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“Driven and Tense, Stressed Out and Anxious”: Clinicians’ Perceptions of Post-Traumatic Stress Disorder Symptom Expressions in Adults with Autism and Intellectual Disability

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ABSTRACT

Introduction: Individuals with autism spectrum disorder (ASD) and intellectual disability (ID) seem to be at increased risk for post-traumatic stress disorder (PTSD), but knowledge is sparse regarding its identification in this population. Previous research indicates that certain symptoms of PTSD may be more easily recognized, and that identifying reexperiencing and avoidance is particularly challenging.

Methods: Interpretative phenomenological analysis was used to explore 18 experienced clinicians’ perceptions of PTSD symptom expression in ASD and ID through individual, qualitative interviews.

Results: Informants provided examples from all symptom groups, but these differed in how frequently they were described. Recognition of reexperiencing may rely on knowledge about individuals’ trauma experience. Avoidance may present in a wider range of ways.

Conclusion: Development of reexperiencing and avoidance may follow different trajectories in this population, contributing to challenges in recognition. Reexperiencing may be more severe in ASD/ID. Implications are discussed in light of current diagnostic criteria.

KEYWORDS

Post-traumatic stress disorder; PTSD; autism spectrum disorder; intellectual disability; assessment

INTRODUCTION

Post-traumatic stress disorder (PTSD) is a common reaction following traumatic events such as sexual violence, witnessed or threatened death, or actual or threatened serious injury (American Psychiatric Association, 2013; Ehlers & Clark, 2000). Individuals with co-occurring autism spectrum disorder (ASD) and intellectual disability (ID) are more frequently exposed to such events (Dinkler et al., 2017; Gotby et al., 2018; McDonnell et al., 2019; Sullivan &

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Knutson, 2000). Recent findings indicate that children with co-occurring ASD and ID are two to three times more likely than typically developing peers to experience maltreatment, and more likely to experience all forms of abuse (McDonnell et al., 2019). Females with ASD seem to have an almost tripled risk of sexual abuse compared to typically developing peers (Gotby et al., 2018), and risk is increased for both females and males with ID (Gil-Llario et al., 2019; Soylu et al., 2013).

In the sample examined by McDonnell et al. (2019), there were maltreatment reports for more than 30% of individuals with co-occurring ASD and ID. While rates of reported abuse were comparable across groups with either ASD/ID or both, reports were more likely to be substantiated in individuals with ID if they did not have a co-occurring ASD (McDonnell et al., 2019). This suggests that ASD involves an additional risk that abuse and trauma are not detected in individuals with ID. Moreover, ASD and ID seem to independently contribute to increasing risk of developing PTSD following potentially traumatic events (Brewin et al., 2019; Kerns et al., 2015; McCarthy et al., 2017; Kildahl et al., 2019; Peterson et al., 2019).

Psychiatric assessment in individuals with ASD and ID is generally challenging (Bakken et al., 2016; Helverschou et al., 2011). Due to these individuals' difficulties with self-report, assessments frequently rely on the recognition of behavioral expressions of psychiatric symptoms (Bakken et al., 2016; Helverschou et al., 2011). Furthermore, individuals with ASD may display symptoms of psychiatric disorder in atypical ways, including changes to ASD symptoms (Bakken et al., 2016; Helverschou et al., 2011; Rosen et al., 2018). Compared to other psychiatric disorders, knowledge regarding identification of PTSD seems particularly limited (Bakken et al., 2016; Kildahl et al., 2019; Rumball, 2019). Moreover, there is an inherent risk of diagnostic overshadowing in these assessments, where symptoms of psychiatric disorder are misinterpreted and attributed, instead, to the underlying conditions (Reiss et al., 1982).

Current criteria for PTSD include four groups of symptoms: intrusion or reexperiencing, avoidance of stimuli associated with the event, negative changes in cognitions and mood, and marked alterations in arousal (American Psychiatric Association, 2013). Of these, alterations in arousal and negative changes in cognitions and mood have been more frequently described in individuals with ASD and ID (Kildahl et al., 2019), suggesting that these symptoms may be more easily observable in this population. This is in line with findings that maltreatment in children with ASD was associated with a higher likelihood of hyperactivity, temper tantrums, and aggression (McDonnell et al., 2019), as well as increased irritability, lethargy, and loss of interest (Brenner et al., 2018). Irritability and angry outbursts have also been described in an adult with ASD and ID following sexual abuse, along with guardedness, anxiety, loss of positive feeling, and indirect expressions of guilt and shame (Kildahl, Helverschou & Oddli, 2020).

However, symptoms involving altered arousal and negative changes in cognitions and mood are not specific to trauma and PTSD, involving a risk that they are attributed, instead, to ASD/ID or other co-occurring conditions such as anxiety or depression (Mevisen et al., 2016; Kildahl et al., 2019; Kildahl, Helverschou & Oddli, 2020). Some symptoms of PTSD and ASD sharing behavioral similarities probably contributes to further increasing this risk of diagnostic overshadowing (Brenner et al., 2018): stereotyped or repetitive behavior in ASD may share surface similarities with repetitive play in PTSD, sensory hypersensitivities in ASD may share similarities with physiological reactions to stimuli triggering trauma memories in PTSD, etc.

Recognition of the more specific symptoms of PTSD may be vital to its identification, and Brenner et al. (2018) found that both intrusive memories and distressing thoughts could be recognized and reported by caregivers who were aware of traumatic experiences in children with ASD. However, caregivers may not be aware that individuals with ASD and ID have experienced a traumatic event, and it is currently unclear how symptoms involving reexperiencing or avoidance may be recognized in individuals with ASD and ID when the traumatic experience is not known to caregivers (Kildahl et al., 2019; Kildahl, Helverschou & Oddli, 2020). There thus seems to be a significant risk that PTSD is not identified if caregivers are not aware of abuse or other potentially traumatic experiences. This is a concern not only because PTSD has implications for care and treatment (Bakken et al., 2014; Brenner et al., 2018; Rumball, 2019; Truesdale et al., 2019), but because the failure to recognize PTSD symptoms may, for example, allow instances of sexual abuse to go on undetected (Kildahl, Helverschou & Oddli, 2020; Rowsell et al., 2013). There is an urgent need for further knowledge on how PTSD symptoms may be recognized in individuals with ASD and ID, particularly in cases where caregivers do not have knowledge of a traumatic event or are unaware of ongoing abuse.

Kerns et al. (2015) have suggested that multi-disciplinary approaches are necessary in the study of PTSD in individuals with ASD. Studies relying on existing criteria and assessment tools may easily overlook atypical or unusual symptom expressions (Daveney et al., 2019; Kerns et al., 2019), indicating the need for more explorative, qualitative approaches to enrich the understanding of manifestations of PTSD in this population. Malterud (2001) suggests that clinicians' knowledge of a disorder is shaped not only by the scientific research literature, but also by their practical experience and the patients they have encountered. Systematic exploration of clinicians' experiences and perceptions concerning a particular group of patients may thus provide important insights, particularly when patients themselves may be unable to convey their feelings and experiences.

