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The challenge of being present with yourself: Exploring the lived experience of individuals with complex dissociative disorders

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ABSTRACT

Aim: The objective of this study was to explore how clients with severe dissociative symptoms describe their experiences of being present in their everyday life. The data in this study stems from a large study conducted at a trauma–outpatient clinic in Oslo, Norway.
Method: 16 participants underwent in-depth interviews six months after a twenty- week group treatment based on psychoeducational stabilization for dissociative disorders. These interviews and participants were part of a larger study, and the interviews in this article are the first 16 of many interviews. Hermeneutic-phenomenological thematic analysis was used to analyze the transcripts.
Results: Four themes were identified: (1) "Being present: To be here and now, and remember it afterward," (2) "To not be present: avoiding challenges but challenged by their inner life," (3) "Being present in a Fragmented Sense of Self," and (4) "Bearing the consequences of not being present in your own life."
Discussion: The findings are discussed in relation to existing theory and research, and reflexivity in the process and limitations of the study are considered.
Conclusion: The results indicate that the experience of being present is an important part of the struggles the participants describe in their everyday lives, as well as a part of the challenges of living with a dissociative disorder.
Implications: The findings indicate that focusing on the ability of staying present could be an important part of treatment of and how we meet and understand dissociative disorders.

1. Introduction

> The challenge is to be present with yourself. It is hard to accept that you are who you are, with the past and skills that one has and when all the skills one has have been shunned. And the entire past one has, is filled with shame and self-contempt. Then the hardest part is to find a reason to stay alive, maybe.
>
> *Participant in the study*

How do people living with dissociation describe their daily life? This participant describe their experience as a challenge of being present with themselves, and connects this challenge to their past. This study explores the experiences of sixteen participants with severe dissociative symptoms in an attempt to understand the impact of trauma in their everyday lives.

Dissociation can be defined as the failure to integrate usually integrated psychological functions such as memory, thoughts, feelings, identity and perception (American Psychiatric Association, 2013; World Health Organization, 2019). Mindfulness can be defined as the intentional and conscious focus or awareness of the present moment with openness, acceptance and non-judgment (Bishop, Lau, Shapiro, Carlson, Anderson & Carmody, 2004; Kabat-Zinn, 1994; Shapiro, Carlson, Astin, & Freedman, 2006; Siegel, 2007). As the term "to be present" is often emphasized and exploredin mindfulness research, we use this as a framework for the participants experience of being present. In this study we explore individuals living with complex dissociative disorders, through the term "to be present," that has been understood through mindfulness. The participants were all diagnosed with complex dissociative disorders (CDD), such as dissociative identity disorder (DID) and Dissociative disorder not otherwise specified (DDNOS).

The myths and controversy around CDD, which is often understood as a response to severe childhood trauma (Dalenberg et al., 2012; Foote, Smolin, Kaplan, Legatt & Lipschitz, 2006; Hart, Nijenhuis & Steele, 2006; Putnam, 1989), as well as the high comorbidity with other severe mental disorders (Leonard, Brann & Tiller, 2005) makes

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it an important subject to understand, for both clinicians and researchers. In CDD, struggling with integrating experiences that are normally integrated, as well as detaching from experience are seen as essential parts of the disorder (Holmes et al., 2005). The control, attention and emotion-regulation processes needed to stay present (Brockman, Ciarrochi, Parker & Kashdan, 2017; Brown, Bravo, Roos & Pearson, 2015; Brown & Ryan, 2003; Siegel, 2007) might be inhibited because of such lack of integration, also known as fragmentation. There also is an implication of a negative correlation between different aspects of dissociation and mindfulness (Escudero-Pérez et al., 2016; Michal et al., 2007; Vancappel, Guering, Réveillère & El-Hage, 2021). The controversy of CDD is mostly located in the etiology of the diagnosis. The post-traumatic model sees CDD as a result of developmental trauma (Gleaves, Hernandez & Warner, 1999). The socio-cognitive model, also known as the iatrogenic or fantasy model, sees CDD as a result of social reinforcement and aided by the help of media, movies and literature (Gleaves, 1996; Merenda, 2007). This discussion seems to have decreased lately, as several studies support the Trauma Model (Dalenberg et al., 2012) and ICD-11 and DSM-V acknowledge the close relationship between dissociative disorders and trauma (Reed et al., 2019; Spiegel et al., 2013). In ICD-11, dissociative disorders have been reorganized from ICD-10, reflecting empirical findings and clinical practice (Reed et al., 2019; World Health Organization, 1992, 2019). For example, "multiple personality disorder" (MPD) is renamed to "dissociative identity disorder" (DID) as well as adding "partial dissociative identity disorder," because of the preponderance of dissociative disorders was diagnosed with "dissociative disorders not otherwise specified" (DDNOS) (Reed et al., 2019). Similar changes have been done from the DSM-IV to the DSM-V (American Psychiatric Association, 1994, 2013; Spiegel et al., 2013).

Studies imply that about 4–21 percent of people at in- and outpatient clinics may qualify for a dissociative disorder (Foote et al., 2006; Latz, Kramer & Hughes, 1995; Modestin, Ebner, Junghan & Erni, 1996; Yanartaş, Öznen, Çıtak, Zincir & Sünbül, 2014). It can take patients with DD between 3 and 10 years before receiving a correct diagnosis (Biswas, Chu, Perez & Gutheil, 2013; Boon, Steele, & van der Hart, 2011; Leonard et al., 2005), and they often receive several diagnoses on the way (Kluft, 2005). Misconceptions and skepticism may affect therapists' abilities to diagnose CDD correctly (Perniciaro, 2014), and correct diagnosis is important to give the right treatment (Brand et al., 2016). In one study, patients with CDD described that therapists who were inexperienced with or were skeptical to the diagnosis CDD could be a negative impediment in their treatment (Jacobson, Fox, Bell, Zeligman & Graham, 2015). More knowledge about the lived experience of individuals who struggle with CDD might help therapists make provide diagnoses and improve the deliverance of therapy for this population.

