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Sexual abuse in individuals with intellectual disability: a psychomotor perspective

Manon J. Smit



**Sexual abuse in individuals with intellectual disability:
a psychomotor perspective**

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Colophon

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Manon J. Smit

Thesis Vrije Universiteit Amsterdam, the Netherlands

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VRIJE UNIVERSITEIT

Sexual abuse in individuals with intellectual disability:
a psychomotor perspective

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door

Manon Jacomarg Smit
geboren te Meppel

promotor: prof.dr. P.J. Beek

copromotoren: dr. C. Emck
dr. M. Scheffers
dr. J.T. van Busschbach

promotiecommissie: prof.dr. C. Schuengel
prof.dr. P.S. Sterkenburg
prof.dr. H.C.M. Didden
dr. J.G. Nieuwenhuis
dr. M. de Witte

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Chapter 1

General introduction

Rosa is a thirty-year-old woman diagnosed with a mild intellectual disability. She lives in a care facility. Rosa loves to watch soccer and attends the local soccer match every Sunday afternoon. Since a few months, she shows aggressive outbursts and injures herself. Rosa's caregivers are concerned and ask the facility's behavioural therapist for advice. She refers Rosa to psychomotor therapy (PMT), an experiential therapy with bodily experiences and movement behaviour as its cornerstones to diminish psychological and behavioural problems. Rosa, in her own words, came up with the following goal for PMT: "I don't want to be angry anymore and hurt myself no longer." The psychomotor therapist translates this statement into a specific treatment goal, namely to diminish aggressive outbursts and self-injury by improving the ability to recognize and interpret bodily signals and regulate tension. In the first PMT session, Rosa opts for a game of soccer. When the psychomotor therapist touches Rosa while trying to steal the ball, she gets very angry and loudly screams "No, Stephen, no". Her psychomotor therapist notices Rosa's aggressive reaction, but the alarm bells ring especially loud by Rosa shouting the unfamiliar name "Stephen". Her psychomotor therapist stops the activity and starts a conversation about what happened. He asks Rosa why she got so angry and who Stephen is. He discovers that Rosa is being sexually abused by a supporter of the soccer club called Stephen, every Sunday afternoon; the physical contact with the male therapist caused a flashback to the abuse. After Rosa's disclosure of sexual abuse, the psychomotor therapist wonders why the sexual abuse was not detected before the PMT referral. Since the flashback was triggered by physical contact, the therapist decides to examine Rosa's body experience in greater depth. He starts looking in the literature for known body-related consequences of sexual abuse and assessment instruments he might use for this purpose. Also, he feels insecure and incompetent how and where to report Rosa's disclosure. He wonders whether policy and protocols on sexual abuse are available within the care facility and where to report Rosa's disclosure.

Rosa's case illustrates one of the many harrowing cases of individuals with intellectual disability (ID) who have been sexually abused. Research has shown that individuals with ID are particularly at risk of sexual abuse (Mailhot Amborski et al., 2021; Tomsa et al., 2021). This serious issue is only beginning to receive attention in both research and clinical practice for about thirty years (Byrne, 2018; Taylor Gomez, 2012). For a long time, the sexuality of individuals with ID had been denied and suppressed; they were seen as individuals without sexual needs and feelings (Kempton & Kahn, 1991; Taylor Gomez, 2012). Since the disability rights movement and deinstitutionalization of individuals with ID, these attitudes towards sexuality in individuals with ID have changed, resulting in growing awareness of the prevalence and impact of sexual abuse in this group (Byrne, 2018; Curtiss & Kammes, 2020; Taylor Gomez, 2012). To my knowledge, this thesis is one of the first that focuses on sexual abuse in individuals with ID.

In pertinent literature, multiple theoretical and legislative attempts have been made to define sexual abuse in individuals with ID (Byrne, 2018; Gill, 2010). Most of these definitions address the lack of consent or willingness to engage in sexual activity, the presence of exploitation and the unequal power relationship between perpetrator and victim (Gill, 2010). In this thesis, a broad definition of sexual abuse is adopted, namely “any sexual activity that a victim does not fully comprehend, is unable to give informed consent to, or for which the victim is not developmentally prepared, or else that violate the laws or social taboos of society (World Health Organization, 1999, p. 15)”.

Research indicates that individuals with ID are more likely to experience sexual abuse in comparison to those with (higher than) average IQ (Byrne, 2018). The estimated worldwide prevalence of sexual abuse in individuals with ID is 33% (Tomsa et al., 2021), as opposed to an estimated worldwide prevalence of 24% in individuals with (higher than) average IQ (Pan et al., 2021). Prevalence rates of sexual abuse in individuals with ID increase as the disability rises from mild (24%) to severe intellectual disability (67%), and are higher in care facilities for individuals with ID (28%) and in social services (34%) than at home (13%) (Tomsa et al., 2021).

Intellectual disability

An intellectual disability (ID) is a neurodevelopmental disorder that manifests itself during development (American Psychiatric Association, 2013). Besides significant impairments in intellectual functioning (i.e. IQ), there are impairments in adaptive functioning (i.e. conceptual, social and practical skills) (American Psychiatric Association, 2013; Schalock et al., 2021). In the former Diagnostic and Statistical Manual of Mental Disorders – fourth edition (DSM-IV) the diagnosis ID was based on an IQ score two standard deviations below the average population ($IQ < 70$) (American Psychiatric Association, 2000), whereas in the DSM-5 impairments in adaptive functioning are indicated as the defining factor in ID (American Psychiatric Association, 2013). Although in the DSM-5 the IQ scores are eliminated from the diagnostic criteria of ID, they still need to be assessed to gain an accurate insight into an individual's functioning (American Psychiatric Association, 2013). Moreover, in the upcoming revision of the fifth edition of the DSM (DSM-5-TR), a sentence has been added stating that although IQ scores are not the most important criteria for defining an ID, the diagnosis ID would not be appropriate for individuals with substantially higher IQ scores than 65-75 (American Psychiatric Association, 2022).

In scientific research and clinical practice IQ scores are still the leading criteria for defining ID. Four levels of ID can be distinguished: profound ID ($IQ \leq 20$), severe ID ($IQ 21-35$), moderate ID ($IQ 36-50$), and mild ID ($IQ 51-69$) (American Psychiatric Association, 2000). Individuals with profound ID cannot live independently, and require 24-hour care.

They are less able to communicate and often have physical disabilities and medical conditions (American Psychiatric Association, 2013; Boat & Wu, 2015). Individuals with severe ID need daily assistance with self-care and safety supervision. They often have the ability to understand speech but have limited communication skills (American Psychiatric Association, 2013; Boat & Wu, 2015). Individuals with moderate ID can take care of themselves and have basic skills related to safety and health, but need moderate levels of support (American Psychiatric Association, 2013; Boat & Wu, 2015). The majority of individuals with ID have a mild ID. These individuals can learn practical skills and live independently with minimal levels of support (American Psychiatric Association, 2013; Boat & Wu, 2015).

In Dutch clinical practice and literature the term mild ID (MID) also refers to individuals with borderline intellectual functioning (BIF) who have problems in adaptive functioning and need professional support. In the former DSM-IV the diagnosis BIF was based on an IQ score between 70 and 85, whereas in the DSM-5 this IQ criterion is no longer formulated; classification is now left to the clinician's judgement based on adaptive functioning (American Psychiatric Association, 2013). In the DSM-5, BIF is a descriptive V-code that can be used when there is a need for care or when treatment or prognosis are negatively influenced by the BIF (American Psychiatric Association, 2013). Although individuals with MID and BIF both need professional support and experience mental health problems, differences exist between these two categories. Nouwens et al. (2017) found that individuals with BIF have more individual and familial problems than individuals with MID. Homelessness, alcohol and drug abuse, divorced parents, inconsistent parenting and neglect by primary caregivers were more prevalent in individuals with BIF than in individuals with MID. In this thesis, individuals with MID and BIF were defined as individuals with MID-BIF.

The prevalence rate of individuals with MID and individuals with BIF who depend on professional support is estimated to be 6.5% of the total Dutch population (Sociaal en Cultureel Planbureau, 2019). This corresponds to approximately 1.1 million individuals (range 0.8 to 1.4 million). However, due to some uncertainty, these rates should be interpreted with caution (Sociaal en Cultureel Planbureau, 2019).

Risk factors of sexual abuse

There is growing evidence that both the individual characteristics of individuals with ID and their context contribute to the heightened risk of sexual abuse (Collins & Murphy, 2022; Curtiss & Kammes, 2020). On an individual level, learned helplessness, lack of self-advocacy skills, communication deficits, previous victimization of sexual abuse, and dependence on others may contribute to the elevated risk of sexual abuse (Briggs, 2006; Brownlie et al., 2007; Curtiss & Kammes, 2020; Fisher et al., 2016). Risk factors on

a contextual level are related to the immediate setting in which individuals with ID live (e.g., home, work, school), such as the lack of comprehensive sex education (Curtiss & Kammes, 2020), and the presence of possible perpetrators amongst peers with ID (Curtiss & Kammes, 2020; Tomsa et al., 2021). In the larger social system, the lack of adequate legal protection from sexual abuse and insufficient (use of) policies and protocols on sexual abuse in care facilities for individuals with ID are also risk factors for sexual abuse (Collins & Murphy, 2022; Curtiss & Kammes, 2020).

In the Netherlands, a protocol on sexual abuse is legally obligated in care facilities for individuals with ID (IGJ, 2016). The protocol in question must describe the course of action in the event of a suspicion or detection of sexual abuse taking place in such care facilities (IGJ, 2016). Furthermore, all suspected and detected forms of sexual abuse taking place in such care facilities must be reported to the Health and Youth Care Inspectorate (in Dutch 'Inspectie Gezondheidszorg en Jeugd', IGJ) (IGJ, 2016). Besides these legal requirements, the Dutch Association for Care for Individuals with Disabilities (in Dutch 'Vereniging Gehandicaptenzorg Nederland', VGN) has developed a guideline for Dutch care facilities for individuals with ID that provides practical tools regarding policies and protocols on sexual abuse (Van Burgsteden et al., 2011). This guideline describes the steps that need to be taken in cases of sexual abuse or suspicion thereof. It also highlights the importance of the appointment of a confidant for clients and staff, the availability of a special-task official who has an advisory role if sexual abuse is suspected, regular cooperation with the vice squad, and opportunities for staff to develop their expertise on, and awareness of, sexual abuse (Van Burgsteden et al., 2011). However, policies and protocols within those care facilities only contribute to the reduction of the risk of sexual abuse and the (early) detection of sexual abuse if they are implemented effectively (Collins & Murphy, 2022; Ottmann et al., 2017; Van Burgsteden et al., 2011). It is unknown if this aspect has been investigated.

Clinical characteristics of individuals who have been sexually abused

In general, research on the clinical characteristics of individuals with ID who have been sexually abused is scarce. In a literature study, Sequeira and Hollins (2003) suggested that victims with ID show the same behavioural and psychological characteristics as victims with (higher than) average IQ, among which aggression, self-injury, sexual behaviour problems, traumatic stress, depression and anxiety. However, these results are inconclusive due to the evidence reviewed. Most included studies were case studies that did not use standardized instruments and in which no distinctions were made based on the severity of ID. Since intelligence level and developmental age play an important role in the manifestation of behavioural and psychological problems (Dosen,

2005), it seems essential to distinguish between mild, moderate and severe levels of ID when investigating the clinical characteristics of individuals with ID who have been sexually abused.