Interpretative phenomenological analysis (IPA) is a widely applicable qualitative research methodology that seems well suited for exploration of clinicians'

experiences and perceptions (Smith, 2011; Smith et al., 2009). IPA focuses on how individuals understand and make sense of their lived experience (Smith, 2017), with the researcher “trying to make sense of the participant trying to make sense of their personal and social world” (Smith, 2004, p. 40). Though previously applied in explorations of health care professionals’ experiences (Smith, 2011), no prior IPA study has explored clinicians’ perceptions of PTSD symptom expression in adults with ASD and ID.

The current paper aims to provide directions and hypotheses for further research and guidance for clinicians facing this issue by answering the following research question:

1. How have experienced clinicians perceived symptoms of PTSD being expressed in individuals with ASD and ID?

MATERIALS AND METHODS

Design

IPA was chosen for the current study due to its idiographic, hermeneutic and phenomenological components (Smith, 2011; Smith et al., 2009) to aid in the exploration of possible atypical or unusual symptom expressions. The study was designed as an explorative, in-depth interview study with mental health professionals who had extensive experience conducting psychiatric assessments in ASD and ID.

As the study aims to provide knowledge relevant for clinical assessments and research, the current conceptualization of PTSD may be viewed as a *sensitizing concept* (Blumer, 1954) in the present study. The study was organized in a clinical context, with all informants being well acquainted with psychiatric nomenclature and diagnostic criteria, making these conceptualizations a relevant frame of reference. According to Blumer: “[while] definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggests directions along which to look” (p. 7), indicating that the latter kind of concept may provide a general sense of reference and guidance in approaching an empirical investigation, while at the same time allowing for explorative approaches. Like with hermeneutic activity (Gadamer, 2006), sensitizing concepts may be revised and elaborated in meeting with the various empirical instances of the phenomenon, thus serving to *enrich* (Stiles, 2015) our understanding of concepts such as PTSD in adults with autism and intellectual disabilities.

Participants

Volunteer informants were recruited through use of convenience sampling (Flick, 2006), via a national network for mental illness in individuals with ASD and ID, and by directly contacting clinicians outside the network.

Included informants were all employed in inpatient or outpatient units providing mental health services for individuals with ASD and ID, and were regularly involved in mental health assessments in this population. To obtain a wide range of perspectives, 18 professionals with varying professional backgrounds were recruited from six different hospitals in Norway (14 female, 4 male) (see [Table 1](#)). All informants provided written, informed consent. They were employed either at units specializing in mental health in ASD/ID (11), or at units providing general services for adults with ID (7). Informants had 4–39 years' experience in ASD and ID ($M = 19.9$, $SD = 11.0$), and 4–29 years in mental health issues in this population ($M = 14.3$, $SD = 8.3$). Eleven of the informants had previously trained or worked in more general mental health services, while ten of the informants had previous experience working with individuals with ASD and ID in other contexts than mental health care. At the time of the study, five informants were employed in specialized inpatient units, while the remaining thirteen were employed in outpatient units. Of the latter, four also had previous experience from one of the inpatient units.

Informants were required to have encountered at least one adult with co-occurring ASD and ID who was either formally diagnosed with PTSD, or who had experienced a traumatic event meeting the DSM 5 criterion A for PTSD (American Psychiatric Association, 2013) and had symptoms understood to be associated with this experience. The range of traumatic events reported by the individual informants is presented in [Table 1](#). Most informants reported having encountered between three and ten individuals with ASD and ID and PTSD or trauma-related symptoms. Thirteen informants also thought it was likely they had overlooked trauma in individuals with ASD and ID due to a lack of focus on trauma in this population in the past.

Materials

The interview guide was developed following recommendations from Smith et al. (2009), see [Appendix 1](#). The first author took the lead in its development, collaborating with the remaining authors and discussing and informally piloting it with experienced colleagues. The interview guide primarily contained open-ended questions, inviting informants to reflect on various aspects of their experiences identifying PTSD in this population. Specifically, informants were asked to anonymously describe characteristics, behaviors and symptom expressions in patients they had encountered and how they had understood these. In line with Blumer's understanding of sensitizing concepts (Blumer, 1954), informants were reminded of symptom groups they did not spontaneously provide examples from. Interviews were conducted in line with recommendations from Smith et al. (2009). Follow-up questions and probing were focused on asking informants to elaborate their



Table 1. Informants.

Gender	Profession	Workplace	Total years of experience working with ASD and ID	Years' experience working with mental health in ASD and ID	Levels of ID where PTSD/trauma-related symptoms were encountered	Trauma events reported
1 F	Specialist Psychologist	S	20	9*	Mild, moderate, severe	Sexual abuse, violence, neglect, rape, severe bullying
2 F	Specialist Psychologist	S	12	10*	Mild, moderate	Violence, death threats, sexual abuse, war and bombings
3 F	Intellectual Disability Nurse	S	25	14	Moderate, severe	Sexual abuse, violence, institutional abuse
4 F	Psychiatrist	S	8	8*	Moderate, severe	Violence, sexual abuse, neglect, institutional abuse
5 F	Psychiatrist	S	6	6*	Mild, moderate, severe, profound	Sexual abuse, violence, neglect
6 M	Intellectual Disability Nurse	S	29	15	Mild, moderate	Sexual abuse, rape, neglect, violence, severe bullying
7 F	Nurse Practitioner	S	24	24*	Mild, moderate, severe, profound	Violence, institutional abuse, sexual abuse
8 M	Psychiatric Nurse	S	20	20*	Mild, moderate	Sexual abuse, violence, severe bullying
9 F	Intellectual Disability Nurse	G	24	12	Mild, moderate, severe	Violence, witnessing violence, sexual abuse, neglect
10 F	Specialist Psychologist	G	5	5*	Mild	Domestic violence
11 F	Intellectual Disability Nurse	G	34	29	Mild	Sexual abuse
12 F	Intellectual Disability Nurse	G	39	28	Mild, moderate, severe	Sexual abuse
13 F	Psychiatric Nurse	S	10	10*	Mild, moderate	Violence, neglect, witnessing violence
14 F	Psychologist	S	4	4*	Mild, severe	Sexual abuse, violence
15 M	Intellectual Disability Nurse	S	23	2*	Mild, moderate, severe	Rape, sexual abuse, violence, war and bombings
16 M	Intellectual Disability Nurse	G	37	28	Mild, moderate, severe, profound	Sexual abuse, neglect, violence, rape
17 F	Nurse Practitioner	G	14	14*	Moderate	Violence
18 F	Special Educator	G	25	16	Moderate, severe	Sexual abuse, violence

"S" or "G" for workplace indicates whether the clinician was employed by in a specialized psychiatric service for individuals with ASD and ID (S), or a generalized service for individuals with ID (G) where participation in mental health assessments was included in their regular tasks. An asterisk (*) indicates that the informant had previous experience training and working in more general mental health services prior to transferring to mental health services for individuals with ASD and ID.

descriptions of symptoms and behaviors, provide further examples, as well as whether they had seen other manifestations of the symptom concerned.