Mindfulness, or practice that focuses on awareness and acceptance of the presentmoment experience, exists in various forms in most cultures, which indicates that mindful awareness may be a universal capacity for human beings (Siegel, 2007). Mindfulness has been operationally defined by Kabat-Zinn (2003) (p. 5) as "the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment." Several treatment approaches for dissociative disorders focus on mindfulness or practices that seek to help the individual stay "grounded" in the present (see e.g. Boon, Steele, & van der Hart, 2011; Fisher, 2017; Steele, Boon & van der Hart, 2016). Integrating mindfulness practice in treatment for CDD might be beneficial (Zerubavel & Messman- Moore, 2015). However, there is little research on how patients with CDD experience being mindful or being present in their everyday lives.

Qualitative studies may provide knowledge about the lived experiences of individuals who struggle with mental health problems, helping us with a richer and nuanced understanding of the potential relevance and impact of psychological interventions (Binder, Holgersen & Moltu, 2012). Unfortunately, little qualitative research has been done specifically on dissociative disorders. A review of published articles on dissociative disorders from 2000 to 2010 indicated that most of the research was descriptive, or case studies that often focused on treatment (Boysen & Vanbergen, 2013). However, there are a few qualitative studies on individuals with dissociative disorders in the research literature.They mainly focus on individuals with dissociation and their experience of treatment (Hunter, 2016; Jacobson et al., 2015; Leonard et al., 2005), on therapists working with CDD (Blewis, 2018; Heimstad & Biong, 2014; McMinn & Wade, 1995; Qu & Liu, 2011) or on refugees (Gušić, Malešević, Cardeña, Bengtsson & Søndergaard, 2018). This indicates a lack of studies in the existing research literature on the lived experiences of individuals with CDD, and how they experience these challenges

1.1. Study aim and research question

The study aimed to explore the lived experience of individuals with complex dissociative disorders. The present study will explore the following research question: How do patients with severe dissociative symptoms describe their experiences of being present in their everyday lives?

2. Method

2.1. Setting

The current study is based on qualitative data from a larger study at a (Norwegian outpatient trauma clinic. The present study is based on qualitative data from in-depth semi-structured interviews conducted six months after the participants had been through the stabilization course.

2.2. Qualitative methodology

Qualitative methodology was chosen for this study, as it gives and allows understanding the human experience from the individual's perspective. A systematic exploration of the data was done with a hermeneutic-phenomenological thematic analysis and NVIVO software (QSR international 2008). Thematic analysis explores different shared experiences and meanings across a data set (Braun & Clarke, 2012). The experiences that are viewed as important within the frame of the research question are formulated as themes. Themes are thought of like something that "captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set" (Braun & Clarke 2006, pp. 82–82). A hermeneutic-phenomenological approach means that one both describes important psychological aspects of a phenomenon and also recognizes and reflects around the researcher's own assumption and interpretations as a part of the analysis (Binder et al., 2012; Gadamer, 2004/1960; Heidegger, 1996/1927). NVIVO is software that gives the opportunity to analyze the data systematically, coding important aspects of qualitative data into nodes (QSR international 2008). We found this to be a fitting method for our study, as we were interested in exploring individuals with CDD and their own experience of living with severe dissociation.

2.3. Participants

Participants in the larger study were recruited from an outpatient trauma clinic in Oslo. All patients were invited to participate and gave written informed consent. Participants had to meet criteria for DID (dissociative identity disorder) or DDNOS (dissociative disorder not otherwise specified), be between 18 and 65 years of age, and

have adequate norwegian language comprehension to be able to follow the course. Several diagnostic assessment tools were used to establish that the participants met the criteria. Exclusion criteria were acute suicidality, severe substance abuse interfering with treatment, ongoing psychotic episodes, neurological disease, mental disability, life-threatening somatic disease, or current life crisis. The interviews were conducted in a randomized order. The sample included in this qualitative study consisted of the first sixteen participants, fourteen women and two men, who were interviewed in the larger study, as these were the available interviews at the time of this study. The participants had an average age of 33.37 (SD=9.41). Nine participants were married or in a cohabitant relationship. Seven of the participants were on sick leave or lived on social support, five were working part- or full time, one was a student. Based on the answers of eleven out of sixteen participants, the average number of years from their first contact with psychiatric health service was 11.45 (8.9) years. Three of them had been diagnosed with a dissociative disorder before their treatment at the outpatient clinic. Twelve of the participants reported emotional abuse, sexual abuse, and emotional neglect on CTQ (Childhood Trauma Questionnaire). Eleven reported physical neglect and eight reported physical abuse. On average they had a CTQ score of 76.1 (SD=19.0) and reported 4.2 forms of abuse (SD=1.2).

2.4. Treatment

The participants underwent a Group Treatment based on psychoeducational stabilization for complex dissociative disorders from the manual *Coping with Trauma-Related Dissociation* (Boon, Steele, & van der Hart, 2011). This manual is based on the theory of structural dissociation (Hart et al., 2006; Nijenhuis & van der Hart, 2011). The twenty-week course had weekly meetings that lasted for 1 hour and 45 min and were given as an addition to individual treatment. The groups had up to nine patients and had two clinical psychologists as course teachers. The course consisted of psychoeducation about complex dissociative disorders and handling typical difficulties in daily life. This could be triggers, regulation, and inner cooperation. The course also included tools to cope with these difficulties.