Correspondingly, research has shown that having an ID makes it difficult to deal with traumatic events (e.g., sexual abuse) and their clinical characteristics (Kildahl et al., 2019, 2020; Mevissen & de Jongh, 2010). More specifically, the limited cognitive ability and lack of verbal skills make it difficult for individuals with ID to share their traumatic experiences and express associated emotions (Kildahl et al., 2020). This renders trauma-related consequences challenging to recognize, leading to misinterpretation of these consequences and diagnostic overshadowing (Kildahl et al., 2020; Rittmannsberger et al., 2020). Furthermore, individuals with ID have fewer resources and skills to cope with trauma. This leads to extensive and severe consequences of traumatic stress and longer duration of these consequences (Kildahl et al., 2020). It also results in a more complex reaction, such as challenging behaviour as an expression of traumatic stress (Kildahl et al., 2020). In addition, harmful social reactions after disclosure of sexual abuse, such as blaming, infantilizing, and inadequate support of the system are associated with more severe impact on victims with ID (Rittmannsberger et al., 2020). Based on the aforementioned reasons it can be assumed that sexual abuse leads to other, more complex clinical characteristics for individuals with ID compared to individuals with (higher than) average IQ.

Recent research on individuals with (higher than) average IQ emphasizes the increased impact of sexual abuse on the relationship victims have with their body (Van der Kolk, 2006, 2014). In particular, studies have shown that the body experience of victims of sexual abuse is often negatively affected by the violation of the body or by the threats to its physical integrity inherent to sexual abuse (Sack et al., 2010). Victims may experience difficulties with attending to and processing body signals, such as (changes) in heartbeat, breath and feelings of hunger, pain or temperature (Van der Kolk, 2014); they either deny having those signals or may feel overwhelmed by them (Van der Kolk, 2006). Furthermore, victims of sexual abuse often experience dissatisfaction with their body or parts thereof (Jaconis et al., 2020); feelings of sexual unattractiveness (Kilimnik & Meston, 2016; Wenninger & Heiman, 1998); disgust or hate towards their body (Fallon & Ackard, 2002), and reduced vitality and health (Sack et al., 2010; Wenninger & Heiman, 1998). Although research on body experience in individuals with intellectual disability who have been sexually abused is not available, it is reasonable to assume that they too will have a disturbed relation with their body, possibly even worse than victims of sexual abuse with (higher than) average IQ. Due to limitations in verbal communication and expression and difficulties with recognizing body signals associated with emotions

(McDonnell et al., 2015), it is likely that symptoms of traumatic stress in individuals with ID manifest themselves in the body and specifically in loss of contact with the body and/or disturbed regulation of arousal and emotions.

Body experience

Body experience is an important facet of psychosocial functioning, health and quality of life in both clinical and non-clinical populations (Fonagy & Target, 2007; Lipowski, 1977; Nayir et al., 2016). How one experiences one's body affects one's overall experience of being in the world (Fuchs & Schlimme, 2009). A broad range of psychopathological phenomena is accompanied by a disturbed or negative body experience (Fuchs & Schlimme, 2009; Lipowski, 1977; Scheffers, 2018).

In pertinent literature, a clear division is apparent between neurophysiological and psychological-phenomenological approaches to body experience (Röhrich et al., 2005; Scheffers, 2018). The present thesis focuses on the psychological-phenomenological dimension of body experience because in therapeutic settings the personal and subjective experience of how clients experience their bodies is of prime interest (Scheffers, 2018).

Unfortunately, the literature is not very clear in defining the psychological-phenomenological concept of body experience. The numerous terms used in the literature to describe body experience and the multidimensionality of body experience contributes to the terminological chaos surrounding the concept (Scheffers, 2018). Scheffers (2018) tried to bring order in this chaos by distinguishing three dimensions of body experience: body awareness, body satisfaction and body attitude. This classification of body experience was followed in the research reported in this thesis.

Body awareness

The term *body awareness* pertains to the conscious perception of bodily states, processes, and actions based on proprioceptive and interoceptive signals (Mehling et al., 2009). Proprioceptive signals refer to muscle tension, movement, posture and balance that an individual has the capacity to be aware of (Mehling et al., 2009, 2012). Interoceptive signals include sensations from inside the body that provide a sense of the physiological condition of the body, such as heartbeat, breathing, or respiration, and somatic markers associated with emotions (Mehling et al., 2009, 2012).

In both pertinent literature and clinical practice, the terms *body awareness* and *interoceptive awareness* are often used interchangeably. However, to clear up this terminological confusion, body awareness refers to the conscious perception of both proprioceptive

and interoceptive signals (Mehling et al., 2009), whereas *interoceptive awareness* refers solely to the conscious level of interoceptive signals (e.g., Bellemans et al., 2020; Mehling et al., 2018).

Body satisfaction

The term *body satisfaction* refers to the degree of satisfaction with the appearance and functioning of one's body. While research on body experience has long been focused predominantly on appearance-related body satisfaction, in the last decade, body functionality, such as energy levels and coordination, has received more attention (e.g., Alleva et al., 2014; Rekkers et al., 2021; Scheffers et al., 2017, 2019; Wood-Barcalow et al., 2010). There is growing evidence that satisfaction with bodily functioning contributes to more positive feelings towards the body and greater satisfaction of body appearance (Alleva et al., 2014).

Body attitude

Body attitude is a multifaceted concept, which includes perceptions, cognitions, emotions and awareness of one's bodily experiences (Pöhlmann et al., 2014; Scheffers, 2018). The evaluation of physical contact, the attitude towards the body in social interaction, sense of body ownership, experienced vitality, and sexuality are all implicated by the term *body attitude* (Pöhlmann et al., 2014; Scheffers et al., 2017).

Body experience in individuals with intellectual disability

Research on body experience in individuals with ID is scarce. Only one study published to date covered body awareness, body satisfaction and body attitude, and evaluated its relation with externalising disorders in children with ID (Emck et al., 2012). This study showed that children with ID and externalising problems have a disturbed body experience, especially with regard to body awareness and body satisfaction (Emck et al., 2012). Other studies on body experience in individuals with ID only focused on one of the aforementioned dimensions of body experience. For instance, Bellemans et al. (2018) examined body awareness in individuals with ID in relation to aggression. They interviewed psychomotor therapists working with individuals with ID, who indicated that enhancing body awareness is a key vehicle in psychomotor therapy to reduce anger and aggression in this group (Bellemans et al., 2018). Furthermore, a study on body satisfaction demonstrated that young adults with ID have positive beliefs about their body and females tend to underestimate their body size (Eden & Randle-Phillips, 2017). Studies on body attitude only focused on one specific aspect of body attitude, namely sexuality. A literature review showed that individuals with ID have fewer positive feelings about and experiences with sexuality than individuals with (higher than) average IQ (Borawska-Charko et al., 2017).

Body- and movement-oriented therapies

Body- and movement-oriented therapies, such as psychomotor therapy (PMT) and dance/movement therapy, are often employed to alleviate psychological or psychiatric problems (Emck & Scheffers, 2019). In this thesis, the focus is on PMT as practiced in the Netherlands and Flanders. PMT offers opportunities for clients in real life to improve their ability to recognize bodily signals and link these signals to emotions and behavioural responses (Emck & Scheffers, 2019). By actively participating in exercises, clients are invited to engage in new movement behaviour and bodily experiences and to practice with new or alternative behaviours in a safe environment (Emck & Scheffers, 2019).

PMT seems to be particularly suitable for individuals with ID, because it places less emphasis on the clients' verbal skills and focuses on the immediate bodily experiences and concrete behaviour of the client (Bellemans & Van Putten, 2021; Kay et al., 2016; McDonnell et al., 2015). Moreover, PMT might be especially suitable for victims of sexual abuse who experience posttraumatic stress symptoms as these are associated with diminished awareness of feelings, cognitions and behaviour (Van de Kamp et al., 2018) and with a negative body experience (Scheffers et al., 2017). Therefore, PMT is often applied as a treatment in individuals with ID who have been sexually abused (Bellemans & Van Putten, 2021). Unfortunately, the evidence base for PMT is limited, especially for this particular group.

Psychomotor assessment

Psychomotor assessment is essential to obtain sufficient information about an individual's body experience (Emck & Scheffers, 2019). Two types of assessment methods are used in PMT: psychomotor observation and self-report (Emck & Scheffers, 2019). Psychomotor observation is focusing on non-verbal information, such as (movement) behaviour, muscle tension, body posture, and facial expression, as observed in a clinical context by the psychomotor therapist (Emck & Scheffers, 2019; Van de Kamp et al., 2018). During movement activities, clients can be observed and asked about their immediate bodily feelings and (movement) behaviour. Such an approach matches the needs and cognitive capabilities of individuals with ID, and is therefore particularly useful for this group (Emck et al., 2012; Emck & Van Damme, 2021; Kay et al., 2016). The PsyMot for adults with MID-BIF (PsyMot-mb; Smit et al., 2020) is an example of a Dutch psychomotor observation tool that has been specifically developed for individuals with ID, and focuses on body acceptance. Body acceptance pertains to the ability to attend to, tolerate, and interpret bodily signals, and the accompanying (movement) behaviour; it thus includes the behavioural responses to body awareness (Emck & Bosscher, 2010; Smit et al., 2020).

Besides psychomotor observation, self-report measures that evaluate body experience are particularly valuable as they reflect an individual's subjective experiences (Emck & Scheffers, 2019). In clinical practice, these measures can help to make shared decisions and enhance communication between client and therapist about treatment goals, which also reinforces the client's empowerment (Nelson et al., 2015). Although several self-report measures for individuals with ID have been used to assess one's subjective experience of the body, these measures neither have been adapted to individuals with ID, nor tested or validated for this group. Due to difficulties with reading, reflective reasoning, and abstract thinking, it is essential that self-report measures are specifically developed for or adapted to individuals with ID. This comprises, for instance, the use of simplified language, supportive visualization and limited response alternatives (Hartley & Maclean, 2006; Kooijmans et al., 2022; Vlot-Van Anrooij et al., 2018). To date, no such measures are available to assess body experience in individuals with ID.

Aims of this thesis

As outlined above, early detection and adequate assessment and treatment of individuals with ID who have been sexually abused are only possible in light of clear policies and protocols regarding sexual abuse within care facilities for this group. Such policies and protocols and their effective implementation are essential for care professionals, including body- and movement-oriented therapists, in order to know how to act if they suspect or detect sexual abuse, and which assessment tools and treatments are suitable. For early detection of sexual abuse in individuals with ID, it is also important that care professionals have knowledge and awareness of the consequences of sexual abuse in this group. For body- and movement-oriented therapists, knowledge about the impact of sexual abuse on body experience is of specific value as body experience is the main focus of their treatment. This knowledge may also improve the use and evaluation of body- and movement-oriented therapies that target problems with body experience in individuals with ID who have been sexually abused.

Before conducting empirical studies aimed at gaining insight into the impact of sexual abuse on body experience in individuals with ID, three steps need to be taken. First, the state of affairs regarding policies on sexual abuse and their implementation within Dutch care facilities need to be assessed. Second, an overview of the literature on the clinical characteristics of individuals with ID who have been sexually abused, with a distinction in severity of ID, is required. Third, in order to acquire the requisite data, a self-report questionnaire focusing on body experience in individuals with ID must be developed.

The research reported in the present thesis thus had the following four aims, with the fourth being its ultimate aim:

- 1) To assess the state of affairs regarding policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID, and to identify potential areas of improvement regarding policies on sexual abuse and their implementation in these facilities;
- 2) To provide an overview of the literature on the clinical characteristics of individuals with ID who have been sexually abused;
- 3) To develop a Dutch self-report questionnaire, the Body Experience Questionnaire for adults with MID-BIF (BEQ-mb), and examine its usability, comprehensibility, internal consistency, and reliability; and
- 4) To compare several aspects of body experience, namely body awareness, body satisfaction, body attitude and body acceptance, in adults with MID-BIF who have and have not been sexually abused.

Outline of this thesis

In line with the aims of this thesis, its contents and composition are as follows:

Chapter 2 focuses on the state of affairs of policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID, assessed by an online survey completed by managers of these facilities. It also presents areas of improvement regarding both policy formulation and implementation, as reported in the survey by the managers. This knowledge is essential since policies on sexual abuse and their implementation are required to reduce the risk of sexual abuse and improve the detection of sexual abuse in care facilities for individuals with ID.