Procedure

The study was approved by the Data Protection Official at the Oslo University Hospital. Informants provided written consent and received a copy of the interview guide prior to the interview. All interviews were completed face-to-face, audio recorded and transcribed verbatim by the first author. Interviews lasted 39–92 minutes ($M = 61.3$, $SD = 17.1$). Three random transcripts were checked against the audio recording in their entirety by a colleague of the first and third authors who was not involved in the project, but has extensive experience transcribing qualitative interviews. No discrepancies were identified. Informants were not compensated for their participation.

Analysis

While the number of informants may be high for an IPA study, IPA is considered well-suited for analysis in samples of this size (Smith et al., 2009). The first author took the lead in the analysis, discussing emergent themes with the second and fourth author until conceptualizations were developed. All authors read the full transcripts of at least five interviews.

Interviews were analyzed individually in order of completion following the procedures described by Smith et al. (2009). Transcripts were read and re-read, with initial descriptive notation in the right-hand margin. This process was repeated several times with different foci before emergent themes were developed and noted in the left-hand margin. All suggested themes were then transferred to word processing software to identify connections and clusters for each interview. Subsequent search for connections across interviews were carried out after individual analyses of all interviews had been completed. All themes from individual interviews were included in informal discussion between authors one, two and four for further development. The primary strategies used in this process were abstraction and subsumption, but also other strategies described by Smith et al. (2009) were used. Final conceptualizations from the preliminary analysis were based on consensus between the authors. Author three was introduced to the process following the preliminary analysis, reading five transcripts prior to assessing the quality and representativeness of the themes. No major changes were done following the introduction of author three to the process.

In accordance with the idiographic and phenomenological principles of IPA (Smith et al., 2009), information from the informants was not weighted differently according to their professional background or experience. No new

themes emerged after interview 11. To avoid overlooking rare or unusual symptom expressions, no limit for recurrence of themes was set prior to analyses (see Smith et al., 2009). However, in IPA samples of this size, density of evidence should be demonstrated by at least three extracts for each theme (Smith, 2011). Themes not substantiated by extracts from at least three informants were therefore not included in the final conceptualizations, and the themes presented all appeared in at least a third of the interviews.

Following the identification of themes, superordinate themes were developed. In line with the understanding of the current conceptualization of PTSD as a sensitizing concept (Blumer, 1954), with all informants having prior knowledge of PTSD criteria and interviews taking place in a clinical context, superordinate themes regarding symptom expressions roughly corresponded to the DSM 5 PTSD symptom groups (American Psychiatric Association, 2013). A master table of themes, superordinate themes and extracts from all interviews was created and reviewed by all authors. This table was used to identify prevalence. No meaningful differences were identified based on informants' professional background, unit of employment, or amount of experience.

The number of themes identified was high. Smith (2011) maintains that in such cases it is preferable to divide findings between multiple papers to be able to do justice to the presentation of each theme. Clinicians' understanding of PTSD and its identification, and their preferred assessment strategies in individuals with ASD and ID, will therefore be presented in a separate paper (Kildahl, Helverschou, Bakken et al., *in press*). This article presents themes describing clinicians' perceptions of PTSD symptom expression in this population, and their understanding of these expressions.

RESULTS

Emergent themes are presented in Table 2. Prevalence of themes and their distribution among individual informants are presented in Table 3. Recommendations by Smith (2011) were followed in choice of extracts, with all informants being represented by at least one extract and each theme being substantiated with extracts from at least three informants. In the extracts below informants are identified by numbers corresponding to numbers in Tables 1 and 3. Extracts were translated from Norwegian and minimally edited for clarity by the first author during finalization of the manuscript, following completion of the analysis. All translations/edits were checked by all authors. Because the superordinate themes roughly corresponded with the DSM 5 PTSD criteria groupings, they are presented in accordance with the order of these (American Psychiatric Association, 2013).

Table 2. Emergent themes.

Superordinate themes	Emergent themes
Reexperiencing: Co-occurring abrupt changes to alertness and responsivity	Reexperiencing may present as a wide range of behavioral expressions Verbal and behavioral reenactment Sudden, unexpected episodes of aggression or self-injury
Avoidance is expressed in a wide range of ways	Specific avoidance of trauma triggers Unspecific or global avoidance Lack of planned avoidance
Negative changes to mood and cognition: The world is unsafe and negative feelings predominate	Fundamental insecurity in other people Negative emotions: Sadness and hopelessness, guilt and shame Loss of positive feelings and vitality Negative self-image
Alterations in arousal are observable as tension, difficulties relaxing, and reduced tolerance for discomfort and frustration	Visibly alert, tense and anxious Restless and unable to calm down Sleep disturbances Reactive aggressive and self-injurious behaviors Irritable and angry

Reexperiencing: Co-Occurring, Abrupt Changes to Alertness and Responsivity

A wide range of examples involving reexperiencing was provided, though two informants doubted they had observed reexperiencing symptoms in this population. Examples seemed to have in common that they involved abrupt, co-occurring changes to alertness and responsivity, with some degree of interpretation of patients’ behavior being necessary for these to be understood as reexperiencing. These interpretations frequently seemed to depend on existing knowledge about individuals’ previous trauma experiences. According to informants, behavioral manifestations of reexperiencing included verbal and behavioral reenactments, aggression and self-injury, but could present in a wide range of ways.

Reexperiencing May Present as a Wide Range of Behavioral Expressions

Behavioral expressions of reexperiencing varied from dramatic and easily observable, to requiring more careful observation. Interpretation of behavior was necessary to identify these expressions, and several informants expressed that it was difficult to discern whether their interpretations had been correct or not. “She’s in a good mood when they go out and then suddenly her gaze just changes, her pupils become dilated and she starts repeating things in an aggressive tone and seems angry. Then suddenly it’s just over” [13]. What was understood as reexperiencing could thus involve clearly observable behavioral changes, often predictable and repeated, in addition to the aforementioned changes to alertness and responsivity. To an outside observer, however, the association with trauma may not have been obvious. “And we

Table 3. Distribution and prevalence of themes and superordinate themes.

Themes and superordinate themes	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Prevalence
Reexperiencing: Co-occurring, abrupt changes to alertness and responsibility	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	16
Reexperiencing may present as a wide range of behavioral expressions	X*	X*	X	X	X*	X*	X*	X*	X*	X*	X*	X*	X*	X	X	X	X	X	14
Verbal and behavioral reenactment	X	X	X*	X*	X*	X	X	X	X	X	X*	X*	X	X	X	X	X	X	10
Sudden, unexpected episodes of violence or self-injury	X*	X*	X*	X*	X*	X	X	X	X	X	X	X	X	X	X*	X*	X	X	8
Avoidance is expressed in a wide range of ways	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	17
Specific avoidance of trauma triggers	X*	X	X*	X	X	X	X	X	X*	X	X	X*	X*	X*	X*	X*	X	X	13
Unspecific or global avoidance	X*	X	X	X	X	X*	X	X	X	X	X	X	X	X*	X	X	X*	X	12
Lack of planned avoidance	X	X	X	X	X	X*	X*	X*	X*	X	X	X	X	X	X	X	X*	X	8
Negative changes to mood and cognition: The world is unsafe and negative feelings predominate	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	18
Fundamental insecurity in other people	X*	X	X	X	X*	X	X	X	X	X*	X	X	X	X	X*	X	X	X	16
Negative emotions: Sadness and hopelessness, guilt and shame	X	X*	X*	X	X	X*	X*	X*	X	X	X	X	X	X	X*	X	X	X	16
Loss of positive feelings and vitality	X	X	X*	X*	X	X	X	X	X	X*	X	X	X*	X	X	X	X*	X	15
Negative self-image	X*	X	X*	X	X*	X	X	X	X	X	X	X	X*	X	X	X	X	X	13
Alterations in arousal are observable as tension, difficulties relaxing, and reduced tolerance for discomfort and frustration	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	18
Visibly alert, tense and anxious	X	X	X*	X	X	X*	X*	X	X	X	X	X	X	X	X	X	X	X*	18
Restless and unable to calm down	X	X	X*	X*	X	X	X*	X	X	X	X	X*	X	X	X	X	X	X	16
Sleep disturbances	X	X	X*	X	X	X	X	X	X	X	X*	X*	X	X	X*	X	X	X	14
Reactive aggressive and self-injurious behaviors	X	X	X	X*	X	X	X	X	X*	X	X*	X	X	X	X	X	X	X	14
Irritable and angry	X	X	X	X	X	X*	X	X	X	X*	X	X	X	X*	X	X	X	X	13