2.5. Data collection

As a part of the larger study, participants were invited to an interview six months and again two years after treatment. This was to explore the effect of the treatment. This study is based on the interviews done six months after treatment. Three clinical psychology specialists at the outpatient clinic conducted the interviews. The interviews had a duration of sixty to ninety minutes (mean=82 min) and were based on a semi-structured interview guide. The interview guide included questions about how the participants experienced the stabilization course and their experiences of living with a dissociative disorder. Questions asked about dissociative symptoms were for example: "what does the term "to be present mean to you?" and "have you had any moments or places in your life where you feel safe in the present?" The interviewers asked follow-up questions to check and validate their conceptions, as well as giving the participant room to elaborate his or her statement. See appendix A for the full interview guide.The first author of this paper transcribed the interviews in verbatim. The interviews were conducted in Norwegian, and the quotes used in this paper are translated to English as close to the participants' use of words and expressed meaning as possible.

2.6. Data analysis

The data analysis proceeded through the following stages and was done by the first author under supervision by the fourth and third author. First, the first author noted initial thoughts and impressions during the transcription process. Second, the first author read and re-read the interviews to obtain knowledge and an overview of the material. Third, important aspects related to the research question were highlighted and labeled as meaning units with descriptions close to the participants' own words. These could be descriptions that seemed to be important or that were recurring. Then, the first author categorized meaning units into larger themes and sub-themes through a process involving several reviews of the themes, to make sure they were representative to the data set. This included merging themes that were overlapping or discarded themes that did not appear relevant to the research question. During this process of analysis, the first author discussed all meaning units and themes with the second, third, and fourth author of this paper. The four themes in this study were the results of the analysis.

2.7. Ethics

The study was approved by the Norwegian Regional Committees for Medical and Health Research Ethics (2013/2350) All procedures comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. Experienced clinical psychologists interviewed the participants, and care was taken to ensure the wellbeing and integrity of the participants during the interviews.

3. Results

We identified four main themes. (1) "Being present: to be here and now, and remember it afterward", (2) "To not be present: avoiding challenges but challenged by their inner life" (3) "Being present in a fragmented sense of self" and (4) "Bearing the consequences of not being present in your own life". These will be described in further detail below. Most of the sample was female, and female pronouns will be used on all participants to maintain anonymity.

3.1. Being present: to be here and now, and remember it afterward

The first theme, "Being present: To be here and now, and remember it afterward" explores the participants' experience of being present in their everyday life when they are going through life with complex dissociative symptoms. All the participants described that they struggled with being present in their everyday life. Their descriptions of "to be present" included that it was an unpredictable and fragile experience. Their present was also experienced "leveled"; as if they were being present in more than one state at the same time.

One participant summarized the experience of being present like this: "to be aware of what's going on (…) and remember it afterward." This description was representative for most participants as it recurred in several descriptions. Another important pattern was how the participants described having several experiences of the present simultaneously; "I'm present at several levels at the same time" or "I was present but at the same time I was maybe somewhere else." The "layered" experience of the present was characterized by a division between the experience in the body and the experience in the mind.

> *The first thing I think about is to be here and now. But also, being in touch with the body and emotions. And how important it is that the body is physically here, and that is okay, and that is right. In a way, the word has gained new meaning after the course. Because being present, before I have thought that "yes, that is here and now" but one can be physically here and now, present, but still not be present in your mind.*

The participants connected bodily and conscious awareness as an important part of being present. Their experience was also affected by their surroundings, situations, and emotional state:

I think it is a bit difficult [to describe to be present] (…) It is that I feel balanced and calm and that I endure being with other people (…) That it's just relaxed inside of me, and that I participate in what's going on.

A description of "being able to take part" in the situation recurred in several accounts. Many of the participants struggled with inner unease, and this impeded their ability to feel fully present. They rarely or never felt safe and were often or always "on guard".

It was hard for the participants to predict whether they would be able to stay present in each situation. They described living with a looming threat of losing touch with the present, and one participant described: "It's kind of like walking on thin ice, it can break at any moment." Another summarized the uncertainty:

No, I do not know. I can be very present at work, but sometimes, I am not. And then it is hard. I can be present at home, but sometimes that does not work out either. But then I run and workout a lot, but other times, that does not work, so I don't know, maybe not any special [situations].

Some participants described not having any situations where they felt more present. Others described general situations where they did feel more present, like being with the family or having time alone. Others mentioned doing specific activities; one participant did for example actively do headstands to feel more present.

While searching for and wanting a stable sense of being present, they struggled also when feeling present. Six of the participants described that they struggled when things were quiet, or when they did not have activities to keep them occupied. "If I do not do anything, then my head goes on overdrive. (…) The voices become so loud." Another participant explained that she avoided quietness as a way of avoiding herself. One described that it took a lot of concentration to be present; "I have to actively focus on where I am to manage to stay here." Quiet surroundings seemed to redirect their attention to unpleasant or unwanted inner experiences:

(…) It is harder to feel these things because I feel more. I am kind of more present, which is progress. Which is good. But it is very intense, more intense feelings than before. (…) And it is like, some things are more difficult, some things are easier to deal with. Dissociating here and there, I do not feel that I have much control over it, now, just as before.

It seemed to be a cost-benefit evaluation between the progress of being more present and dreading an increased experience of intense feelings. The participants both dreaded and struggled when they felt present; at the same time, they searched for it and wanted it.