Chapter 3 provides an overview of the literature on the clinical characteristics of individuals with ID who have been sexually abused. This knowledge is indispensable to improve the early recognition of sexual abuse, and is important in order to develop and implement adequate treatment programs for individuals with ID who have been sexually abused.

Chapter 4 presents the development of the BEQ-mb and the evaluation of its usability, comprehensibility, internal consistency and reliability. The BEQ-mb is the first self-report questionnaire on body experience specifically developed for adults with MID-BIF, and focuses on three domains of body experience, namely body awareness, body satisfaction and body attitude. This self-report questionnaire can be used to shed light on the specific disturbances of body experience in individuals with MID-BIF, as well as to give directions to the kind of treatment that may alleviate those disturbances.

Chapter 5 reports a study focusing on body experience in adults with MID-BIF who have and have not been sexually abused. Body awareness, body satisfaction and body attitude were measured by self-report using the BEQ-mb. Body acceptance was assessed by psychomotor observation using the PsyMot-mb. The resulting knowledge is essential for an adequate use of body- and movement-oriented therapies that target problems with body experience in adults with MID-BIF who have been sexually abused.

In **Chapter 6** the main findings of this thesis are summarized and discussed. This chapter also reports strengths and limitations of this thesis, suggestions for future research, and implications for clinical practice.

Chapter 2

Policy on sexual abuse: a survey study amongst managers of care facilities for individuals with intellectual disability in the Netherlands

Smit, M. J.^{1,2}, Scheffers, M.¹, Emck, C.², van Busschbach, J. T.^{1,3},
Engelsman, L.¹, Beek, P. J.² (2023).

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¹ School of Health, Movement & Education, Windesheim University of Applied Sciences, Zwolle, the Netherlands

² Department of Human Movement Sciences, Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

³ University Center of Psychiatry, University of Medical Center Groningen, University of Groningen, Groningen, the Netherlands

Abstract

Individuals with intellectual disability (ID) living in a care facility are at high risk of sexual abuse. Formal policies on sexual abuse within these care facilities and their effective implementation are a prerequisite to decrease the risk of sexual abuse in this group. The present study aimed to determine the state of affairs in this regard in the Netherlands and identify areas of improvement regarding both policy formulation and implementation. An online survey was sent to the management boards of 129 Dutch care facilities for individuals with ID. Sixty-nine managers completed the survey on behalf of their care facility. Descriptive statistics was used to characterize the state of affairs regarding policies on sexual abuse. Areas of improvement reported by the managers were examined qualitatively by thematic analysis. Most care facilities complied with the national legal requirements on sexual abuse, which includes the availability of a protocol on sexual abuse and mandatory reporting. It varied across the care facilities to what extent the protocols on sexual abuse are brought to the staff's attention and used in practice. About half of them provided no staff training on the protocol on sexual abuse, while nearly one-third of the care facilities provided no organizational protective factors on sexual abuse, such as a special-task official on sexual abuse, a sexuality or sexual abuse department or cooperation with the vice squad. Most areas of improvement reported by the managers pertained to the need for staff training and the improvement of practical use of policies and protocols on sexual abuse. In conclusion, the availability of policies and protocols on sexual abuse in care facilities for individual with ID does not guarantee a caring culture in which these policies and protocols are implemented effectively, and in which sexual abuse is prevented and detected timely.

Keywords: sexual abuse; intellectual disability; policy; prevention; detection

Introduction

Sexual abuse is a worldwide problem and a violation of human rights that has far reaching consequences for health and psychosocial functioning (World Health Organization, 2013). Research has shown that individuals with ID are at greater risk of sexual abuse than individuals with (higher than) average IQ (Mailhot Amborski et al., 2021; Tomsa et al., 2021). The estimated worldwide prevalence of sexual abuse in this group is 33% (Tomsa et al., 2021), as opposed to an estimated worldwide prevalence of 24% in individuals with (higher than) average IQ (Pan et al., 2021). Moreover, Tomsa et al. (2021) showed that living in a care facility for individuals with ID poses a high risk of sexual abuse, with an estimated worldwide prevalence of 28% for women and 51% for men.

To decrease the risk of sexual abuse in care facilities for individuals with ID, formal policies and procedures regarding sexual abuse within these facilities and their effective implementation, are a prerequisite (Collins & Murphy, 2022). Other organizational factors that protect individuals with ID against sexual abuse include clear leadership of a manager whose values are in line with those of other staff and the organization, regular staff training, supervision of staff, consistent use of procedures by staff, support for staff who report sexual abuse, and good connections with the community (Collins & Murphy, 2022). These organizational protective factors might contribute to the establishment of a positive caring culture within a care facility for ID in which policies and procedures on sexual abuse are embedded (Collins & Murphy, 2022).

The United Nations state in their Convention on the Rights of Persons with Disabilities (CRPD) that States Parties “shall put in place effective legislation and policies (...) to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted” (article 16 (5)) (UN General Assembly, 2007). In the European Union (EU), all Member States, except Germany, have legislation obligating care professionals to report violence and abuse (FRA, 2014). In addition all Member States of the EU have specific policies in place on violence and abuse, be it in the form of policies on child protection (e.g., Ireland, Spain), policies on individuals with disabilities (e.g., Austria, Germany), or policies on different types of violence and abuse in specific settings (e.g., Finland, the Netherlands) (FRA European Union Agency for Fundamental Rights, 2015).

In the Netherlands, specific legislation and policies are in place regarding sexual abuse taking place between a staff member and a client or between clients (IGJ, 2016). The Dutch governmental institution that supervises public health, the Health and Youth Care Inspectorate (in Dutch ‘Inspectie Gezondheidszorg en Jeugd’, IGJ), stipulated that health care facilities are legally obligated to have a procedure on sexual abuse (IGJ,

2016). Such a procedure must describe the course of action in the event of a suspicion or detection of sexual abuse taking place in a care facility. Furthermore, health care facilities are legally obligated to report all suspected and detected forms of sexual abuse taking place in those care facilities to the IGJ (IGJ, 2016).

Between 2017 and 2019, the IGJ received a total of 186 incident reports of sexual abuse by care facilities for individuals with ID (Amelink et al., 2021). Given the prevalence rates of sexual abuse in individuals with ID (Tomsa et al., 2021), and the fact that in 2018 about 70.000 individuals with ID were living in a Dutch care facility for individuals with ID (CBS, 2018), the number of incident reports seems an underestimation of the factual occurrence of sexual abuse in this group (Amelink et al., 2021). This might be caused by a variety of client, staff and organizational factors. Clients may have been ashamed or reluctant to report the sexual abuse to staff, or may not have recognized the abuse (Gil-Llario et al., 2019). Their communication difficulties, such as the inability to provide verbal information and the need for an experienced interpreter, may also contribute to the underreport of sexual abuse (Ottmann et al., 2017). Staff might be hesitant to report sexual abuse to the manager if they had not witnessed the abuse themselves, if they were concerned about the trust relationship with the client, if the abuse was not proven or if they disbelieved the client in view of their severe mental health problems (Taylor & Dodd, 2003). Organizational factors that contribute to the relatively low number of reports might be lack of staff training, lack of time and resources to conduct a thorough investigation, downgrading the severity of a suspicion of sexual abuse by management, overly hierarchical processes, and fear of losing organizational reputation (Collins & Murphy, 2022; Ottmann et al., 2017). Additionally, sufficient (use of) policies and protocols are essential to suspect, detect and report sexual abuse (Ottmann et al., 2017).

In line with the international and national requirements, The Dutch Association for Care for Individuals with Disabilities (in Dutch 'Vereniging Gehandicaptenzorg Nederland', VGN) has developed a guideline for managers working in Dutch care facilities for individuals with ID that provides practical tools regarding policies and protocols on sexual abuse (Van Burgsteden et al., 2011). The premise of this guideline is that prevention and detection of sexual abuse is only possible if a clear policy and protocol regarding sexual abuse is present (Van Burgsteden et al., 2011). Besides the legal requirements of having a protocol on sexual abuse and mandatory reporting to the IGJ, the guideline of the VGN describes the steps that need to be taken in cases of sexual abuse or suspicion thereof. It also mentions several organizational protective factors against sexual abuse, such as the appointment of a confidant for clients and staff, the availability of a special-task official who has an advisory role if sexual abuse is suspected, cooperation with the vice squad, and the opportunities for staff to develop their expertise on, and awareness of, sexual abuse (Van Burgsteden et al., 2011).

Given the legal requirements of the IGJ, it is expected that care facilities for individuals with ID in the Netherlands possess a protocol on sexual abuse and report (suspicion of) sexual to the IGJ. However, it is unknown which steps are described in the protocol that need to be taken in cases of sexual abuse or suspicion thereof, how such a protocol is implemented in practice, and which specific organizational protective factors are provided by the care facility. As policies and protocols on sexual abuse are required to reduce the risk of sexual abuse in care facilities and improve the (early) detection of sexual abuse in care facilities for individuals with ID (Collins & Murphy, 2022; Ottmann et al., 2017; Van Burgsteden et al., 2011), it is essential to investigate the state of affairs regarding policies on sexual abuse in these care facilities. Against this background, the aims of this study were twofold, namely 1) to assess the state of affairs regarding policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID, and 2) to identify potential areas of improvement regarding policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID; both aims were pursued by using an online survey completed by managers working in these facilities.

Methods

Survey development

The survey was developed by the authors of this study who are experts in the field of sexual abuse and ID. The survey was based on the guideline 'Sexuality and sexual abuse' of the Dutch Association for Care for Individuals with Disabilities (Van Burgsteden et al., 2011). Qualtrics was used to create the survey. Prior to its distribution, it was piloted and assessed for clarity and utility by two policy makers working in a care facility for individuals with ID.

Sampling

All Dutch care facilities for individuals with ID affiliated with the VGN ($n = 129$) were recruited through probability sampling between November 5th, 2021 and December 1st, 2021. An information letter with the URL link and QR code to the online survey was sent (via physical and digital mail) to management board of these care facilities. Two weeks after the first mailing, a reminder via digital mail was sent.

In total, 89 managers started filling out the survey on behalf of their care facility (i.e. 31% dropout). From this group, 20 managers did not complete the survey (i.e. 16% of the original sample); most of them stopped while filling out the first questions asking for general information of the care facility (size, type(s), IQ level(s) of clients). Only the managers who completed the survey were included ($n = 69$; i.e. 54% response rate of the original sample).

Procedure

The study was approved by the local ethics committee of the Faculty of Behavioural and Movement Sciences of the Vrije Universiteit Amsterdam (VCWE-2021-182) before it was conducted.

If the potential respondents followed the link or QR code to the survey, they were presented an information letter about the aim of the study, and the voluntary and anonymous nature of participation. It was also mentioned that the study aimed to provide descriptive data rather than compare care facilities on policy on sexual abuse. If interested in participation, they were asked to sign an informed consent form that was provided as a separate page within the online survey. Without having completed the informed consent form, it was not possible to complete the survey.

Data analysis

Descriptive statistics was used to report on the size, type(s) and IQ level(s) of clients in the care facilities the managers work for, and to provide information on policy on sexual abuse within these care facilities (i.e. legal obligations, steps described in a protocol on sexual abuse, implementation of a protocol on sexual abuse, organizational protective factors). Some items in the survey included open answer categories of the form: "Others, namely ...". These answers were carefully read, categorized and added to the analysis as a new category by the first author (MJS). The analyses were performed in SPSS version 28 for Windows.

The comments on possible improvements were examined using inductive thematic analysis, a qualitative method for identifying, analysing and reporting patterns within data (Braun & Clarke, 2006). All comments were coded by hand. First, the fifth author (LE) independently coded the comments on improvement and sorted the initial codes in a set of subthemes. For instance, the comment "Providing training on assessment and intervention of sexual abuse" was coded as "training on assessment and intervention" and sorted under the theme "training". Second, the first author (LE) compared the set of subthemes with the original comments on improvement, and further refined the themes by merging, adding and removing redundant subthemes. Lastly, both authors (MJS, MS) discussed their analyses, clarified cases of disparity and established agreement.