The table shows total prevalence, i.e. how many informants contributed to each theme and superordinate theme, as well as which individual informants contributed. Informant numbers (1–18) correspond to those provided in Table 1 and with the extracts in the results section. Asterisks (*) indicate the distribution of the extracts provided in the results section, demonstrating that all informants are represented by at least one extract and that at least three extracts were provided for each theme.

were about to lead him into his room and someone turned off the light, and then he just snapped completely. [...] He started sweating and started acting out and showed signs of anxiety and panic” [7]. This example showing the suddenness and dramatic change described by several informants involved a nonverbal patient who had previously been repeatedly locked inside a dark room. “Intense anxiety: Screaming, sweating, you could tell they were afraid. Arms flailing and running away” [9]. Most examples involved clear signs of distress as well as physiological reactions, and many included attempts to escape. “If her family is mentioned, she sometimes has a change in her breathing pattern which sounds as if someone is trying to calm themselves. She just sort of disappears ... ” [2]. Changes to alertness and responsivity could thus be more subtle, with recognition requiring careful observation. “It often started with wandering, increasing restlessness, expressions of despair, and then suddenly you aren’t able to reach them. They’re in a world of their own” [1]. What informants understood as reexperiencing could also develop more gradually, not necessarily involving a dramatic onset. This example involved gradually increasing alertness until an apparent threshold was reached, where the patient’s responsivity also changed. “Some of them can tell us about flashbacks [...] He has these visions, I think he dreams it quite often, that his mother is coming toward him with a knife. He describes signs of anxiety accompanying these visions” [2]. Even if patients had been able to verbally disclose signs of reexperiencing, interpretation in light of trauma history and co-occurring alertness had often been required.

Verbal and Behavioral Reenactment

Several informants described verbal and behavioral reenactments of traumatic events. These included observable changes to alertness and responsivity, but recognition of behavior as reenactment often seemed to rely on knowledge of trauma histories.

During phases with more symptoms, these episodes happened more frequently. She would scream “take that dick away” or “take your hands off me”. You sort of saw her reliving it. It was hard to reach her and help her get out of it [9].

Reenactments seemed to be more easily recognized if they included verbal utterances. Changed responsivity was described by several informants as patients being difficult to reach. “There were these repetitive phrases, like ‘no, no’ or ‘man’. The same phrases in similar situations, for instance, when she was going to bed” [3]. Reenactments in patients with limited verbal language could thus be harder to recognize, with identification requiring careful observation. In this example, the repeated use of the same phrases in a similar situation, along with changes to responsivity and alertness, led the informant to interpret these phrases as behavioral signs of reexperiencing. “She has these sexualized behaviors including inserting things down there.

And she doesn't know a lot about sexuality, but it seems kind of stressful and hectic. She doesn't seem to enjoy it" [12]. Sexualized behaviors that did not seem pleasurable were mentioned by several informants, with examples involving patients seeming under pressure to perform these.

I met one patient who sort of threw himself out the door while using a different voice. Those who knew his life history thought this was something that he had experienced many times. He sort of acts it out. [...] I wouldn't have understood it if I hadn't spoken to someone who knew him well [5].

Knowledge of patient's life stories, including trauma history, was thus viewed as necessary for informants to be able to recognize reenactments.

Sudden, Unexpected Episodes of Aggression or Self-Injury

Certain episodes involving sudden, aggressive outbursts or self-injury were understood as behavioral expressions of reexperiencing. These were different to aggression or self-injury described as expressions of altered arousal, primarily by also involving changed responsiveness, and the suddenness with which they appeared. These episodes also involved an apparently more severe loss of behavioral control. "He just blacks out and it's like he looks right through you and just attacks. There's nothing you can do. We've tried all kinds of things to get him out of it, but it's impossible to reach him" [15]. Episodes thus involved patients being difficult to reach, with staff withdrawing rarely contributing to calming the situation. "If they become aggressive and sort of disappear, it may be reexperiencing. It's difficult to know. But it's easier to think of it and interpret it as such if you know exactly what the trauma has been" [1]. Recognition of these episodes as trauma related frequently depended on knowledge of trauma histories. "She got very, very afraid and hit herself on her body and on her head, scratched her face and screamed 'no' or 'don't' [...] she was in a sort of fight-mode, but directed toward herself" [3]. Similar patterns were thus described for self-injury and aggression.

Avoidance is Expressed in a Wide Range of Ways

Informants described having encountered patients who specifically avoided stimuli associated with known trauma experiences. Moreover, informants described avoidance following trauma manifesting in more generalized ways, as well as individuals showing an apparent lack of planned avoidance.

Specific Avoidance of Trauma Triggers

Recognition of symptoms involving specific avoidance frequently relied on caregivers having knowledge of the traumatic event, as recognition seemed to involve some degree of behavioral interpretation: "We knew she had been

a victim of sexual abuse. She had difficulties showering and didn't want help washing, particularly intimate hygiene" [3]. Sexual abuse was understood as leading to avoidance of situations that reminded the patient of the abuse, even though she could not express this verbally. "After getting beat up, he did not want to walk the streets of that town" [14]. "I've met some who've suddenly started refusing to sleep in their beds following abuse" [16]. Descriptions of specific avoidance included both geographical sites and places within patients' homes, and types of situations: "She often refused to change her clothes or be naked in specific situations" [9]. "With one of them, it was when people coughed. He got aggressive and threatening to get them to stop" [1]. In a few cases, avoidance had extended to patients attempting to control caregivers' actions to avoid stimuli they found distressing, resulting in avoidance being expressed as socially inappropriate behaviors.

Unspecific or Global Avoidance

Avoidance following a traumatic event was described as being expressed in more generalized ways in some individuals, with patients displaying apparently unspecific or global avoidance. Several informants suggested this happened due to trauma interacting with coping and information processing strategies associated with ASD. Informants seemed to understand this as reflecting the level of anxiety experienced by these patients. More global avoidance could be challenging to associate with PTSD if its development had not been investigated.

