til og røynslar med å ha personar som er pedofile som pasientar. Det vil bli gjort lydopptak under intervjuet, og dette vil bli transkribert i ein ikkje personidentifiserbar form.

Moglege fordelar og ulemper

Ulemper ved å delta er å setje av tid til å gjennomføre intervjuet, og at studien omhandlar tema som kan vekke negative kjensler og assosiasjonar.

Fordelar ved å delta er å bidra til ein studie om eit tema som blir lite undersøkt, sannsynlegvis mykje pga. stigma og tabu. Meir kunnskap kan gjere at ein kanskje kunne bidrege til å førebyggje overgrep ved at personar med pedofile kjensler blir møtt på ein betre måte i helsetenesta.

Kva skjer med informasjonen du bidreg med?

Informasjonen du gir skal berre brukast slik som skildra i denne teksten. Lydopptaka blir oppbevart digitalt på ein passordbeskytta PC, og blir sletta når prosjektet avsluttas seinast 01.12.2017. Det transkriberte intervjuet, som vil bli brukt i analysearbeidet, blir oppbevart utan namn eller andre personidentifiserande opplysningar om deg. Analysen av intervjuet vil skrivast som ei studentoppgåve, og eventuelt skrivast om til artikkel for publisering. Det vil ikkje vere mogleg å identifisere deg i verken transkripsjonen av opptaket eller i resultata av studien. Alle personopplysingar vil anonymiserast ved prosjektslutt, og seinast innan 01.12.2017.

Frivillig deltaking

Det er frivillig å delta i studien. Du kan når som helst og utan å gi nokon grunn trekke ditt samtykke til å delta. Dersom du har spørsmål om studien eller seinare ønskjer å trekkje deg, kan du kontakte medisinstudent Nora Haaland Serigstad, norahaaland@gmail.com, 91169617. Ansvarlig rettleiar kan òg kontaktast: Aslak Steinsbekk, aslak.steinsbekk@ntnu.no, 41559076

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitskapelege datatjeneste AS (NSD).

Samtykke til deltaking i studien

Eg har motteke informasjon om studien, og er villig til å delta

Dato:

Signatur informant:

Eg har gjeve informasjon om studien

Dato:

Signatur av intervjuar:

Appendix 2: Interview guide (in Norwegian)

Intervjuguide

Målsetting med studien (for å halde fokus):

Haldningar til og røynsler med å ha personar som er pedofile som pasientar

Opningsspørsmål

Kan du seie kva du tenkjer om å ha personar som er såkalla pedofile som pasient?

Hovudtema som skal introduseras viss informanten ikkje tar dei opp sjølv:

- Eigne kjensler om pedofili, erfaringar med pasientar
- Kva er pedofili/kunnskap og haldningar – både eigen og i helsevesenet generelt (kontrollerbarheit, fare, sosial avstand)
- Kompetanse/tilbod - Korleis møte personar som er pedofile i praksis (i konsultasjonar, behandling – skal dei ha eit tilbod?)

Utfyllande spørsmål som kan brukast for å formulera spørsmål og markere viss dei er snakka om.

Demografi – ta dette når det passar

- Demografiske spørsmål om intervjudeltakar: Alder, yrke, år arbeida som helsepersonell, ungar og alder på desse

Erfaringar/kjensler

1. Har du i ditt yrke møtt nokon som søkte hjelp for ei seksuell tiltrekking til ungar (før pubertet eller tidleg pubertet) eller problem kopla til dette? Eventuelt, har det i samtale med nokre av dine pasientar kome fram at dei har ei slik seksuell tiltrekking, utan at dei spesifikt søkte hjelp for dette?
 - a. Korleis var dette møtet?
 - b. Korleis responderte/handla du?
 - i. Kva var bakgrunnen for handlinga (enten det blei gjort noko eller ikkje)?
 - ii. Ville du reagert ulikt på jobb vs privat?
 - c. Kva tankar/kjensler vekka dette i deg?
 - i. Kvifor trur du det var slik?
2. Spurte du om personen hadde søkt hjelp for dette tidlegare, og kva respons han/ho evt hadde fått då?