Results

General information

Table 1 provides a description of the care facilities the managers were in charge of. Care facilities were of medium to large size, offered multiple forms of care and had clients of all levels of ID ($IQ \leq 85$). Most care facilities offered sheltered housing/24-hour care, most of them in combination with day care and/or outpatient care. Care facilities that only offered day care and/or outpatient care formed a minority. Furthermore, most of the clients in the care facilities had a mild to moderate disability; clients with borderline intellectual functioning and severe/profound IQ were represented less.

Table 1. Size and type(s) of the care facility and IQ level(s) of clients in the care facility

	% (n)
Size of the care facility (n = 69)	
Small (≤ 100 clients)	22 (15)
Medium (101 – 1000 clients)	39 (27)
Large (≥ 1001 clients)	39 (27)
Type(s) of the care facility (n = 69)	
Sheltered housing/24-hour care, day care and outpatient care	64 (44)
Sheltered housing/24-hour care and day care	9 (6)
Sheltered housing/24-hour care and outpatient care	3 (2)
Sheltered housing/ 24-hour care	22 (15)
Daycare and outpatient care	2 (1)
Day care	2 (1)
IQ level(s) of clients in the care facility (n = 69)	
BIF, mild ID, moderate ID, and severe/profound ID	49 (34)
BIF, mild ID, and moderate ID	16 (10)
Mild ID, moderate ID, and severe/profound ID	16 (10)
BIF and mild ID	6 (4)
Mild ID and moderate ID	6 (4)
Moderate ID and severe/profound ID	4 (3)
Mild ID	4 (3)
Moderate ID	2 (1)

BIF: borderline intellectual functioning ($IQ\ 70-85$); mild ID ($IQ\ 50-69$); moderate ID ($IQ\ 36-49$); severe/profound ID ($IQ \leq 35$)

Policy on sexual abuse

Legal obligations

The vast majority of the managers reported that a protocol on sexual abuse is available in their care facility that describes the course of action in the event of a suspicion or detection of sexual abuse ($n = 67$, 97%). They also reported that in case of suspicion or detection of sexual abuse, a reporting obligation for staff is in order ($n = 67$, 97%), implying that they must report such cases to the manager. Additionally, 93% of the managers declared that they routinely report a suspicion or detection of sexual abuse to the Health and Youth Care Inspectorate (IGJ) ($n = 64$).

Steps described in a protocol on sexual abuse

The majority of the managers reported that after suspicion or detection of sexual abuse a multidisciplinary team is formed to start an investigation ($n = 63$, 91%). Such a team typically involves a behavioural therapist ($n = 62$, 98%) and a care worker ($n = 54$, 86%). The team may also include the manager of the organization ($n = 25$, 40%), the team leader ($n = 17$, 27%), the physician ($n = 17$, 27%) and less often the sexologist ($n = 8$, 13%). Furthermore, the majority of the managers stated that parents, family and/or legal representatives of the client are informed after suspicion or detection of sexual abuse ($n = 64$, 93%), and that a report is written when the investigation on the (alleged) sexual abuse has been completed ($n = 65$, 94%).

Implementation of a protocol on sexual abuse

The extent to which the protocol is brought to the staff's attention and is actually used in practice varied considerably across the care facilities, as is reflected in the following numbers and percentages. The managers who stated that the protocol is brought to the staff's attention ($n = 66$, 95%) indicated that the protocol is mostly but not consistently discussed during team meetings ($n = 44$, 66%) and posted on the intranet ($n = 37$, 55%). However, 54% of the managers declared that the care facility does not provide staff training on the protocol, and that in 94% of the cases the protocol is not discussed in the care facility's newsletter ($n = 65$). Five percent of the managers indicated that the protocol on sexual abuse is not brought to the staff's attention at all ($n = 3$).

Organizational protective factors on sexual abuse

Nearly all managers reported that a confidant for clients and staff is available in the care facility ($n = 65$, 94%). In 4% of the cases ($n = 3$), only a confidant for clients is available. These confidants are responsible for the reception and referral of clients and staff who are confronted with sexual abuse and have a duty of confidentiality. Conversely, nearly one-third of the managers reported that the care facility has no sexuality or sexual

abuse department ($n = 30$, 43%) or a special-task official on sexual abuse who has an advisory role if sexual abuse is suspected ($n = 29$, 35%). Also one in three organizations does not cooperate in a structural manner with the vice squad ($n = 27$, 39%).

Although the majority of the managers stated that the care facility offers opportunities for staff to develop their expertise on sexual abuse ($n = 65$, 94%), the kind of opportunities they provide varied across the care facilities. Nearly all care facilities offer staff training ($n = 62$, 95%), while about two-third enables staff to use e-learning ($n = 45$, 69%), attend seminars ($n = 41$, 63%), attend conferences ($n = 39$, 60%), and/or take part in intervision ($n = 39$, 60%). It appeared from the managers' responses that only 26% of the care facilities offer supervision to their staff in cases of sexual abuse ($n = 17$). Furthermore, the majority of the managers reported that the care facility deliberately employs staff who are experts in the field of sexual abuse ($n = 58$, 84%). These experts have acquired specific expertise on sexual abuse by having followed specialized training on the topic. In most cases, the experts are behavioral therapists ($n = 50$, 86%), but also care workers ($n = 21$, 36%), creative arts- or body- and movement-oriented therapists ($n = 10$, 17%), sexologists ($n = 10$, 17%), physicians ($n = 7$, 12%), systemic therapists ($n = 6$, 10%), or psychiatrists ($n = 2$, 3%) may be experts.

Areas of improvement

Based on the comments of the managers, the authors (MJS, LE) identified two main areas of improvement, namely 1) the content of policy on sexual abuse, and 2) the implementation of policy on sexual abuse. Three-fourths of the managers' comments were related to the second theme.

Suggested content improvements in policy on sexual abuse

The managers frequently mentioned that they are aware that the standing policy on sexual abuse within the care facility they work for should be evaluated based on the most recent (scientific) insights. Some managers commented that clients and their legal representatives should be involved when evaluating the policy on sexual abuse. Furthermore, they indicated that the policy should describe more clearly the roles of staff when sexual abuse is suspected or detected. They also stated that more attention should be paid in the policy to assessment and intervention on sexual abuse and to specific groups, such as individuals with severe and profound ID.

Suggested improvements in the implementation of policy on sexual abuse

The managers declared most frequently that their care facilities should offer more training to their staff on sexual abuse in general, detection, prevention, assessment and intervention on sexual abuse, use of conversational skills with victims of sexual abuse, and healthy sexual development. Furthermore, the managers mentioned that the

policy on sexual abuse should be brought to the attention of the staff more often. Some managers indicated that discussing the policy on sexual abuse should be a fixed agenda item during staff meetings. The managers also indicated that the policy on sexual abuse should be embedded in practice and improved for practical use. For instance, they mentioned that the policy on sexual abuse should be better readable and accessible for the staff. Lastly, the managers indicated that they should appoint a special-task official on sexual abuse within their care facility.

Discussion

The first aim of this study was to assess the state of affairs of policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID. The results indicated that almost all care facilities comply with the national legal requirements on sexual abuse, that is, the availability of a protocol on sexual abuse and mandatory reporting to the IGJ. Additionally, in the majority of the care facilities, the protocol on sexual abuse conforms to the steps described in the guidelines of the VGN on policies and protocols on sexual abuse (Van Burgsteden et al., 2011). It may thus be concluded that the managers of care facilities for individuals with ID in the Netherlands are aware of possible sexual abuse, and that they believe to pay sufficient attention to sexual abuse in a formal sense.

However, the results also indicated that the extent to which the protocols on sexual abuse are brought to the staff's attention and are actually used in practice varies considerably among the care facilities. As it turned out, 54% of the care facilities does not provide staff training on the protocol on sexual abuse, while this is a prerequisite for its implementation (Read et al., 2018). Furthermore, nearly one-third of the care facilities has not implemented specific organizational protective factors on sexual abuse, such as a special-task official on sexual abuse, a sexuality or sexual abuse department or cooperation with the vice squad. Also, the opportunities for staff to develop their expertise on sexual abuse varies considerably among care facilities. Only 26% of the care facilities offer supervision for staff to develop their expertise on sexual abuse, even though this is an important factor that protects against sexual abuse within care facilities (J. Collins & Murphy, 2022). Although 95% of the care facilities offer staff training, it is not evident what these training opportunities entail, to what extent staff members make use of them, and, if so, which functions these staff members have. Furthermore, 84% of care facilities employs behavioural therapists who are experts in the field of sexual abuse, while care workers are experts in the field of sexual abuse in only 36% of the cases.

The latter is remarkable since care workers are most engaged with clients, and have, therefore, an important role in the prevention and detection of sexual abuse (Eastgate et al., 2012; O'Malley et al., 2019).

The second aim of this study was to identify the potential areas of improvement regarding policies and their implementation on sexual abuse in Dutch care facilities for individuals with ID. The most reported areas of improvement were related to the implementation of policies and protocols on sexual abuse; only a few of them were related to the content in policies and protocols on sexual abuse. Concerning policy and protocol implementation, the need for staff training on sexual abuse in general, detection, prevention, assessment and intervention on sexual abuse, use of conversational skills with victims of sexual abuse, and healthy sexual development, were frequently reported by the managers. This is in line with the organizational factors that protect against sexual abuse in care facilities for ID found in the review by Collins and Murphey (2022). Additionally, awareness and knowledge among staff regarding what sexual abuse entails and when immediate action is needed, might contribute to the (early) detection of sexual abuse (Aylett, 2016; J. Collins & Murphy, 2022). Other suggested points of improvement related to the implementation of policies and protocols were that they need to be brought to the attention of staff more often, that they need to be (better) embedded in practice and improved for practical use, and that a special-task official on sexual abuse needs to be appointed. The latter directly contributes to bringing the policy to the attention of staff, as this could be one of the main roles of a special-task official.

An area of improvement related to the content in policies and protocols on sexual abuse is that clients and their legal representative(s) need to be involved when evaluating the care facility's policy on sexual abuse, which is essential for its effective implementation (Dew et al., 2014). Additionally, for effective implementation, both the individuals who experience the consequences of the policy when implemented (the individuals with ID, legal representative(s) and staff) and the implementers (the managers) need to consider the policy as meaningful (Dew et al., 2014; Grin & Van de Graaf, 1996). Moreover, if individuals with ID, their legal representative(s) and staff will be involved, this might positively affect the practical use of policy on sexual abuse (i.e. readability, accessibility), which was an area of improvement related to the implementation of policy.

In sum, the availability of policies and protocols on sexual abuse alone does not guarantee a caring culture in which these policies and protocols are implemented, and in which clients are protected against sexual abuse. This finding seems to be not limited to Dutch practice, but generic from an international perspective. Specifically, a similar conclusion was formulated in a Welsh study by Northway et al. (2006) on development

and implementation of policy on protection against abuse in care facilities for individuals with ID. Furthermore, the European Union Agency for Fundamental Rights (2015) stated that, in member states of the EU, legislation and policies on violence against individuals with disabilities are often fragmented at national and local level and that their implementation is a weak point. Member states of the EU generally agreed that lack of staff training and few practical tools are one of the main challenges to implementation of legislation and policies on violence and abuse (FRA European Union Agency for Fundamental Rights, 2015), which is also in line with the findings of the present study. It can thus be assumed that the main conclusion of the present study is generalizable to other countries, even though it was focused on the Netherlands.

To improve the implementation of policy and protocols on sexual abuse in care facilities for individuals with ID, the following actions need to be carried out, aimed at respectively the practical, educational and research context. First, care facilities for individuals with ID should bring the topic sexual abuse and the policy and protocols on sexual abuse regularly to the attention of staff, for instance by promoting staff training on sexual abuse, appointing a special-task official on sexual abuse, and noting sexual abuse as a fixed agenda item during staff meetings. Second, the implementation of policy and protocols must constantly be monitored and evaluated within the care facility. By monitoring and evaluating policy and protocols in consultation with managers, staff, and clients, direct attention is paid to the familiarity and awareness of the policy and protocols on sexual abuse, inducing reflection on one's own standing practice (Forrest et al., 1996). Where the educational curriculum of future staff is concerned, attention should be paid to the high prevalence of sexual abuse, its pervasive impact on well-being, and the value of policy and protocols on sexual abuse. And lastly, from a research perspective, more insight is needed in the adequacy of implementation of organizational preventive factors. Also, future research is needed to explore the knowledge, attitude and experiences of both managers and staff that hamper prevention and careful client centered handling of sexual abuse.