And it was a sort of avoidance, but it was very direct and specific "I'm not going back to school" or "I don't want to go home". Specific utterances that weren't immediately understood as avoidance, but maybe more as expressions of willfulness. [...] They quickly became more general: "I'm never going to school" or "I'm never going home again" [14].

The informant seemed to understand avoidance initially expressing as specific to the trauma situation, with the patient quickly generalizing from not wanting to do something in the present moment to never wanting to do it again. According to the informant, this may easily have been misinterpreted as obstinacy. "It often starts gradually. Something happens and they just stop doing things, can't be with other people, and just stay in bed – isolating themselves" [1]. Informants suggested that the development of global avoidance could be a gradual process following trauma, possibly associated with a lack of ability to regulate discomfort, which had not been understood and compensated for by patients' surroundings. "I think she just experienced that her life got harder and harder, and in the end she didn't have any way out" [6]. Global avoidance was thus also seen as reflecting a sort of helplessness. "He just avoids everything. He's inside his apartment all day and has been for

three years. He can go outside during summer, but then it's just right outside his window. He avoids anything that isn't safe and familiar" [17]. This informant understood this severe avoidance as an expression of the patient's level of anxiety.

Lack of Planned Avoidance

Several informants described patients displaying a conspicuous and somewhat surprising lack of planned avoidance following trauma. Rather than avoid situations involving known trauma triggers, these patients would enter them voluntarily. When faced with trauma triggers they would show signs of altered arousal and spontaneously attempt to escape the situation. They thus repeatedly displayed symptoms of apparent reexperiencing without attempting to protect themselves against these in any observable way. "Avoidance in those with autism and intellectual disability often isn't planned, I think. It's more triggered by the situation, and then they try to get away" [7]. These responses were understood as avoidance interacting with autism-related difficulties planning and generalizing previous experiences to future situations. "They would just run away or scream if they saw something they were afraid of. One of them was scared of men following the abuse, so if she saw a man she would just run" [9]. This pattern was repeated, and patients failed to develop specific avoidance, even if it was obvious to care staff what triggered these responses.

I've been told by a patient about having been raped at a party, and then I suggested that maybe you shouldn't go to the party this weekend because the guy is going to be there. She agreed. And then she got an SMS from the rapist promising he wouldn't do it again, and she agreed to come to the party and then she got raped again [16].

Lack of planned avoidance thus included examples of victims of abuse seeking out perpetrators, which may be understood as reflecting a sort of social naivete in combination with the failure to develop specific avoidance.

Negative Changes to Mood and Cognition: The World is Unsafe and Negative Feelings Predominate

Negative emotions, lack of positive emotions and vitality, and negative self-image were all described by informants as observable following trauma in individuals with ASD and ID. Moreover, informants described a somewhat striking fundamental insecurity in other people characterizing these patients.

Fundamental Insecurity in Other People

Informants described patients seeming generally skeptical and suspicious, displaying what was understood as a fundamental insecurity in other people.

Its expression varied somewhat with the level of ID, with patients with mild ID often being able to express it verbally and those with more severe levels of ID displaying it by social withdrawal. Insecurity in other people was further reflected in patients ascribing negative intentionality to others, expressing that others did not wish them well. In some cases this was understood as having developed into paranoid or hostile attitudes toward staff or family members. “There’s a basic suspiciousness, guardedness toward other people. Are you after me in a bad way?” [10].

If someone said something, it was sort of “he said it because he doesn’t wish me well” or “he’s a bad person”. If somebody said “no”, she quickly concluded that that person did not like her, and then she didn’t want anything to do with them [14].

Negative interpretations were described as involving patients quickly assuming negative intentionality in others. This intentionality could be generalized into a negative interpretation of the entire social relationship with a staff member following a single interaction.

They trust people less. It varies with degree of ID. In mild ID, it’s like in the general population; they’re more guarded and skeptical. In more severe ID, they might withdraw more and be more uncertain about people they don’t know [5].

Fundamental insecurity was thus understood as an expression of how unsafe other people made these patients feel and how challenging it was for them to trust others. “It takes longer to build trust and make them feel safe [...] longer than for other psychiatric disorders” [1]. This fundamental insecurity was seen as characterizing these patients, possibly differentiating them from patients with ASD, ID and other psychiatric disorders.

Negative Emotions: Sadness and Hopelessness, Guilt and Shame

Informants described negative emotions as typical for these patients, particularly sadness, hopelessness, guilt and shame. Hopelessness was reported to occasionally involve suicidal ideation. Verbal expressions of guilt and shame were rare, but informants had interpreted behaviors or utterances by patients as expressions of these feelings. Negative emotions were described throughout the ID spectrum, but were seen as more challenging to identify and differentiate in those with more severe levels of ID. “They have little hope that life will ever be good. At least one of them, she has negative and pessimistic thoughts about it ever feeling good to be her” [2]. Though expressed indirectly, this was understood as an expression of hopelessness. “They are deeply unhappy. It’s characteristic for this group. They’re deeply unhappy, have lost faith, don’t trust their surroundings” [7]. Sadness and unhappiness were seen as typical. “Hopelessness and darkness and a situation that you can’t see any solution to, sort of. It

was really dark” [6]. Informants had observed negative emotions and hopelessness to become severe and persistent: “The pain they’re experiencing. [...] And the despair, it’s different. It’s strong. It’s unbelievably strong” [8].

It sort of wasn’t depressive mood all the time, because he had some interests he was able to have fun with, if we managed to get into it. But still there was a sort of depressive cloud looming in the background. And it didn’t take much to bring it out and for him to say “now this day is ruined” [14].

Hopelessness and negative emotions were thus not all-encompassing in all cases, but could be expressed in varying degrees of severity. “One of them had a lot of guilt. He often asked if he had done something wrong and whether I was going to tell him off” [14]. Preoccupations with doing something wrong or getting corrected was understood as an expression of guilt by this informant.

Something happened in her eyes. We could observe that something negative was afoot, and then there was negative self-directed speech or self-injurious behavior like hitting her head. You could tell that she had some feeling or thought that wasn’t good, but it was difficult to grasp [3].

While more challenging to differentiate in more severe levels of ID, negative emotions were described also in these patients.

Loss of Positive Feelings and Vitality

Informants described patients as being characterized by a loss of positive feelings and vitality. This could be expressed as a sort of emotional flatness, where it was difficult to discern any expression of emotion in patients whatsoever.

We spent a lot of time trying to figure out whether she showed any sign of feeling good. It was difficult to see, she seemed to be feeling bad so much of the time. When the search for positive emotional expressions is that challenging, it says something about how difficult their lives are [4].

Informants described occasionally having to actively search for expressions of positive emotions in these patients, because they could be challenging to identify. “Vitality. And vitality affects. I see more of that in patients who haven’t experienced trauma” [10]. Lack of vitality and positive feelings were viewed as possibly differentiating patients who had experienced trauma from other patients with ASD and ID. “I don’t think I’ve ever seen him relaxed or happy” [13], indicating a stability to this lack of positive expressions that could easily be misunderstood by someone who had not known them prior to the trauma event. “Emotionally he’s very flat all the time. Except when he’s scared, then you can tell that he’s scared” [17]. Lack of positive emotionality was also described as patients seeming to show little emotion.