3.2. To not be present: avoiding challenges but challenged by their inner life

The second theme, "To not be present: avoiding challenges but challenged by their inner life", explores the participants' descriptions of not being present, as well as the following inner conflict. To not be present was described as a beneficial "avoidance" of challenging experiences, a search for safety, and a tool to manage everyday life. At the same time, they experienced that not being present had unwanted consequences and could be frightening. Often, they connected the experience to traumatic events of the past, and used sentences such as "falling back in time". This theme will explore their descriptions of what it means for them to not be present, and the comfortable avoidance in it. Also, it will try to describe their fear connected to not be present.

They described their experience of not being present with words like "I disappeared", "to shut off", "removing myself", "keeping a distance", "not being here", or "to be stuck". The result of this was often a lack of memory for the incident. They also described their experiences of not being present in terms of physical symptoms or perceptual changes. This could be experiences of losing senses such as touch, sight, or hearing, feeling like the head is "empty", or "filled with cotton", losing contact with the body, losing the sense of time, getting cramps, or feeling that either they or the world was not real. One participant explained how she noticed she was losing touch of being present: "I notice it at first in my head and on my eyes, really. That my sight gets worse. And it gets heavy inside my head." She explained how she could register the words that was said but struggled with understanding what was said.

These symptoms tended to arise when the participants were facing challenging situations or unwanted experiences. It was described as "a break" or as a way of managing difficult situations. One participant reflected on the benefits of dissociative symptoms:

(…) Or that is why; it is a defense for- because it hurts too much to feel that your mother and father do not love me, kind of. I do think that a schoolchild, to manage to go to school, you cannot feel all the time that no one loves me. So, then you probably must push it away to a dark corner of your consciousness, because if not, you will not be able to learn the multiplication table. (…)

Many participants described their avoidance of being present as beneficial in managing challenging situations. One described it like this; "When I face challenges. Then it is easier if you are not present." Another connected not being present to why she couldn't remember the situation where she got her diagnosis: "But it is kind of erased, because, I think I was so nervous that I just… No, I am not here." To not be present helped them with coping or tolerating situations perceived as challenging or overwhelming. At the same time, fear and discomfort were connected to not being present:

To not be present is the most horrible thing you can experience. I think. I have had a lot of feelings of unrealness and not being able to- (…) Several years that have gone to this feeling of unrealness, right. So, and, when you are always re-experiencing things, and do not feel anchored or present, it is just like being on a fever high. That you cannot, no, that thing is really awful. (…) It was like a code I was unable to solve; I did not understand why I could not be present. And it felt like I was doomed to be in that feeling of unrealness for the rest of my life.

Another participant who experienced frequent out-of-the-body episodes described, "You hear your own voice, and you are not in your body or something, and it begins to be very scary, really. Powerful and scary." They could be afraid of what would happen the next time they lost control or contact with the present, or afterward, not knowing or remembering what had happened. One described it like this: "[in challenging periods] I am unable to not walk into the dissociative fog. And inside that, I have done so many weird things before. (…) Now, so that fear becomes, I carry it with me always, what will I do next." They could try to avoid situations that made them prone to lose control; "(…)I cannot allow myself to… sleep at night because… imagine if the… evil in me takes over or…" Another example is one who mentioned how she did not drink alcohol or took drugs because it felt like she lost control.

Trying to avoid challenging experiences in the present, and at the same time not wanting to experience the frightening conditions of not being present, seemed to be a constant dilemma. The participants described avoiding external situations, such as concerts or public

transport. They also described avoiding their inner experiences, such as thoughts or feelings. Several participants described this as an evasive part of their everyday life, and as energyconsuming.

> *I feel that I use a lot of energy to actively hold back doors and windows that open by themselves, and I cannot bear to deal with what is on the inside, and then it becomes chaotic. And then I can bear it tolerably when I am doing activities, but, yes, it is that part with rest that is kind of hard.*

It was also important for them to hide their struggles from others, "so I feel kind of that I always have tried to almost strangle [the feelings]. Before it… develops or expands so that others can see." Trying to avoid challenging situations, inner experiences, and hiding their struggles from others was energy-consuming and a defining part of their struggles with staying present.

To not be present could be a way to protect themselves when facing challenges, but also had unwanted and sometimes unbearable consequences.

3.3. Being present in a fragmented sense of self

The third theme explores the participants' sense of self and how this impacted their sense of being present. All participants described some form of feeling fragmented in their inner life. They described having several "parts" or experiencing "modes" or "states". These will here be described as "parts". The participants described that they experienced that their past was blended with the present, or that parts were not oriented in the present, e.g. not knowing which year it was. Their relationship with themselves and their parts seemed to be a part of their experience of being present:

> *The challenge is being present with yourself. It is hard to accept that you are who you are, with the past and skills that one has, and when all the skills one has have been shunned. And the entire past one has, is filled with shame and self-contempt. Then the hardest part is to find a reason to stay alive, maybe.*

Connecting the past to the present self and struggling with acceptance of the self, recurred in several descriptions, also involved in their experience of fragmentation. They seemed to accept their parts or states differently. While some said they accepted these parts as themselves, others declined these experiences or behavior as their own, even when being aware of the parts' presence and behavior. The participants experienced feeling fragmented as disturbing. The experience of not being whole was a part of their perceptions. Not sharing an experience, thought or knowledge with "all of me", recurred in their descriptions. The parts seemed to affect their perception of the present and other experiences in everyday life, e.g. affecting their experience of safety in the present:

> *(…) Even though you know, even though I know I am safe, I feel like I cannot get any rest because it is so much inside of me that do not believe it. (…) I am so fragmented that… I thought if I killed myself, I would not die, because I am so disturbed in my soul that my soul will keep on being disturbed.*

The experience of inner unease and fragmentation affected their ability to be present with their whole selves. They talked about their parts with a distanced language and referred to parts of themselves in third person. Their parts could have a different experience of the present than the participants themselves had. One described: "I cannot seem to completely - to kind of help the parts with understanding that it is now, for example, 2017." When the interviewer asked how she noticed that her parts did not know it was the present year, she explained: "I notice by the things that they say." It was recurring how the parts belonged to the past; one participant described it as the parts were "stuck" in the past. It seemed like they tried to convince themselves and their parts that their trauma was in the past, and not happening now:

> *(…) I am seeing two circles. (…) A red [circle] that says "it is happening, it is happening!" and a green [circle] that says "no, it is not happening, this is the past, this is the present." I am telling my brain, it is not only the past, I say to the brain, it is also a present. (…) Before, the circles were together. Now the circle for my present is larger, and my past becomes smaller and smaller. (…) I won over my past. (…) My present is really big; it is a big circle. And the past is very small.*

The parts could be expressed in different ways, some heard voices, others not. Describing her parts as voices that belonged to the past, one participant described how her parts could be both other people and child parts she identified as herself:

> *It is kind of my own child voices from different parts of life. And some voices that, are not mine, but are others', but voices I really know it is physically impossible to hear. Like that. But, some of these voices, from, still, I cannot bear to listen to them. (…) But I know they have important things to say.*

The parts were described as younger child parts, evil parts, angry parts, sad parts, protective parts, and several others. Experiences of estrangement, "this is not me" recurred in some of the descriptions:

> *What I am thinking is, it is really not me. It is, it sounds really stupid, but I had a really horrible… sadist where father-… so I have thought that he has lived inside of me in all these years, so it has taken many, many- when he died 29 years ago, or something like that, but he lives inside me already. Everything he meant that I did not deserve, that I even did not deserve to live. It is him, and he lives inside me, I have that fight in me still.*

Many of them described how they seemed to be present, but "with a part of me". One of the participants thought it was hard to describe how "I am me, but I am not me" when explaining her condition to others: "I am still here, but it is another part of you, but then it is like, how can another part of you-". Other participants described how she could be present with one large part of her, while other parts were not. She asks, "how are you with this and that, and it is like, yes, with which part?" Their fragmented sense of self and the blending and identity confusion connected to it made the present hard to describe.

3.4. Bearing the consequences of not being present in your own life

The final theme, "Bearing the consequences of not being present in your own life", explores the participants' experiences of the long-term personal consequences of losing touch with the present. Twelve of the participants mentioned memory loss as a result of not being able to be present. A couple of them described how they could not recognize people they knew well or saw every day. Many of them struggled with social relationships, upholding friendships, being in intimate relationships, work, or having a family life. They also had descriptions of loss, grief, and sorrow as experiences they had because of their struggles.

Memory difficulties affected both big and small parts of their lives. One participant described her memory losses in everyday life:

> *Have I taken my medication today? Have I eaten? Have I not? Have I been drinking water, have I brushed my teeth? (…) And, such everyday things, that many people forget. I do know that ordinary people also forget. But it has been like completely blank. And it is, I have, been so gone that I, earlier I have not eaten because I have thought that I had eaten, and then I have completely forgotten to- yes, it has*

been a lot of memory loss concerning everyday life, and also to events you should remember.

She described her symptoms as somewhat normal, but with a frequency and severity that differ from the "normal" forgetfulness in people who do not experience dissociative symptoms. Many of the participants were not able to work because of their struggles and received social support. Others struggled at work. One who worked with children was wondering whether she should quit her job because she met situations that reminded her of her trauma. Another participant had to take notes, record, and memorize the looks of clients they met, because if not they would forget. Another struggled with knowing what she did at work:

Because it has always been like that. But it is that I, kind of, it sounds completely crazy in a way, but, for example with work. I have no idea what I do at work. I do know that I work a lot and that I kind of like in general, but it does kind of feel like another part of my life. And then it is, yes, several things that are remote to me, like how we sit like this now.

This experience of a distant relationship to different parts of their lives recurred in different forms with many of the participants. E.g. one described how "it can suddenly feel weird that I am a mom" and made a connection to how she did not feel "grown-up". In many ways, their life felt remote or unreal to them.

Their struggles could put them in unwanted situations. One participant described that she could use hours to get home after going out because she could not remember her name, who her boyfriend was, or where she lived. Two of them had experienced that their therapist had been acting sexually inappropriate towards them. One of them said she did not know about it because it was another part of her that was present during the abuse.

Not being present also had consequences for their family life and relationships. Often, they had to ask others to repeat what they said or did not recognize people they knew or saw every day. Some struggled with intimacy with a partner or with close friendships. One participant described her frustration of how she struggled to be present with her children; another used all her energy on being present when she spent time with her child. A third participant described the wider consequences of not being present in everyday life:

Yeah, no, it becomes like a black hole, really. After. I can remember some small things. That I have been to the movies, for example. I can remember being there with the kids, but I cannot remember how we got there. Cannot remember anything afterward, not before, it is frustrating, I cannot remember anything from the childhood to the youngest [child], not the birth, not when she was a baby, it is completely blank. But in some periods, I have the energy to write on an app that I have on my phone and iPad. And there it appears, every day with what has happened on that date. So, I think in a way that I remember by cheating, kind of. If you understand. Oh, yeah, we were in Thailand, and we rode on elephants. But I cannot remember that I did it. So, it is like, yes, I do not know what I remember and what I am reminded of, really.