A strength of the study is that the use of an online survey is ideally suited to research on sensitive topics (Braun et al., 2017), such as sexual abuse, because it offers a high level of anonymity (Terry & Braun, 2017). This may have resulted in a more open and detailed response of the managers about the policy on sexual abuse in the care facility they work for. Furthermore, the response rate of 54% in this study is in line with average response rates of 55% in survey research on an organizational level (Holtom et al., 2022). It is known that survey research on organizational level is faced with lower response rates than research on an individual or group level (Baruch & Holtom, 2008; Holtom et al., 2022). Research on an organizational level often requests managers to respond to a survey, a target group that receives many similar requests, have intense time demands and

are careful in sharing sensitive information in view of reputational concerns (Solarino & Aguinis, 2021). Lastly, the fact that 16% of the managers stopped while filling out the survey can be considered as strength since, despite of the sensitivity of the topic, this rate is in line with the average rate of 15% of the respondents who quit an online survey prior to reaching its end (Galesic, 2006).

The present study may have suffered from a non-response bias (Berg, 2010), in that managers of a care facility without a formal policy on sexual abuse might have chosen not to fill out the survey. Such care facilities might thus have been underrepresented in the sample. Another limitation is that due to the anonymous nature of this study it was not possible to obtain policy documents and protocols of the participating care facilities. These documents and protocols could have provided relevant additional information on policy on sexual abuse such as the practical use of the protocols on sexual abuse. Also, no information was acquired about the managers' relation to their profession or length of service within the care facility, which makes it impossible to explore the impact of these characteristics on the results of the study.

Conclusion

The present study aimed to assess the state of affairs of policies on sexual abuse and their implementation in care facilities for individuals with ID in the Netherlands and identify areas of improvement regarding the standing practices of both policy formulation and implementation. The results showed that in care facilities for individuals with ID sufficient attention is paid to sexual abuse in a formal sense. However, the extent to which the protocols on sexual abuse are actually brought to the staff's attention and used in practice varied considerably across care facilities. It can therefore be concluded that the availability of policies and protocols on sexual abuse in care facilities for individuals with ID does not guarantee a caring culture in which these policies and protocols are effectively implemented, and in which sexual abuse is prevented, detected early and addressed in a timely and adequate manner. This conclusion might be generalizable to other countries, even though the present study was focused on the Netherlands.

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Chapter 3

Clinical characteristics of individuals with intellectual disability who have experienced sexual abuse. An overview of the literature

Smit, M. J.^{1,2}, Scheffers, M.¹, Emck, C.², van Busschbach, J. T.^{1,3}, Beek, P. J.² (2019).

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¹ School of Health, Movement & Education, Windesheim University of Applied Sciences, Zwolle, the Netherlands

² Department of Human Movement Sciences, Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

³ University Center of Psychiatry, University of Medical Center Groningen, University of Groningen, Groningen, the Netherlands

Abstract

Background: Sexual abuse in individuals with average IQ or above is associated with a wide range of behavioural, psychological and body-related characteristics. It is unknown whether individuals with intellectual disability (ID) and a history of sexual abuse suffer from similar clinical characteristics.

Objective: The aim of the review is to provide an overview of the literature on the clinical characteristics of individuals with ID who have experienced sexual abuse.

Method: PubMed, Embase, PsycInfo, CINAHL, Cochrane Library and Web of Science were searched for relevant publications using terms related to concepts of “intellectual disability” and “sexual abuse”. Two independent reviewers screened and selected articles for inclusion in the study, resulting in seven studies.

Results: The studies mostly reported behavioural and psychological characteristics such as aggression, self-injury, or posttraumatic stress-, anxiety- or depressive symptoms associated with sexual abuse in individuals with ID. None mentioned body-related characteristics.

Conclusions: Similar to individuals with average IQ or above, sexual abuse in individuals with ID is associated with a broad range of behavioural and psychological characteristics. Conduct disorders, self-injury, inappropriate sexualized talk and poor feelings of personal safety seem to be more indicative for the ID population. Anxiety, depression and PTSD are prevalent in individuals with and without ID who both have experienced sexual abuse. Whether individuals with ID experience body-related characteristics is unclear.

Keywords: intellectual disabilities; sexual abuse; clinical characteristics; consequences; sequelae

Introduction

Sexual abuse is a global problem with prevalence rates in individuals with average IQ or above varying from 3% to 31% in children (Barth et al., 2013; Stoltenborgh et al., 2011) and 5% to 9% in adults (Abrahams et al., 2014). In the present review, sexual abuse is defined as unwanted sexual activity, with perpetrators using force, bribes or coercion, making threats or taking advantage of victims who are unable to give consent by virtue of age, immaturity or intellect (Graham, 1996).

In comparison with individuals with average IQ or above, individuals with intellectual disability (ID) are more likely to experience sexual abuse (Byrne, 2017). Prevalence rates of sexual abuse in individuals with ID range from 14% to 32% in children (Balogh et al., 2001; Briggs, 2006) and from 7% to 34% in adults (Lin et al., 2009). It is suggested that both the impairments that individuals with ID face and their context make them more vulnerable to sexual abuse. For example, lack of knowledge regarding sexuality, dependence on others, trained compliance, and social isolation (e.g., Akbaş et al., 2009; Briggs, 2006) may contribute to their increased risk of becoming the victim of sexual abuse. Given this enhanced risk, individuals with mild intellectual disability or borderline intellectual functioning (MID-BIF, IQ 50-85) are more likely to actually experience sexual abuse than individuals with a moderate or severe intellectual disability (IQ < 50) (Balogh et al., 2001; Morano, 2001), because they are more visible in society and have more possibilities to participate in social activities, such as school, work and leisure time (Morano, 2001).

The clinical characteristics of individuals with average IQ or above who have experienced sexual abuse are well studied. Most of these studies have focused on the behavioural and psychological characteristics of individuals who have experienced sexual abuse. In a systematic meta-review, Maniglio (2009) presented depression, anxiety, posttraumatic stress, self-injury, persistent feelings of anger and dissociation as established behavioural and psychological characteristics of individuals who have experienced sexual abuse. While the majority of studies address the behavioural and psychological characteristics of individuals who have experienced sexual abuse, some recent studies focus on body-related clinical characteristics. For instance, Van der Kolk (2014) describes that traumatic events, such as sexual abuse, have a wide-ranging effect on the victim's relationship with his or her body. Victims experience difficulties with processing inner body signals, such as change in heartbeat, breath and feelings of hunger, pain, or temperature. They either deny having inner signals or are overwhelmed by these signals (Van der Kolk, 2006). In addition, Scheffers et al. (2017) found that traumatic events, such as sexual abuse, not only negatively influences this form of body awareness but also affects the way in which the body is experienced in terms of satisfaction with and attitude towards

the body. More specifically, victims of sexual abuse frequently develop feelings of hate towards their body (Fallon & Ackard, 2000) and experience reduced physical vitality and health (Sack et al., 2010).

Studies on the clinical characteristics of individuals with ID who have experienced sexual abuse are limited. In a review of the literature, Sequeira and Hollins (2003) suggest that individuals with ID experience a range of behavioural and psychopathological symptoms following sexual abuse, similar to those with average IQ or above. However, these results are inconclusive due to the evidence reviewed. More specifically, most studies were case studies, did not use control groups, and did not use standardised, reliable and valid diagnostic instruments (Sequeira & Hollins, 2003). Given the fact that the review of Sequeira and Hollins was published in 2003, we deemed it relevant to investigate if there has been renewed knowledge regarding the clinical characteristics of individuals with ID who have experienced sexual abuse and their similarity to those with average IQ or above. Moreover, recently, Mevissen and De Jongh (2010) found in their review study that limitations in intellectual functioning and adaptive functioning in the conceptual, social, and practical domains (American Psychiatric Association, 2013) make it more difficult to deal with traumatic events. This might also lead to other or different clinical characteristics for the group of people with ID that have experienced sexual abuse compared to individuals with average IQ or above.

Whether clinical characteristics of individuals with ID who have experienced sexual abuse, especially those with MID-BIF (IQ between 50 and 85), are similar to individuals with average IQ or above, needs to be further investigated. More knowledge on clinical characteristics of individuals with ID who have experienced sexual abuse might improve early recognition of sexual abuse. Such knowledge is also important in order to develop and implement adequate treatment programs that decrease behavioural and psychological problems, prevent re-victimisation and improve quality of life for this already vulnerable group. Therefore, the aim of this review is to provide an overview of the literature on the clinical characteristics of individuals with ID (e.g., MID-BIF) who have experienced sexual abuse.

Method

Search methods

In June 2018, the following databases were searched: PubMed, Embase, PsycINFO, CINAHL, Cochrane Library and Web of Sciences. The concepts in the search were related to “intellectual disability and “sexual abuse” (see Table 1 for search terms). The reference lists of the included studies were also examined and several experts in the field of sexual abuse and ID were asked to suggest other relevant publications.

Table 1. Search terms

Intellectual disability AND	Sexual abuse
Intellectual disab*	Sexual trauma
Mental disab*	Sexually trauma
Mentally disab*	Traumatic sex
Intellectual retard*	Sexual abuse
Mental retard*	Sexually abuse
Mentally retard*	Rape
Intellectual deficien*	Raped
Mental deficien*	Sex offence
Learning disab*	Sexual offence
Mental handicap*	Sexual violen*
Mentally handicap*	Sexual violat*
Developmental disab*	Sexual molestat*
Borderline intellectual disabil*	Sexually molest*
Borderline intellectual function*	Sexual maltreatment*
Borderline mental retard*	Sexual assault
Intellectual development disorder*	Sexual assaults
Intellectual dysfunct*	Sexual assaulted
Mental dysfunct*	Sexually assaulted
Intellectual impair*	Sexual victim*
Mental impair*	Sexual harass*
Mentally impair*	Sexually harass*
	Sexual aggression
	Sexual coercion
	Sexual exploit*
	Sexually exploit*

Inclusion criteria

Studies were considered for inclusion if they were 1) empirical in nature (reviews and narrative and case studies were excluded; case-control studies were included); 2) published between 1998 and 2018; 3) published in English; 4) published in academic peer-reviewed journals; 5) focused on at least one individual with mild intellectual disability or borderline intellectual functioning (MID-BIF, IQ 50-85); and 6) focused on sexual abuse.

Screening and study selection

After removing duplicates, 1302 studies were screened by title and abstract. The selection of studies was made independently by two researchers (MJS and MS) and consensus had to be reached for every selected article. The screening by title and abstract resulted in 41 studies for full-text assessment. Next, the remaining studies were read in full and selected when inclusion criteria were met. This resulted in a selection of seven studies on the clinical characteristics of individuals with ID who have experienced sexual abuse. No extra studies were found by examining the reference lists of the included studies or from the suggestions of relevant experts in the field. Figure 1 presents a flow diagram of the study selection.

After selection of the seven studies, the diagnostic instruments used in these studies were summarized. Based on the primary outcomes of the diagnostic instruments used, the clinical characteristics of individuals with ID who have experienced sexual abuse were divided into several categories.