Negative Self-image

What informants understood as expressions of negative self-image was described throughout the ID spectrum. Individuals with mild to moderate ID were frequently able to express this verbally in a way that had made informants able to infer that they did not seem to like themselves very much. However, it could also be expressed in more indirect ways, such as patients talking about how others saw them negatively, or as negative, self-directed speech. “Some are very guilt-ridden and ‘sorry, everything is wrong with me’” [1]. Ideas about there being something wrong with them were viewed as one expression of negative self-image, while social withdrawal could be another: “She concluded that she wasn’t worth anyone’s time” [6]. “They think he’s stupid and sick, he thinks they’re saying only negative things about him. But I can’t remember him ever saying that he feels that way about himself” [13]. This informant seemed to understand this as the patient projecting his own ideas about himself on other people. “Two of them had negative self-directed speech. I remember one of them shouted at himself, shouting ‘no’ and his own name repeatedly” [3]. Thus, in more severe ID, repeated examples of negative, self-directed speech were interpreted as expressions of negative self-image.

Alterations in Arousal are Observable as Tension, Difficulties Relaxing, and Reduced Tolerance for Discomfort and Frustration

The only theme in the current study involving contributions from all informants concerned altered arousal: Patients being visibly alert, tense and anxious. Moreover, expressions of restlessness, sleep disturbances, irritability and anger, as well as aggression and self-harm were all described as possible manifestations of altered arousal following trauma in this population.

Visibly Alert, Tense and Anxious

All informants provided examples of patients displaying observable alterations in arousal, seeming visibly alert, tense and anxious. Several informants described this to be what had struck them at first encounter, understanding it as signifying a chronically altered state of arousal. “They have a lot of anxiety, generally alert, guarded. They seem extremely driven and tense, stressed out and anxious” [3]. This state was viewed as characteristic. “He gets visibly afraid when he’s outside. We can tell that his whole body is mobilizing to cope with something” [17]. Alertness and anxiety could be observed in body posture and muscle tension. “She was anxious and would pee herself and everything. She had that extreme jumpiness and readiness, always on guard, which you don’t see as much of in those with anxiety disorders. She was sort of sneaking around the corners” [7]. Visibly increased startle-responses were described, as well as alertness and tension being continuously present. “He

has more intense repetitive behaviors, and he hyperventilates. And if he is asked to calm down because he's disturbing others, he gets really stressed out and desperate" [18]. Increased repetitive behaviors were viewed as indicators of altered arousal, particularly if this occurred in conjunction with other signs of altered arousal. "When you're speaking, you can observe that their attention is not completely with you. If there's a sound, they're interrupted and you have to help them back on track" [6]. Thus, alertness could also be observed as distractibility.

Restless and Unable to Calm Down

Patients were described as restless, including an apparent inability to halt motor activity. This was generally understood as an expression of patients' lack of ability to regulate altered arousal states. It could be observed as chronic wandering, but also in difficulties waiting, frequent interruptions, or as an inability to calm down or relax. Several informants used the word *driven* to describe restlessness, indicating that in their view it was experienced as neither voluntary nor pleasurable by patients.

She wandered, and we worked more or less continually to help her sit down. She wandered all the time. [...] Many couldn't sit through a meal either; they had to get up and walk a little and then come back and eat some more [3].

Restlessness could thus be expressed both as continuous motor activity, but also as an inability to finish routine activities such as eating a meal. "They get sort of hectic and can't stay calm or wait" [12]. Apparent impatience was understood as one expression of this restlessness. "She seemed so driven all the time. The only place we could get her to relax was in the car" [4]. This informant described how going on car rides had been the only way to help the patient stop wandering. "They can't relax, they move a lot. And if they're in a wheelchair you can still see it, because they're sort of edgy" [7]. Restlessness was thus understood as expressing in varying kinds of motor activity.

Sleep Disturbances

Sleep disturbances were described by most informants and were understood as an expression of altered arousal. In particular, patients in an apparently restive state suddenly getting up, seeming alert and restless, was seen as a possible indication that sleep disturbances were associated with PTSD: "At least two of them had sleep difficulties that I think of as typical for trauma: They were about to fall asleep and then suddenly just jumped out of bed" [3].

You often see that they suddenly wake up, and whether it's nightmares or something else, I don't know, but it's very sudden. They sort of wake up and are

immediately on the way somewhere, but it's not because they want something, it's because of restlessness [15].

This pattern was not only described when going to bed, but also when patients woke up during the night. "She used to lie on the floor by the door, but when staff started sitting with her, she managed to stay in bed and relax. Our interpretation was that she was afraid when she woke up during the night" [12]. How patients responded to interventions aimed to make them feel safe thus aided informants in connecting sleep difficulties to PTSD.

Reactive Aggressive and Self-injurious Behaviors

Numerous descriptions of aggression and self-injurious behavior were provided by informants, some of which were understood to be associated with altered arousal and reactivity. Because these patients were generally tense, any stimuli perceived as a disturbance could elicit such behaviors, including stimuli that staff did not notice at first. Informants seemed to understand self-injurious and aggressive behaviors associated with arousal and reactivity as attempts to manage discomfort and alertness. These behaviors were described to occur throughout the ID spectrum, with level of ID affecting their expressions.

Even in a calm situation if someone just entered through a door, she would just attack the staff or herself. We didn't always understand what triggered it. [...] All of us walked around with scratch marks for a while. It didn't feel like she wanted to hurt us, we understood it more like clinging, that she was desperate for physical contact [4].

This informant understood this apparently aggressive behavior as the patient attempting to cling to staff because she was afraid. "It came if they were very confused and anxious, if you got too close or ... then they could act out by hitting or pushing or things like that" [9]. A similar understanding was thus expressed regarding patients pushing or hitting staff. "She would frequently hit her head or scratch herself [...] any sound could trigger it" [11]. This informant described the patient's alertness apparently interacting with her prior hypersensitivity to sound, with sounds leading to self-injurious behaviors when the patient was in an alert state. "The self-injurious behavior was new for him. It appeared following the abuse. He hit himself with his hand all over his body and slammed his head against the floor" [9]. Several informants described having observed a temporal association between abuse and development of self-injurious behaviors, particularly in more severe levels of ID.

Irritable and Angry

Altered reactivity could be expressed as irritability and anger outbursts. Informants seemed to understand this similarly to how they understood

aggression due to altered arousal; as expressions of discomfort and distress. Examples involving observable irritability more frequently seemed to concern individuals with mild to moderate ID.

Irritability was reported in all cases. It was probably what was easiest to see, as it was almost always present. You felt you had to watch what you said and did if you were with them, because it felt like you were always balancing, always on the edge, like they were about to explode all the time. There was no buffer [14].

Irritability was understood as an expression of the patient's lack of capacity to manage disturbances or things not proceeding according to plan. "A lot of anger and acting out [...] but it was more connected to this sensitivity or guardedness. They are sort of ready to attack" [10]. "They're so vulnerable that everything hurts" [6]. Informants thus seemed to understand also anger in these patients as expressions of individuals' more or less reflexive attempts at protecting themselves.