Kunnskap/haldningar/stigma

3. Korleis vil du definere pedofili?

Generelt til gjennomføring av intervjuet

- Hugs å be om døme, spør alltid «kvifor»
- Bruk stillheit
- Oppfølgingsspørsmål ut frå kvar informanten fører samtalen

4. Ser du på det som ein sjukdom/liding eller legning? Kan det behandlast?
5. I kor stor grad trur du ein kan kontrollere om ein er seksuelt tiltrekt av ungar eller ikkje?
6. I kor stor grad meiner du pedofili er farleg? Kven er det farleg for?
7. Når du tenkjer på pedofili, kva kjensler vekkjer det i deg då?
 - a. (dersom det trengst forslag: Frykt, sinne, tristheit, omsorg, syns synd på, anna?)
8. Kva ville du ha tenkt om å ha hatt nokon med pedofili som pasienten din?
 - a. Korleis skal ein møte dei?
9. Trur du at dine haldningar er representative for dine kollegaer i helsevesenet?

Kompetanse (personleg/generelt i helsevesenet), kva skal ein gjere i praksis

10. Kunne du ha spurt nokon om ei mogleg seksuell tiltrekking til ungar?
11. Kjenner du deg kompetent til å tilby nokon form for hjelp/tiltak/behandling/henvising? Kva type hjelp/tiltak kunne du ha tilbydd?
12. Kvar har du henta din kunnskap/kjennskap til pedofili? (lest artiklar/anna, foredrag/undervisning, møte e.a.)
13. Kva kompetanse/tilbod finst i helsetenesta?
14. Kva bør ein gjere med pedofili?
 - a. Dersom det trengst forslag: Ingenting, terapi (psykologisk, medisinsk, kirurgisk), fengsling, dei fortener å dø, anna
15. Har helsevesenet ei rolle for pedofile? Burde/burde det ikkje har det?

Appendix 3: Approval from the Norwegian Social Science Data Services (NSD) (in Norwegian)

Aslak Steinsbekk
Institutt for samfunnsmedisin NTNU
Postboks 8905
7491 TRONDHEIM



Vår dato: 12.09.2016

Vår ref: 49407 / 3 / AGH

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 10.08.2016. Meldingen gjelder prosjektet:

49407	<i>How primary health care workers perceive working with people with pedophilia</i>
Behandlingsansvarlig	NTNU, ved institusjonens øverste leder
Daglig ansvarlig	Aslak Steinsbekk
Student	Nora Haaland Serigstad

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 01.12.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Agnete Hessevik

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Vedlegg: Prosjektvurdering

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Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.



Rekruttering skjer via kontakter og videre ved hjelp av snøballmetoden der personer som allerede inngår i prosjektet rekrutterer nye deltakere fra sin bekjentskapskrets. Ved sistnevnte fremgangsmåte anbefaler personvernombudet at vedkommende som videreformidler forespørsel ber interesserte kontakte student, eller eventuelt få vedkommendes tillatelse til at student kan ta kontakt.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet. Vi ber imidlertid om at følgende endres/tilføyes:

- at alle personopplysninger anonymiseres ved prosjektslutt

Det er ikke meldt at det skal innhentes sensitive personopplysninger (f.eks. om helseforhold eller seksuelle forhold) om utvalget. Personvernombudet legger til grunn at det ikke behandles sensitive opplysninger om utvalget.

Personvernombudet forutsetter at det ikke innhentes opplysninger underlagt taushetsplikt. Dette innebærer at informantene ikke kan gi opplysninger som direkte eller indirekte kan knyttes til en enkeltpasient. Intervjuer og informant har sammen ansvar for dette, og bør innledningsvis i intervjuet drøfte hvordan dette skal håndteres. Informantene må være svært forsiktige med å gi eksempler, da de ikke kan gi eksempler som indirekte kan identifisere enkeltpasienter. Du bør stille spørsmål til informantene på en måte som hjelper dem til å uttale seg på generelt grunnlag og overholde sin taushetsplikt.

Personvernombudet legger til grunn at forsker etterfølger NTNU sine interne rutiner for datasikkerhet. Dersom personopplysninger skal lagres på privat pc/mobile enheter, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 01.12.2017. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette lydopptak