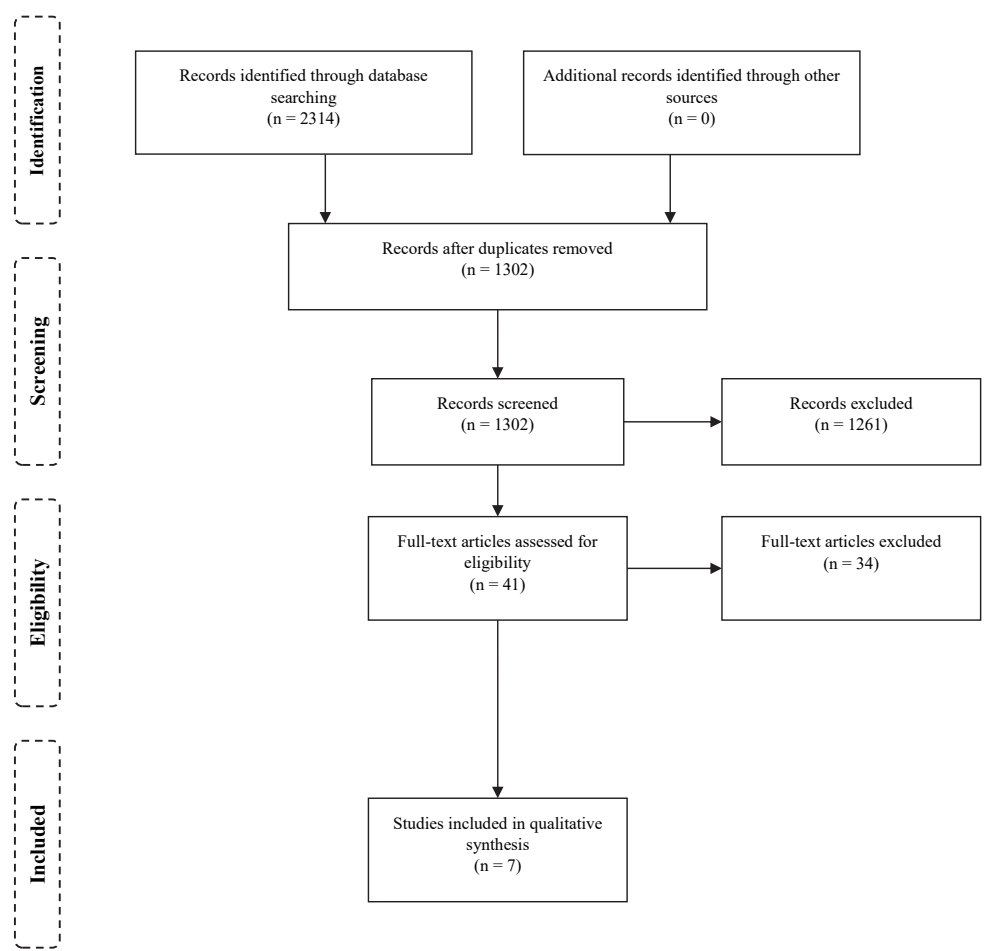


Figure 1. Study selection

Results

Study characteristics

Table 2 provides an overview of the characteristics of the included studies. The studies in question were conducted in the UK ($n = 3$), South-Africa ($n = 1$), US ($n = 1$), Turkey ($n = 1$) and Canada ($n = 1$). Four studies focused on adults with ID who have experienced

sexual abuse (Matich-Maroney, 2003; Peckham et al., 2007; Sequeira et al., 2003; Shabalala & Jasson, 2011) and three studies focused on children and adolescents with ID who have experienced sexual abuse (Firth et al., 2001; Mansell et al., 1998; Soylu et al., 2013).

Three studies compared adults with ID who have and have not experienced sexual abuse (Matich-Maroney, 2003; Sequeira et al., 2003; Shabalala & Jasson, 2011) and one quasi-experimental study concerned an adults survivor group (Peckham et al., 2007). Two studies compared children and adolescents with and without ID who both have experienced sexual abuse (Mansell et al., 1998; Soylu et al., 2013) and one retrospective study concerned child- and adolescent perpetrators of sexual abuse, survivors of sexual abuse and survivors who were also perpetrators of sexual abuse (Firth et al., 2001).

Characteristics of the diagnostic instruments

Table 3 presents the diagnostic instruments used to assess the clinical characteristics of individuals with ID who have experienced sexual abuse in the different studies. Two diagnostic instruments specifically focused on challenging behaviour and one specifically focused on sexualized behaviour. Several diagnostic instruments focused on a specific psychiatric diagnosis or on specific symptoms, such as posttraumatic stress disorder (PTSD) and depression. Three other instruments focused on various psychiatric disorders and symptoms. Furthermore, one diagnostic instrument measured self-esteem, one anger, and one focused on various clinical characteristics. No diagnostic instruments were found that focused specifically on body-related clinical characteristics. With regard to the type of instrumentation, six instruments were self-report instruments, four instruments were completed by informants, and three instruments used both types. Furthermore, seven instruments were developed for individuals with ID, and six instruments were developed for individuals with average IQ or above.

Clinical characteristics of individuals with ID who have experienced sexual abuse

After analysing the results of the studies reviewed, categories of the clinical characteristics of individuals with ID who have experienced sexual abuse were formed based on the primary outcomes of the diagnostic instruments used in the studies included. Two categories were distinguished: behavioural characteristics and psychological characteristics.

Table 2. Characteristics of the studies

Study	Country	Type	Sample	Age	Type ID	Tests and scales
1. Sequeira et al. (2003)	United Kingdom	Case-control study	Individuals with ID who have experienced sexual abuse (n=54); Individuals with ID who have not experienced sexual abuse (n = 54)	16-44	Mild (n=24); Moderate (14); Severe/profound (n=16)	ABC-C, ABS-RC, PAS-ADD, PCL-C/PR
2. Shabalala & Jasson (2011)	South-Africa	Case-control study	Individuals with ID who have experienced sexual abuse (n=27); Individuals with ID who have not experienced sexual abuse (n=27)	11-35	Mild (n=11); Moderate (n=10); Unspecified (n=6)	CPC
3. Match-Maroney (1998)	United States	Case-control study	Individuals with ID who have experienced sexual abuse (n=18); Individuals with ID who have not experienced sexual abuse (n=25)	Adults	Borderline (n=6); Mild (n=26); Mild to moderate (n=11)	PSAS, PIMRA
4. Peckham et al. (2007)	United Kingdom	Quasi-experimental study	Females with ID who have experienced sexual abuse (n=7)	26-47	Mild (n=7)	IES, CFSEI, NAS, BDI, CBI
5. Firth et al. (2001)	United Kingdom	Retrospective study	Children and adolescents with ID who have experienced sexual abuse (n=21)	7-21	Borderline (n=3); Mild (n=11), Moderate (n=7));	-
6. Mansell et al. (1998)	Canada	Retrospective study	Children with ID who have experienced sexual abuse (n=43); Children without ID who have experienced sexual abuse (n=43)	5-7	ID (n=43)	SAIR
7. Soyly et al. (2013)	Turkey	Case-control study	Children and adolescents with ID who have experienced sexual abuse (n=102); Children and adolescents without ID who have experienced sexual abuse (n=154)	6-16	Mild (n=89), Moderate (n=12), Severe (n=1)	-

ABC-C: Aberrant Behaviour Checklist-Community; ABC-RC: Aberrant Behaviour Scale; BDI: Beck Depression Inventory; CBI: Challenging Behaviour Interview; CFSEI: Culture-free Self Esteem Inventory; CPC: Child PTSD Checklist; ID: intellectual disability; IES: Impact of Event Scale; NAS: Novaco Anger Scale; PAS-ADD: Psychiatric Assessment Schedule for Adults with Developmental Disabilities; PCL-C/PR: PTSD Checklist for Children/Parent Report; PIMRA: Psychopathology Inventory for Mentally Retarded Adults; PIMRA: Psychopathology Inventory for Mentally Retarded Adults; PSAS: Prout-Strohmer Assessment System; SAIR: Sexual Abuse Information Record

Table 3. Characteristics of the diagnostic instruments used in the included studies

Name of test or scale	Primary outcome	Instrumentation	Target group
Aberrant Behaviour Checklist-Community (ABC-C; Aman et al., 1995)	Challenging behaviour	Informant questionnaire	ID
Adaptive Behaviour Scale – Residential and Community – sexual behaviour domain (ABS-RC; Nihira et al., 1993)	Sexual behaviour	Informant questionnaire	ID
Challenging Behaviour Interview (CBI; Oliver et al., 2002)	Challenging behaviour	Informant questionnaire	ID
PTSD Checklist for Children/Parent Report (PCL-C/PR; Ford et al., 1999)	PTSD	Informant questionnaire	Non-ID
Beck Depression Inventory (BDI; Beck & Steer, 1987)	Depression	Self-report	Non-ID
Child PTSD Checklist (CPC; Amaya-Jackson, 1995).	PTSD	Self-report	Non-ID
Culture-free Self Esteem Inventory (CFSEI; Battle, 1992)	Self -esteem	Self-report	Non-ID
Impact of Event Scale (IES; Horowitz, Wilner, Alvarez, 1979)	PTSD	Self-report	Non-ID
Novaco Anger Scale (NAS; Novaco, 1994)	Anger	Self-report	Non-ID
Prout-Strohmer Assessment System (PSAS; Strohmer & Prout, 1989)	Psychiatric symptoms	Informant questionnaire and self-report	ID
Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD; Moss et al., 1997)	Psychiatric symptoms	Informant questionnaire and self-report	ID
Psychopathology Inventory for Mentally Retarded Adults (PIMRA; Matson, 1988)	Psychiatric symptoms	Informant questionnaire and self-report	ID
Sexual Abuse Information Record (SAIR; Moskal, 1995)	Overall symptoms	-	ID

Behavioural characteristics

The behavioural characteristics were divided into two subcategories, namely challenging behaviour and sexualized behaviour. Challenging behaviour is defined as culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or seriously limit use of ordinary community facilities (Emerson, 1995). Sexualized behaviour is defined as abnormal behaviour of a sexual nature.

Challenging behaviour

Challenging behaviour was found to be associated with sexual abuse in individuals with ID in four of the seven studies (Mansell et al., 1998; Peckham et al., 2007; Sequeira et al., 2003; Soylu et al., 2013). Peckham et al. (2007) investigated challenging behaviour of female adults with ID who have experienced sexual abuse participating in a survivor group. Before the start of the survivor group, the participants scored high on the following subscales: self-harm, verbal aggression, physical aggression and destruction of property.

One study compared challenging behaviour of adults with ID who have and have not experienced sexual abuse (Sequeira et al., 2003). On the subscale irritability/agitation/crying, the group of people that have experienced sexual abuse showed significantly more aggression to others, self-injury, temper outbursts, and changes of mood, than the non-abused group. Furthermore, more repetitive rocking and bizarre behaviours were found in the group of people that have experienced sexual abuse, which are elements of stereotypical behaviour. Adults with ID who have experienced sexual abuse were also more likely to seek isolation from others, to be preoccupied, to resist any form of physical contact and to be listless, sluggish or inactive, according to the sub scale lethargy/social withdrawal. With regard to the subscale hyperactivity/non-compliance, the group of people that have experienced sexual abuse showed more excessive activity, disobedience and distractibility, and were more likely to disturb others and act impulsively.

The above studies focus on a comparison between adults with ID who have and have not experienced sexual abuse, which raises the question whether the clinical characteristics found in the studies are specific for individuals with ID or similar to those without ID. In line with this question, two studies compared children and adolescents with ID and without ID who both have experienced sexual abuse (Mansell et al., 1998; Soylu et al., 2013). Mansell et al. (1998) found that children with ID who have experienced sexual abuse showed more self-injury (hairpulling, head banging) than those without ID. Soylu et al. (2013) compared the occurrence of conduct disorders in children and adolescents with and without ID who both have experienced sexual abuse. They found that children

and adolescents with ID who have experienced sexual abuse were significantly more likely to develop a conduct disorder than their peers without ID who have experienced sexual abuse.