DISCUSSION

The superordinate themes roughly corresponded to the DSM 5 PTSD criteria groups (American Psychiatric Association, 2013), and informants provided numerous examples of symptoms from all groups. However, individual themes did not directly correspond to the individual criteria within these groups: Examples were unequally distributed among criteria, with behaviors pertaining to certain, specific criteria rarely being described. Moreover, examples included qualitative aspects of symptom presentation that seemed to differ compared to other patients with PTSD. This suggests that informants viewed PTSD in adults with ASD and ID as identifiable and conceptually equivalent to PTSD in other patient groups, but had experienced symptom expressions to differ due to ASD and ID. In line with previous suggestions that these are the most easily observable symptoms of PTSD in this population (Kildahl et al., 2019), examples involving alterations in arousal and negative changes to mood and cognition were described by all informants. Knowledge regarding individuals' trauma experiences and interpretation of behavior were seen as important to identify the more PTSD-specific symptoms reexperiencing and avoidance, underlining the need for psychiatric assessment in this population to be trauma sensitive, thorough, and multi-dimensional.

Challenges recognizing and identifying reexperiencing and avoidance in individuals with ASD and ID have previously been suggested to relate to these symptoms' intra-psychic nature and patients' lack of verbal abilities (Kildahl et al., 2019; Rittmannsberger et al., 2019). Current findings indicate that this may only be a partial explanation, as development of reexperiencing and avoidance may follow different trajectories in some individuals with ASD

and ID and thus be expressed in a wider range of ways. Most examples of reexperiencing included abrupt, co-occurring changes to alertness and responsivity, descriptions which seem to be in line with the “dissociative reactions (flashbacks)” criterion for reexperiencing (American Psychiatric Association, 2013). However, also distress and physiological reactions at exposure to external triggers were described. There were few examples involving less severe reexperiencing symptoms such as intrusive memories. Possible explanations include the latter symptoms being more challenging to observe or identify due to their intra-psychic nature, as well as interviews focusing on recognizable behavioral expressions. However, it is also possible that ASD and ID are associated with an increased risk that reexperiencing symptoms become more severely intrusive and thus more frequently manifest as flashbacks.

It has been suggested that reexperiencing symptoms are unlikely to depend on a certain level of cognitive or verbal ability (Kildahl et al., 2019). In line with this, descriptions from informants included examples of behavior understood as reexperiencing in individuals with severe ID and limited verbal language skills. Reexperiencing seems to develop due to the neural and cognitive processing of traumatic experiences, with trauma memories being stored in an involuntary perceptual memory system distinct from ordinary episodic memory (Brewin, 2015; Whalley et al., 2013). Sensory or perceptual processing of an experience leads to the formation of fragmented or disjointed memories that are poorly contextualized and primarily consists of sensory impressions (Ehlers & Clark, 2000; Halligan et al., 2002; Kleim et al., 2008; Sündermann et al., 2013). Findings by Sündermann et al. (2013) indicate that lower verbal intelligence is associated with enhanced sensory or perceptual processing of distressing events, suggesting that individuals with lower verbal intelligence may be more susceptible to development of reexperiencing symptoms. While the current study did not provide any conclusive answers as to how to recognize reexperiencing symptoms in individuals with ASD and ID when trauma is not known, the findings suggest that abrupt, co-occurring changes to alertness and responsivity deserves further investigation. Clinically, it may be particularly important to investigate such behavioral expressions if they occur in the context of other behaviors or verbal utterances that are unusual for the individual, difficult to understand, or seem unrelated to their current context.

Reexperiencing manifesting as behavioral reenactments is included as a possibility in the adapted criteria for PTSD in individuals with ID in the Diagnostic Manual – Intellectual Disability 2 (DM-ID 2; McCarthy et al., 2017). While reenactments of traumatic events may be observed during play in typically developing children (American Psychiatric Association, 2013), examples elicited in the current study seem to be more spontaneous and uncontrolled than such reenactments in children (Scheeringa et al., 1995).

The subjective recognition of an experience as an intrusive memory may depend on the ability to use contextual cues in interpretation of experience, and the ability to separate subjective experience from objective reality (Ehlers & Clark, 2000). According to theories of emotional development (Sappok et al., 2014), individuals with ASD and moderate, severe or profound ID may be unable to understand that their subjective experience does not constitute objective reality. Without access to contextual cues aiding in the recognition that the current situation is different to the trauma situation, these individuals may be experiencing trauma memories differently, possibly as a re-occurrence of the traumatic incident. They may thus be affected by reexperiencing symptoms similarly to how others are affected by repeated trauma exposure. However, further research is needed on the characteristics of reexperiencing in this population.

Avoidance was described as expressing in a wider range of ways, involving either specific avoidance of trauma triggers, development of more general or unspecific avoidance, or a somewhat surprising lack of planned avoidance. Current PTSD criteria for preschool children do not require the presence of specific avoidance (American Psychiatric Association, 2013), and it is possible that these criteria may also be applicable for individuals with ASD and ID; particularly those with moderate, severe or profound ID (McCarthy et al., 2017). This is in line with previous suggestions that manifestation of PTSD in adults with developmental disabilities may in some aspects resemble manifestations in typically developing children (McCarthy, 2001; Mevissen et al., 2016). Specific avoidance of trauma triggers may require the ability to associate feelings of discomfort with specific contextual stimuli, as well as the ability to differentially connect these stimuli to possible future experiences of discomfort, and subsequently use this association to guide behavior. This is likely to be challenging for many individuals with ASD and ID (Robic et al., 2015). These challenges may lead to either over-generalization of discomfort and thus more global avoidance strategies, or failure to generalize discomfort to future situations and an apparent lack of planned avoidance of distressing stimuli.

For negative alterations in cognitions and mood, descriptions from informants seemed to revolve around some, but not all, corresponding DSM 5 criteria (American Psychiatric Association, 2013). Persistent and exaggerated negative beliefs or expectations about oneself, others, or the world were frequently described, as were negative emotional states, diminished interest or participation in activities, and inability to experience positive emotions. Feelings of detachment or estrangement were not directly described, but there were numerous examples involving social withdrawal or isolation. Distorted cognitions about the cause or consequence of the traumatic event, including self-blame or shame, were described by few informants and usually as occurring in indirect manners, requiring interpretation on

clinicians' part. This is in line with previous descriptions from an adult male with ASD and ID who had experienced sexual abuse (Kildahl, Helverschou & Oddli, 2020), suggesting that these emotions may be difficult to grasp for individuals with ASD and ID. Finally, inability to remember aspects of the traumatic event was not described by any of the informants, but this may be due to this symptoms' exclusively intra-psychic nature.