Many of them used tools and practical strategies such as writing things down, using apps, or taking pictures to help them remember. Some experienced this as helpful, such as one participant who used pictures during a party and could remember most of the event, which was progress for her.

Many of them described not being present during important events in their lives. One participant had no recollection of her wedding. She expressed both frustration over not remembering it, as well as an experience of loss. But she also connects how the "ultimate intimacy" that the wedding symbolized for her was frightening and made it difficult to stay present:

(…) It is really frustrating, me and him, we are married, but I have no recollection of the day we got married. It is gone. It is like; it's just as a fog. And it is something of the most tender thing of all. I wish that I were able to be present in it. (…) And, maybe it says something about- I think that it says something about the aspects of close relationships. That, when you get married to someone it is kind of the closest you can get to anyone. One becomes a unit, and then, I do not know if it was that did it in itself, I, what that made, that makes it so I don't remember anything, I do not know. But I suspect that there is a connection. (…) I was much more present before the wedding, but not that day. No, it is completely gone.

These examples of what the participants had memory loss for, also gave an impression of how many things they lost in their lives. Two of them explicitly stated how they felt sorrow or grief of the moments of their life that they lost. The participants had to make changes in their lives to be able to be more present. These could be tools that helped them remember, cutting down at work or not working, and working with their experienced parts of the self. One participant explained how she reduced her life to the bare minimum to be able to stay present:

I have obtained this little life of mine, I have social security support, I have a couple of friends, I have this regular coffee place I go to sometimes (laughs). And it is this little life. It was nothing like I had hoped it would be before when I still did a large effort and hoped it would be really good. But when you have struggled for so many years, you cannot deal with it anymore.

The participants made practical adjustments to make it easier to be present. At the same time, not being present helped them avoid unwanted experiences. Experiencing a fragmented self, complicated their experience as the past and present were blended. The participants experienced the tension between wanting to be more present and the avoidance of difficult situations as an ongoing and energy-consuming conflict in their everyday life.

4. Discussion

The themes describe different aspects of the participants' experience of being present. They both yearned for and avoided the experience of being present, usually finding themselves in a place in between, somewhat present, but not fully. Their fragmented sense of self seemed to be a part of their fragile experience of being present. They struggled to be present in their own lives, which affected their relationships, personal narratives and limited their lives.

The first theme, "Being present: To be here and now, and remember it afterward", includes the participants' descriptions of being present. The participants described mental and physical awareness, as well as participation in the situation, as important parts of their experiences of being present. This corresponds with definitions of mindfulness in the literature (Dryden & Still, 2006; Kabat-Zinn, 1994, 2003; Shapiro, Carlson, Astin, & Freedman, 2006). Corresponding with a study on mindfulness and stress (Nezlek, Holas, Rusanowska & Krejtz, 2016), the participants' fragile experience of the present might be related to their day-to-day function- and energy levels. It was unexpected that the participants defined memory after an experience as a part of being present. Memory problems such as memory integration are common in dissociative disorders (American Psychiatric Association, 2013; Bedard-Gilligan & Zoellner, 2012). Still, memory is not necessarily considered related to being present.

The second theme, "To not be present: avoiding challenges but challenged by their inner life", described the "tug of war" between

trying to be present and the adaptive function of detachment. To not be present was used as a survival mechanism in unbearable situations, which corresponds with theories of psychological trauma and dissociation (Boon, Steele, & van der Hart, 2011; Fisher, 2017; Herman, 1992; Putnam, 1989). A part of their descriptions of willingly removing themselves from the present is similar to the immobilization response described in Porges' polyvagal theory (Porges, 2001), and the detachment described by Holmes et al. (2005). The participants' descriptions of their experiences around being present indicate that they have some degree of awareness of their experience. It seems to be a paradoxical "present in not being present". The participants' experience and reflection around being present could be affected by the course's focus on awareness of and grounding oneself in the present.

The third theme, "living in a fragmented sense of self", describes the participants' experience of being present, but not with their whole self. They described struggling with being present with themselves, as well as a blended past and present, often represented through the experience of fragmentation of identity or "parts of the self". According to structural dissociation theory (Hart et al., 2006; Nijenhuis, Van Der Hart & Steele, 2010), emotional parts (EP) of the personality holds on to the trauma, while the apparently normal part of the personality (ANP) moves on and holds a phobia for the EP. This is quite like the participants' descriptions of avoiding themselves and their inner experience, as well as avoiding challenging experiences in the present. Many treatments for dissociation focus on orienting the EP "action systems" in the present (Boon, Steele, & van der Hart, 2011; Fisher, 2017; Steele, van der Hart & Nijenhuis, 2005).

The final theme, "Bearing the consequences of not being present in your own life", describes how the participants' lives were affected in a long term perspective by their struggles of being present, and how they adjusted and compromised their lives to be able to be more present. Amnesia of bigger and smaller events in their lives was recurring in the participants' descriptions. Tulving (1983) distinguished between episodic and semantic forms of memory. The participants described how they "knew" they had been on holiday or worked a lot. This suggests that the semantic memory, the" factual knowledge" is present, but not the episodic memory, the experience of self in the memory, "this is my memory, this happened to me". This is necessary for episodic memory (Lin, 2018), but for the participants' the sense of self was fragmented or distanced. This seemed to impede their experience to participate in the experiences in their lives, which is a part of the participants' definition of being present.