Sexualized behaviour

Three studies showed sexualized behaviour to be a possible result of sexual abuse in individuals with ID (Mansell et al., 1998; Matich-Maroney, 2003; Sequeira et al., 2003). Matich-Maroney (2003) found that adults with ID who have experienced sexual abuse showed more sexualized behaviour, such as talking inappropriately about sex, being preoccupied with sexual issues, wearing provocative clothing, engaging in inappropriate sexual contacts or behaviour, exposing unusual or atypical sexual interests or, in contrary, avoiding sexual activities, than adults with ID who have not experienced sexual abuse. Consistently, Sequeira et al. (2003) found that adults with ID who have experienced sexual abuse showed more sexualized behaviour than adults with ID who have not experienced sexual abuse. Again, the question arises whether the clinical characteristics mentioned above are specific to individuals with ID or similar to those without ID. Evaluating children with and without ID who both have experienced sexual abuse, Mansell et al. (1998) confirmed a higher occurrence of sexualized behaviour, such as inappropriate sexual talk, in children with ID.

Psychological characteristics

The psychological characteristics were subdivided into three psychopathological symptoms, namely, posttraumatic stress, depression, and anxiety. Several psychological characteristics did not correspond to aforementioned psychopathological symptoms and were described in the category 'other psychological characteristics'.

Posttraumatic stress symptoms

Six of the seven studies found that posttraumatic stress symptoms might be associated with sexual abuse in individuals with ID (Firth et al., 2013; Mansell et al., 1998; Peckham et al., 2007; Sequeira et al., 2003; Shabalala & Jasson, 2011; Soylu et al., 2013). A survivor group study investigated two clusters of PTSD symptoms following the DSM-IV, re-experiencing and avoidance, in female adults with ID (Peckham et al., 2007). The participants met criteria for re-experiencing and avoidance before the start of the survivor group.

In the two studies comparing adults with ID who have and have not experienced sexual abuse (Sequeira et al., 2003; Shabalala & Jasson, 2011) similar conclusions were drawn. Sequeira et al. (2003) found that significantly more adults with ID who have experienced sexual abuse met the criteria for a posttraumatic stress disorder (PTSD), than adults with ID who have not experienced sexual abuse. The criteria for PTSD following the DSM-IV

include the following three clusters: re-experiencing, avoidance and hyperarousal. These findings are in line with Shabalala and Jasson (2011), who studied a group of individuals with PTSD and found that the group that has experienced sexual abuse showed higher rates of a PTSD diagnosis and a higher intensity of PTSD symptoms, following the DSM-IV, than the ID-group that has experienced other traumatic events such as extreme illness or death of a close other. More specifically, the intensity of re-experiencing, avoidance and hyperarousal, was significantly higher in the group of people that have experienced sexual abuse than in the group of people that have experienced other traumatic events.

In two studies that compared children and adolescents with and without ID who both have experienced sexual abuse ambiguous results were found concerning trauma-related symptoms. Mansell et al. (1998) found that specifically the children with ID showed more avoidance symptoms, namely extreme withdrawal and withdrawal into fantasy, than the children without ID. Soylu et al. (2013), however, found no significant differences between the groups with respect to the severity of the trauma-related symptoms and found equal prevalence's of PTSD.

In their retrospective study on children and adolescents with ID who have experienced sexual abuse, Firth et al. (2013) focused on the three clusters of PTSD symptoms in DSM-IV. Amongst 21 victims, no victims reported symptoms in all three clusters and two reported only symptoms of re-experiencing. Symptoms of avoidance and hyperarousal were not found in this study.

Depressive symptoms

In the survivor group study of female adults with ID who have experienced sexual abuse (Peckham, et al., 2007), participants showed symptoms of depression as a possible consequence of the abuse. In the two studies that compared adults with ID who have and have not experienced sexual abuse, this result was confirmed. Matich-Maroney (2003) found that adults with ID who have experienced sexual abuse showed more depressive symptoms, such as decreased energy levels, feelings of sadness, frequent crying, social withdrawal and/or isolation and sleep disturbances, than adults with ID who have not experienced sexual abuse. In addition, Sequeira et al. (2003) found that adults with ID who have experienced sexual abuse fulfilled significantly more criteria for a psychiatric diagnosis of depression following the International Classification of Diseases (ICD-10; World Health Organization, 2010) than adults with ID who have not experienced sexual abuse. No studies analysed differences in depressive symptoms between individuals with and without ID who both have experienced sexual abuse.

Anxiety symptoms

Two studies comparing adults with ID who have and have not experienced sexual abuse indicated that sexual abuse in adults with ID leads to anxiety symptoms. Matich-Maroney (2003) found that adults with ID who have experienced sexual abuse showed more anxiety symptoms, such as inability to relax, excessive worry, proclivity towards self-consciousness and/or extreme shyness, difficulties in concentration and decreased frustration tolerance, than adults with ID who have not experienced sexual abuse. Furthermore, Sequeira et al. (2003) found that adults with ID who have experienced sexual abuse fulfilled significantly more criteria for a psychiatric diagnosis of anxiety disorder following the ICF-10 (ICD-10; World Health Organization, 2010) than adults with ID who have not experienced sexual abuse. No studies were found investigating differences in anxiety symptoms between individuals with and without ID who both have experienced sexual abuse.

Other psychological characteristics

Some of the psychological characteristics found in the studies reviewed, did not correspond with the categories mentioned above. Mansell et al. (1998) found that children with ID who have experienced sexual abuse showed a poorer sense of personal safety compared to those without ID. In their survivor group study of female adults with ID, Peckham et al. (2007) found low self-esteem and persistent feelings of anger in the participants before the start of the survivor group.

Discussion

The aim of the present review was to provide an overview of the clinical characteristics of individuals with ID who have experienced sexual abuse and to compare these characteristics to individuals with average IQ or above who have experienced sexual abuse. The seven studies included demonstrated that sexual abuse in individuals with ID is associated with a broad range of clinical characteristics, namely, behavioural, mainly challenging behaviour and sexualized behaviour, and psychological, that is psychopathological symptoms of PTSD, depression and anxiety, and poorer sense of personal safety, low self-esteem and persistent feelings of anger.

Since the review of Sequeira and Hollins (2003), there has been renewed knowledge regarding the clinical characteristics of individuals with ID who have experienced sexual abuse. With respect to the question whether individuals with ID with a history of sexual abuse suffer from behavioural and psychological characteristics similar or different to individuals with average IQ or above, some interesting findings came to the fore. First, especially children and adolescents with ID were more likely to develop a conduct dis-

order than those without ID. Second, children and adolescents with ID were more likely to injure themselves than those without ID. The higher rate of self-injury may be due to limitations in adaptive functioning, such as insufficient self-care skills, poor general communication, lack of expressive language and lack of social interaction skills (McClintock et al., 2003). Third, with regard to sexualized behaviour, children with ID were more likely to have inappropriate sexualized talk than those without ID. Despite the fact that literature is sparse on this subject, we cannot rule out the possibility that due to their poor control of impulses, individuals with ID are more likely to show challenging and sexualized behaviour (Firth et al., 2001).

With regard to the symptoms of PTSD, findings were inconclusive. It is as yet unclear if individuals with ID who have experienced sexual abuse are more likely to meet specific criteria of PTSD than individuals without ID who have experienced sexual abuse.

Depressive and anxiety symptoms were only reported in the studies on adults. These studies show that adults with ID who have experienced sexual abuse are more likely to experience depressive and anxiety symptoms than adults with ID who have not experienced sexual abuse. However, it is unknown if individuals with ID experience these symptoms following sexual abuse while the onset of the sexual abuse is unclear. They might already show more anxiety and depressive symptoms than adults with ID who have not experienced sexual abuse in childhood (Emerson, 2003). Whether individuals with ID who have experienced sexual abuse are more or less likely to experience depressive and anxiety symptoms than individuals without ID who have experienced sexual abuse is as yet unclear.

As was acknowledged in the introduction, sexual abuse in individuals with average IQ or above is not only associated with behavioural and psychological characteristics, but also with body-related characteristics. Remarkably, no body-related characteristics were reported in the included studies on individuals with ID who have experienced sexual abuse. Thus, it is as yet unclear whether individuals with ID experience body-related characteristics similar to those described in individuals with average IQ or above.

In the months after our literature search, additional, more recent studies on sexual abuse in individuals with ID have been published. While most of these studies did not focus on the clinical characteristics of sexual abuse in individuals with ID, one study (Gil-Lario et al., 2018) presented new findings about the behavioural, psychological and social impact of sexual abuse in this group. Their results are mostly in line with the results of our literature study. They also found that individuals with ID with documented sexual abuse are more likely to present social isolation and self-harm. Finally, they found that individuals with ID with self-reported sexual abuse experience poorer quality of life

than individuals with ID who not have experienced sexual abuse (Gil-Lario, et al., 2018). However, the study by Gil-Lario et al. (2018) offers no more than the current review regarding the body-related characteristics.

Strengths and limitations of the present study

One of the strengths of the present study is that it specifically investigated the clinical characteristics of individuals with ID who have experienced sexual abuse, both in studies comparing victims with and without ID who have experienced sexual abuse, and victims with ID who have and have not experienced sexual abuse. Another strength lies in the fact that multiple databases were searched systematically by two independent researchers and that clear inclusion criteria were used.

The limitations of the current study are threefold. First, the possibility of publication bias exist. As in all articles based on published research, significant positive findings were more reported than negative, nonsignificant or inconclusive findings (Sutton, 2009). Especially with the absence of results on body-related clinical characteristics, on the one hand, it is possible that research on this topic has been conducted, but was not published due to ambiguous findings, or on the other hand, that no researchers investigated the body-related clinical characteristics. Second, the studies included were generally methodological limited; none of the studies were longitudinal and few studies used matched comparison groups. Furthermore, a small number of studies were included. Due to this number, non-western studies (Shabalala & Jasson, 2011; Soylyu et al., 2013) were also included. Therefore, it is important to note that the results of the studies included may differ due to cultural differences. Third, the measurement of the clinical characteristics of individuals with ID who have experienced sexual abuse are achieved through a variety of diagnostic instruments. In addition, several diagnostic instruments used in the included studies were not adapted or developed for individuals with ID. Therefore, possible differences may be overlooked or overrated.

Implications for research

Given the limitations in the design of the reviewed studies, future research on the clinical characteristics of individuals with ID who have experienced sexual abuse should preferably be longitudinal, use matched comparison groups, and use diagnostic instruments specifically developed and validated to be used also for individuals with ID.

In future research, it is also recommended to provide information about the presence of sexual abuse by professionals and based on documentary resources because this information seems more likely to be reliable than information about the presence of sexual abuse provided by the victim's self-report (Gil-Lario et al., 2018). More specifically, Gil-Lario et al. (2018) found in their study that professionals, in most cases, did not have

any documentary evidence of sexual abuse, while the participants had reported to be victim of sexual abuse. Therefore, it is possible that the self-reported group may not have experienced sexual abuse; this would coincide with the absence of psychological problems (Gil-Lario et al., 2018). In contrast, most participants with documentary evidence of sexual abuse did not report to be victim of sexual abuse (Gil-Lario et al., 2018), because they are not aware that they suffered sexual abuse or fear the consequences (Díaz et al., 2014; McGuire & Bayley 2011; Liou, 2014). Nevertheless, both in documented and self-reported sexual abuse, structural bias has to be taken into account.

Account must also be taken of the possibility that sexual abuse is not the only risk factor related to the clinical characteristics mentioned in the present review. Concurrent third variables may be responsible for the results in the studies included. More specifically, other adverse life events than sexual abuse as well as environmental stressors may also contribute to behaviour difficulties and mental health problems reported (Emerson & Brigham, 2014; Wigham & Emerson, 2015). Therefore, future research is needed to investigate the role of third variables (e.g., other life events, environmental stressors).

Since no study specially reported on the body-related clinical characteristics, future research is also required to explore whether individuals with ID experience body-related clinical characteristics following sexual abuse, similar to those experienced by individuals with average IQ or above. Since, Scheffers et al. (2017) found that several domains of body experience, such as body attitude, body satisfaction and body-awareness, are often negatively associated with traumatic events, further research should be carried out to explore if and how sexual abuse is associated with these domains in individuals with ID. In addition, whether individuals with ID who have experienced sexual abuse develop feelings of hate towards their body (Fallon & Ackard, 2000) and experience reduced physical vitality and feelings of health (Sack et al., 2010) deserve also to be studied.