Behaviors relating to all diagnostic criteria concerning altered arousal and reactivity (American Psychiatric Association, 2013) were described by informants, but few examples involving concentration problems and exaggerated startle response were obtained. Self-injury, irritability/angry outbursts, and sleep problems are common issues in individuals with ASD (Oliver et al., 2017; Samson et al., 2014; Verhoeff et al., 2018), and do not specifically relate to trauma and PTSD. However, informants suggested that the hypervigilance seen in trauma-related disorders in this population may differ from the physiological activation seen in anxiety disorders by being more chronic, which may be in line with previous findings that "persistent fear" was associated with PTSD diagnoses in children and adolescents with ASD (Brenner et al., 2018). Informants also suggested that there may be particular, qualitative aspects of sleep disturbances more likely to be associated with trauma. Moreover, the current findings suggest that altered arousal may present as a general excess of motor activity/restlessness and difficulties calming themselves in individuals with ASD and ID. This is currently not reflected in the DSM 5 PTSD criteria for either adults or young children (American Psychiatric Association, 2013), while the DM-ID 2 suggests agitated behavior to be an expression of intrusion symptoms (McCarthy et al., 2017). However, trauma-related restlessness may develop due to an interaction between altered arousal and the difficulties regulating emotions frequently observed in individuals with ASD and ID (Samson et al., 2014), further indicating that restlessness as a possible symptom of PTSD may be particularly relevant in more severe levels of ID.

Informants described aggression and self-injurious behaviors in PTSD to have varying functions and expressions, understanding them as relating to different symptoms both between and within individuals, including altered arousal and reexperiencing. It thus seems unlikely that these superficially similar behaviors are specifically associated with a single symptom group in PTSD. Though it was not reported in the current study, it is possible that these behaviors may also occur as expressions of avoidance or negative changes to mood or cognition. They may also be signs of other co-occurring conditions, underlining the need for systematic exploration of these behaviors' causes and functions in clinical assessments involving PTSD in ASD and ID.

Limitations

The current study was designed as a qualitative, explorative study and therefore has limited generalizability. However, the current methodology allowed for exploration of clinical observations involving possible atypical or unusual symptom presentations, which would not have been possible using a less explorative approach, and which may serve to enrich our understanding of symptom manifestations in this particular group. This understanding may be useful and applicable to other clinicians working with and doing research on PTSD in this population, and these findings may therefore be *transferrable* (Stiles, 2015). Interview data involved mainly retrospective reports, which may have been affected by recall bias. Findings are also limited by what the clinicians reported, as there may have been symptoms of PTSD in some of these cases that they had not recognized as such. As the interviews primarily focused on eliciting examples and descriptions, and not necessarily how common these were, reported symptoms may not be representative of how PTSD presents in this population.

The researchers' pre-understanding is assumed to have an effect on the research process in IPA research, including analyses and interpretations (Smith et al., 2009). The first author's background as a clinical psychologist working in mental health in ASD/ID is likely to have affected development of themes and interpretations. The second author has a similar background and has extensive experience working in mental health in ASD/ID, as well as doing research in this field. However, to counter possible bias, initial development of themes also involved the fourth author, who has not worked clinically with the population in question but has extensive experience conducting qualitative research. Author three, also an experienced researcher and clinician in the field of ASD/ID, was introduced later in the process for validation purposes. The authors further sought to counter these biases by rigorously adhering to the principles of the analytic process and providing extracts to substantiate interpretations. Only the first author knew the identities of the informants.

The four superordinate themes roughly corresponded to the DSM 5 criteria groups for PTSD (American Psychiatric Association, 2013), indicating that neither the informants nor the analyses were able to extricate themselves completely from previous knowledge of PTSD. In line with the view of PTSD as a sensitizing concept (Blumer, 1954), however, the aim of the current study was to develop hypotheses and descriptions for a clinical context, and the clinical conceptualization of PTSD at any time is primarily derived from its diagnostic criteria. While the superordinate themes corresponded, correspondence between themes and specific criteria was not present to the same degree, indicating that informants were not bound by specific criteria even if their understanding of PTSD had been shaped by criteria groupings.

Recommendations for Future Research

Hypotheses and questions generated by the current study deserving of further exploration include restlessness as a possible sign of altered arousal in PTSD in ASD and ID, the more varied presentation of avoidance symptoms, as well as whether less intrusive reexperiencing symptoms may be recognized – or if reexperiencing symptoms are generally more severe in this population. While a number of case studies have previously been published (Kildahl et al., 2019), there seems to be a dearth of case studies and case series systematically describing PTSD symptom manifestations in individuals with ASD and ID reporting on specific criteria and using systematic assessment tools. Building on Brenner et al. (2018), further exploration of how trauma-related symptoms manifest on common assessment tools used for individuals with ASD and ID would probably also be helpful to clinicians. Together with the findings from the current study, such exploration may in the future provide a foundation for a checklist of behavioral symptoms of PTSD in this population, alternatively recommendations for how existing checklists for PTSD in individuals with ID could be adapted for those with co-occurring ASD.

The current study explored views of experienced clinicians whose perceptions of PTSD were influenced by psychiatric concepts and nomenclature. Future studies exploring PTSD manifestations in ASD and ID using informants who are less likely to be as influenced by these concepts, such as professional caregivers or families, would be a valuable addition to the field. Finally, further use of qualitative research methodology to directly explore reexperiencing in individuals with ASD, ID and good verbal skills could also provide important insights.

Conclusions

PTSD symptomatology in individuals with ASD and ID was understood by clinicians as similar to PTSD symptomatology in others, but with symptom expressions differing due to ASD and ID. Interactions between ASD, ID and PTSD symptoms seemed to vary between symptom groups, with the findings suggesting an association between symptom expressions being more influenced by ASD and ID and being more challenging to recognize. Altered arousal and negative changes in mood and cognition were described as more easily observable, while avoidance and reexperiencing were described as more challenging to recognize. Avoidance may be expressed in a wider range of ways in this population including more global and unspecific avoidance, and there may be an apparent lack of planned avoidance of trauma triggers. Finally, recognition of reexperiencing seemed to rely on a combination of knowledge of patients' trauma histories and interpretation of behavior, particularly behavior involving co-occurring abrupt

changes to alertness and responsivity. It is also possible that reexperiencing symptoms may be experienced in especially impactful ways in this population.

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The authors declare that there is no conflict of interest.

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Appendix 1. Interview guide

- What have been your experiences concerning trauma and PTSD in patients with co-occurring autism and intellectual disability (ID)?
 - What characterized the patient(s) with co-occurring autism and ID that you have encountered, who had experienced significant trauma or abuse? What level of ID? What trauma had they experienced?
 - Did the patient(s) differ from others you have encountered with co-occurring autism and ID and other mental health problems or challenging behaviors?
 - How did you proceed to assess trauma and PTSD?
 - What symptoms did you observe? How did you notice them? *If no examples were provided for any of the four DSM 5 symptom groups (reexperiencing, avoidance, negative changes to mood and cognition, changed arousal or reactivity), further probing involved first asking if informants had observed this group of symptoms in individuals with co-occurring autism and ID, and then how this had manifested and how they had observed it*
 - Was there anything in these assessments or symptom presentations you found peculiar?
 - How did you go about differentiating symptoms of autism and trauma/PTSD? Were there any challenges?
 - What are your thoughts regarding this assessment/these assessments now, in retrospect?
 - Do you think presentation of PTSD in individuals with co-occurring autism and ID differ from presentation of PTSD in others? What about PTSD in individuals with autism who do not have ID? Or in those with ID who do not have autism?
 - Do you think there are particular strategies that are helpful to identify PTSD in co-occurring autism and ID?
 - Is there any way you think identification of PTSD in co-occurring autism and ID may be improved?
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