The participants' avoidance or phobia of their parts becomes a phobia of their own narrative (Boon, Steele, & van der Hart, 2011; Fisher, 2017; Steele et al., 2005). According to Chefetz (2015) this "fear of feeling real" is connected to upholding the dissociation, as one is unable to integrate the traumatic past. One could argue that this keeps you from being present with yourself, or your "whole self". Some of their challenges with their present could be connected to compartmentalization (Holmes et al., 2005) or the disintegrative cognitive nature of dissociation and trauma (Brewin, 2001; Fisher, 2017). Inhibited working memory and attention is not uncommon in CDD (Dorahy, Irwin & Middleton, 2002; Kimble, Fleming, Bandy & Zambetti, 2010; Olsen & Beck, 2012), but it is necessary for cognitive control (Kimble et al., 2010; Shipstead, Lindsey, Marshall & Engle, 2014).

Some qualitative studies imply that the sense of self is connected to the ability of to be present; Fragmentation has been connected to memory loss (Somer & Nave, 2001), and a conscious sense of self is related to the ability to be present (K. W. Brown & Ryan, 2003). The participants experience their self as fragmented, and this could be connected to their experience of the present as "leveled". This is supported by Somer & Nave (2001) where the participants said that they had to be more integrated with their parts to be more present.

This is also implied in our study, as the participants could be present, but "not with their whole self". Integrating parts and focusing on the whole self is often important in several treatment approaches for dissociative disorders (Boon, Steele, & van der Hart, 2011; Fisher, 2017; Steele et al., 2016), and might be important for patients as well (Jacobson et al., 2015). Some qualitative studies have similarities to this regarding the experience of being present, such as intrusions of mental images hovering over their present experiences (Eisikovits, Tener & Lev-Wiesel, 2017), or relating memory loss to struggling with being present (Gušić et al., 2018). To struggle with being present seemed to be an important aspect of the participants' experience with CDD. They connected the experience to their avoidance and sense of fragmentation, as well as describing it as a protective strategy of non-realization or unrealness (Boon, Steele, & van der Hart, 2011; Chefetz, 2015).

4.1. Reflexivity

Reflexivity, to critically self-reflect around one's position in the interpersonal context of qualitative research, is important to uphold transparency and trustworthiness (Binder et al., 2012). It is also important as the research might be affected by the researchers' assumptions, preconceptions, and knowledge (Finlay, 2003). This paper was written in collaboration with the outpatient clinic that was responsible for the larger study. The first author has had a practical internship at this clinic. During her internship, she worked with patients who resemble the participants in the study. The interviews were conducted by therapists working with trauma and dissociation daily at the outpatient clinic. Both the first authors' and interviewers' allegiance could therefore have an impact on the interviews and interpretation of the results.Throughout the research process, the authors have reflected upon these by openly discussing them

4.2. Limitations

The present study has important limitations. First, qualitative research aims to study how individuals experience and make sense of their experiences (Binder et al., 2012), and cannot draw strong inferences about causality. Second, the interviews were primarily focused on the experience of the twenty-week stabilization course. This could have affected this study in several ways. First, it might have affected how the participants reflected upon their experience of being present. Secondly, the course itself might have affected the participants' experience of being present, as it has a lot of focus on mindfulness techniques, e.g. focusing on "grounding" in the "here and now". Collecting data by using interviews that only focused on the experience of being present could have been one solution to this. Another solution could have been to collect data before and after the course to make sure potential differences were detected. A third limitation is the unclarity of several terms used in this paper. The term "dissociation" is somewhat unclear and debated (Nijenhuis & van der Hart, 2011). This might have some effect on how this study is understood. Also, some of the research focus on dissociative symptoms after trauma or exclusively on DID. They will therefore not give an accurate description of living with CDD. It is also important to acknowledge the limitations of the sample. It consisted primarily of women, and this decrease the possibility to draw any conclusions about genders and the experiences we explored. It is also important to note that we might lose important nuances of the experiences and if it differs between genders. The sample is also primarily Norwegian. This limits the possibility to generalize the results to other contexts, cultures, and nations.

4.3. Implications for research and clinical practice

This study explored individuals with complex dissociative disorders and their experience of being present. As the participants saw to be more present as progress and were something they wanted.

Therefore, implementing mindfulness techniques or focusing on the ability to help to be safe in the "here and now" might be a beneficial focus in clinical practice for dissociative disorders (Zerubavel & Messman-Moore, 2015). Although, more research would be necessary to understand the mechanisms and benefits.

The lack of qualitative studies indicates a need for more research to better understand the lived experiences of individuals with CDD. Even though this study suggests that the participants' experience of being present was a pervasive part of their lives with CDD, more studies are needed. Other aspects of CDD life experiences would also be important, both quantitative and qualitative research would be beneficial.

5. Conclusion

This study aimed to explore individuals with severe dissociative symptoms and their experience of being present. We identified four main themes:1) "Being present: To be here and now, and remember it afterwards", 2) "To not be present: avoiding challenges but challenged by their inner life", 3) " Being present in a Fragmented Sense of Self " and 4) "Bearing the consequences of not being present in your own life". The results suggest that they struggle with being present and that this has consequences for their personal lives and function. They experience an adaptive function in avoiding the present when it became too challenging or overwhelming, and a fragmented sense of self that impeded on their experience of being present, such as being present with only parts of themselves.

Author contribution statement

All authors have contributed to the manuscript. Ingunn Holbæk was responsible for the data collection, Ylva Øyehaug Opsvik conducted the analyses and writing with supervision from Aslak Hjeltnes and Kjersti Arefjord. All authors have revised and contributed to the manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Ylva Øyehaug Opsvik: Writing – original draft, Formal analysis. **Ingunn Holbæk:** Writing – original draft, Data curation. **Kjersti Arefjord:** Writing – original draft, Supervision. **Aslak Hjeltnes:** Writing – original draft, Supervision.

Appendice

Semi-structured interview guide

Semi- structured interview guide for patients with dissociative disorder, six months after treatment

Introduction

7.1.1. Presentation of interviewer, name, professional background, knowledge to the stabilization course and so on.

7.1.2. "We have three wishes with this interview. First, we want to have your own personal description of how you experience your symptoms and challenges in life. Further, we will ask you of your own experience with getting taught a specific model and your experiences of inner communication. Throughout the interview we want to get a hold of what you experience as inhibiting and what promotes a good process for you. Your experiences and reflections are very valuable information that can help us to better understand how it is to live with dissociative disorders and what could help. Our hope is that this could contribute to develop a new understanding so that others can receive the best treatment option as possible. The interview will last 1–1,5 h. If you need a break during the interview, or of other reasons wish to stop, it is nice if you just tell us. You can also ask me to stop the recording. Do you have any questions before we start? Then I'll start the recording."

"I would like to ask for your verbal consent on record"

1. **First, I want to know if there have been any episodes or events that have affected you in a positive or negative way?** (On an inner or external level.)
2. **What is the first thing you think about when you think about the course that you went to for twenty weeks?** Explore and specify this.
3. **Have the course been of any help? In what way?** E.g. things that have changed. Some changes in everyday life.

3b. If it has not been helpful, why?

1. **When it got close to the day of the of the course every week. Can you remember what you thought or felt about meet up at the course?**

- Explore degree of inner struggle/ambivalence/avoidance connected to taking the course
- Are these reactions you recognize from other situations in your life?
- Did it affect whether you went to course or not?

2. **You might remember the form that you filled out every time (show the process form) Here, we asked about your experience of being present in the different parts of the course.**
3. **What does the term "to be present" mean to you?**

- In what situations would you say that you experience to be present in your life today?

And in what situations are you not present?

- Have this changed the last year; the way you experience it, and how much?

1. **How do you experience to be given a specific understanding model of dissociative disorder? (Show the model with rings, attachement four.)**

- What was good with such a model, and what was not that good?

2. **Now we have looked at a general model. How would you describe your inner world?**

What words and pictures makes sense for you?

- Why do you think it is like this for you? (Experience of that it is expedient inner organization?)

1. **Here you can see a scale from missing knowledge on what is inside, to inner cooperation (Show second attachment and read all steps.)**

- Where do you think that you are on this scale now?
- Where do you think you were when you started the course?

- Can you give us an example on that area in your life (feelings, thoughts, parts) where you have had the best progression? (What must be there to move? How was the experience the first time, do you still have it, could it be helpful in your life or has it scared you?)
- Can you give an example on where you experience the least progress?

2. **How would you describe your relationship to the group leaders? Were they important to you? In what way?**
3. **How would you describe your relationship to the other participants at the course?**

Were they important to you? In what way?

- Do you experience any change in how you relate to other people? (More connected to other people or more disconnected than before?

1. **How did you experience individual treatment while taking the course?**

- Have you had the same therapist?
- How often did you meet?
- Do you still meet?
- How did you/do you experience your relationship to the therapist?
- Did you focus on the course material?
- Have you worked with the course material after the course was over? (Did the course become a bubble?)
- Have you had any other treatment (communal health service, inpatient treatment, psychomotor treatment, or others?) How has this affected your process?

2. **It is common to be on guard when you have lives in danger, and many struggles with finding inner safety. We worked on this on the course. How is this for you now?**
3. **Have you had any moments or places in your life where you feel safe in the present?**

14.b How was this for you when you took the course?

1. **Was there anything at the course that was not good for you, that have made your life more difficult after?**

"Now I want to ask you some questions about your lived experiences of dissocative disorders and potential changes you have had."

1. **What do you think of having got the diagnosis dissociative disorder?**

- Was it new or did you know about it when you were assessed at the clinic?
- What do you think of it? How does it feel?
- How much do you agree of the diagnosis on a degree of 0–100%?

2. **What is the hardest part of living with a dissociative disorder?**

- Describe e.g. from everyday life. (What challenges has it created)
- Some struggles with forgetting. How is this for you?

3. **When did you start to notice these challenges?**
4. **Does your symptoms have any benefits?**

- In what way?
- Are there anything you would have missed if this/these symptoms disappeared?

5. **Have you noticed if the symptoms have changed throughout your life?**

- In what way?
- Have they changed after you took the course?

6. **When you think about these difficulties that you have described- have you learned or experienced anything that makes you relate to them differently?**

- **NB. Check if they have resources or skills that they use.**

7. **Have the course affected your view on you?**
8. **Many with a dissociative disorder experience confusion and uncertainty about who they are. How is this for you (now)?**
9. **Many describe self-loathing and shame and struggles with accepting themselves.**

How is this for you?

1. **Do you wish for any changes in your future life? What?**

- How do you think you will manage to make them happen?
- Have you learned or experienced anything that you think can affect how you make decisions?

2. **Have you any expectations for your future life?** (Moreoverall.)

- Have this changed the last year?

3. **Is there anything thing that you have not had the possibility to say and that you want to add?**

- Conversation/reflection about participating in the interview. (Dreaded/looking forward to it on beforehand, how was it?)
- Have you felt ambivalent about participating on the interview (degree of inner struggle before and during?)

(Note non-verbal observations during the interview.)

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