Finally, future research is needed to study whether specific characteristic of individuals with ID who have experienced sexual abuse, such as a younger age of abuse onset, familial relationship with the perpetrator, longer duration of abuse and higher frequency of abuse, are related to higher degree of mental health problems and behavioural difficulties, as found in studies focused on individuals with average IQ or above (Maniglio, 2009; Sequeira, 2006).

Implications for clinical practice

Sexual abuse is highly prevalent in individuals with ID and, therefore, it is important that clinicians consider the possibility of a history of sexual abuse in this group. Considering the possibility of sexual abuse should be a part of the standard assessment and admission procedures. Early recognition of sexual abuse and monitoring over time is impor-

tant in order to decrease the risk of behavioural and psychological problems (Maniglio, 2009). More specifically, clinicians should be aware of the possibility that behavioural and psychological problems, such as aggression, self-injury, sexualized talk, posttraumatic stress, depression, anxiety, poorer sense of personal safety, low self-esteem and persistent feelings of anger may be associated to sexual abuse. If so, adequate, appropriate and effective treatment of sexual abuse in individuals with ID can be arranged.

While early recognition and assessment of clinical characteristics of individuals with ID who have experienced sexual abuse is important, few standardised diagnostic instruments that specifically assess the clinical characteristics of individuals with ID who have experienced sexual abuse in this group have been developed. Several existing instruments use informant questionnaires to complete by parents or keyworkers. These questionnaires give less adequate information because informants cannot be totally aware of the internal subjective experience of an individual (Charlot & Mikkelsen, 2005). Other studies have used self-report questionnaires, but due to the limited language skills or the inability to describe internal feelings, these questionnaires may give incomplete information as well (Charlot & Mikkelsen, 2005). As only use of self-report and informant questionnaires may not suffice, a combination of these types of questionnaires may be a more reliable way to investigate the clinical characteristics of individuals with ID who have experienced sexual abuse (Charlot & Mikkelsen, 2005). Assessment as used by body- and movement oriented therapists, who often work with individuals with ID because their interventions match the needs and learning style of individuals with ID, may also form a useful contribution to a reliable assessment procedure of sexual abuse in individuals with ID (Kay et al., 2015; Mourfouace, 2010). This type of assessment places emphasis on body signals, body experience, and regulating and expressing feelings, which might, as in individuals with average IQ or above, be related to sexual abuse in individuals with ID (Van der Kolk, 2014).

Conclusion

The purpose of the present review was to provide an overview of the literature on the clinical characteristics of individuals with ID who have experienced sexual abuse. We also examined whether individuals with ID who have experienced sexual abuse experience clinical characteristics similar to those with average IQ or above. The current review shows, as with individuals with average IQ or above, that sexual abuse in individuals with ID has a broad range of psychological and behavioural characteristics. Conduct disorders, self-injury, inappropriate sexual talk and poor feelings of personal safety seem to be more indicative for the ID population. Anxiety, depression and PTSD are prevalent in individuals with and without ID who both have experienced sexual abuse. Whether individuals with ID experience body-related characteristics, as with individuals with average IQ or above, is unclear. More research is needed to investigate the body-related characteristics of individuals with ID who have experienced sexual abuse.

Chapter 4

The Body Experience Questionnaire for adults with mild intellectual disability or borderline intellectual functioning (BEQ-mb): development and initial evaluation

Smit, M. J.^{1,2}, Scheffers, M.¹, Emck, C.², van Busschbach, J. T.^{1,3}, Beek, P. J.² (2022).

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¹ School of Health, Movement & Education, Windesheim University of Applied Sciences, Zwolle, the Netherlands

² Department of Human Movement Sciences, Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

³ University Center of Psychiatry, University of Medical Center Groningen, University of Groningen, Groningen, the Netherlands

Abstract

Background: Body experience is an important facet of psychosocial functioning and health. However, to date no test exists to measure body experience in adults with mild intellectual disability and borderline intellectual functioning (MID-BIF). We therefore adapted the Body Experience Questionnaire (BEQ) to this group, resulting in the BEQ-mb, and evaluated its usability, comprehensibility and reliability.

Method: The BEQ-mb was developed in five stages: concept development, focus group, verbal reports, pilot testing and evaluation.

Results: The BEQ-mb is applicable in, and comprehensible by, adults with MID-BIF. Internal consistency is good for the total scale and the body awareness and body satisfaction subscales, but low for the body attitude subscale. Test-retest reliability is excellent for the total scale and the subscales.

Conclusions: The BEQ-mb unlocks new opportunities for clinical examination and research on body experience. Future research is needed to investigate its structural validity.

Keywords: body experience; body awareness; body satisfaction; body attitude; self-report questionnaire; mild intellectual disability and borderline intellectual functioning

Introduction

Body experience is an important facet of psychosocial functioning and health (Fonagy & Target, 2007; Lipowski, 1977; Nayir et al., 2016). How one experiences one's body affects one's overall experience of being in the world. Moreover, a broad range of psychiatric disorders is accompanied by a disturbed body experience (Fuchs & Schlimme, 2009; Lipowski, 1977). Improving body experience is therefore a main objective in body- and movement-oriented treatments, such as psychomotor therapy (PMT) (Röhrich, 2009). However, appropriate instruments for measuring body experience are lacking, especially in individuals with limited cognitive abilities and intellectual disability (ID).

Body experience encompasses different dimensions (Cash & Pruzinsky, 2002; Joraschky et al., 2009), which have been classified as body awareness, body satisfaction and body attitude (Röhrich et al., 2005; Scheffers et al., 2017). Body awareness pertains to the conscious perception of bodily states, processes and actions based on proprioceptive and interoceptive signals (Mehling et al., 2009). Body satisfaction refers to the degree of satisfaction with the appearance and functioning of one's body (Alleva et al., 2014), while body attitude relates to cognitive, affective and behavioural aspects of embodiment (Pöhlmann et al., 2014; Scheffers, 2018).

Research on body experience in individuals with ID has been scarce. Most studies published to date focus on body satisfaction in relation to body weight and shape (Eden & Randle-Phillips, 2017; Napolitano et al., 2010). Only two studies have examined body awareness in individuals with ID, both in relation to aggression (Bellemans et al., 2018; De Looft et al., 2019). (Bellemans et al., 2018) interviewed psychomotor therapists working with individuals with ID, who indicated that enhancing body awareness is a key vehicle in PMT to reduce anger and aggression in this group, while De Looft et al. (2019) measured several physiological variables, such as heart rate and skin conductance, before the onset of aggressive behaviour, without directly assessing body awareness itself.

Only one study (Emck et al., 2012) covered all three dimensions of body experience in individuals with ID and evaluated the relation between psychopathology and body experience in this group. This study showed that children with ID and externalising problems have a disturbed body experience, especially regarding body awareness and body satisfaction.

Although there is a paucity of research on body experience in individuals with ID, body experience is important in individuals with ID for three reasons. First of all, as already mentioned, body experience is often disturbed in individuals with psychiatric disorders, including trauma-related disorders (Sack et al., 2010; Scheffers et al., 2017a), anxiety

disorders (Aderka et al., 2014), depressive disorders (Scheffers et al., 2019), somatoform disorders (Scheffers et al., 2018), eating disorders (Gaete & Fuchs, 2016), psychotic disorders (Sakson-Obada et al., 2018) and autism spectrum disorders (Schauder et al., 2015). Since psychiatric disorders are significantly more prevalent in individuals with ID than individuals with (higher than) average IQ (Emerson, 2003; Whitaker & Read, 2006), the same presumably holds for negative body experiences.

Second, individuals with diagnosed ID may show different psychiatric disorders than individuals with (higher than) average IQ (Fletcher et al., 2016), including more body related symptoms such as aggression or self-harm. In general, a more bodily manifestation of psychiatric disorders appears likely in individuals that are limited in verbal communication and expression.

Third, body awareness appears to play a key role in emotion regulation (Craig, 2015; Price & Hooven, 2018). Since individuals with ID are known to have problems with emotion regulation, reflected in labelling emotions and dealing with anger and aggression (Bellemans et al., 2018; McClure et al., 2009), body awareness might be an important focal point for therapeutic interventions, such as PMT, in these individuals. Through actively participating in physical exercises in PMT, they may learn to become aware of body signals, to correctly label their corresponding emotional states, and to adequately regulate those states (Bellemans et al., 2018).

However, due to the absence of suitable assessment instruments, few empirical data are available to support or reject these hypotheses and impressions. Moreover, the assessment instruments used in studies on body experience in individuals with ID have neither been adapted to individuals with ID, nor tested or validated for this group. Although the figure rating scales that have been used to measure the subjective experience of one's perception of body shape (Collins, 1991; Stunkard et al., 1983) might be applicable to individuals with ID (Eden & Randle-Phillips, 2017), they do not focus on the appearance and functioning of the body, i.e. the key elements of body satisfaction (Alleva et al., 2014). Emck et al. (2012) measured body experience in children with ID with a psychomotor observation tool, the PsyMot for children (Emck & Bosscher, 2010), and a pilot version of a Dutch self-report questionnaire, the Body Experience Questionnaire for Children (BEQC) (Emck, 2015). However, many participants in this study proved to have problems with reading and reasoning while completing the BEQC. In sum, although some assessment instruments have been used in individuals with ID, suitable self-report questionnaires measuring all aspects of body experience remain to be developed for this group.

For individuals with average IQ (and higher), several self-report questionnaires measuring the three domains of body experience are available. Examples include the Multidimensional Assessment of Interoceptive Awareness 2 (MAIA-2; Mehling et al., 2018) for body awareness; the Body Cathexis Scale (BCS; Balogun, 1986; Secord & Jourard, 1953) for body satisfaction, and the Dresden Body Image Questionnaire (DBIQ; Pöhlmann et al., 2014; Scheffers et al., 2017) for body attitude. However, these questionnaires have not yet been tested in or adapted to individuals with ID.

Self-report questionnaires for individuals with average IQ (and higher) need to be adapted to individuals with ID, especially those with mild intellectual disability or borderline intellectual functioning (MID-BIF, IQ 50-85¹) (Hartley & Maclean, 2006; Rittmannsberger et al., 2020; Vlot-Van Anrooij et al., 2018), because they have difficulties with reading and reflective reasoning (Finlay & Lyons, 2001). Once this has been accomplished, and the reliability of the resulting questionnaires has been established, they may be suitable to study body experience and its relation to psychopathology and emotion regulation in individuals with ID. Such research may shed light on the pathology specific disturbances of body experience in this group, as well as the kinds of interventions that may alleviate those disturbances. To this end, we developed a Body Experience Questionnaire for adults with MID-BIF (BEQ-mb) in the Dutch language, and examined its usability, comprehensibility, internal consistency and reliability.

Methods

The study protocol was approved by the local ethics committee of the Faculty of Behavioural and Movement Sciences of the Vrije Universiteit Amsterdam (VCWE-2020-125). The study consisted of five stages: (1) concept development, (2) focus group with experts, (3) verbal reports (Conrad et al., 2000), (4) pilot testing, and (5) evaluation.

Stage 1 Concept development

The original BEQC (Emck, 2015) was taken as starting point for the concept development of the BEQ-mb. The BEQC consists of 24 items that were construed to assess the three dimensions of body experience - body awareness, body satisfaction and body attitude. At first, potentially suitable items in the BEQC for adults with MID-BIF were identified. Next, six other self-report questionnaires for adults with average IQ (and higher) covering the three dimensions of body experience were reviewed to identify additional suitable items for adults with MID-BIF. Items were considered suitable if (1) they

1 Individuals with MID (IQ 50-70) or BIF (IQ 70-85) experience similar psychosocial problems and deficits in cognitive and adaptive functioning. Therefore, they are approached as one group in Dutch clinical practice and literature (Wieland & Zitman, 2016b)

measured body awareness, body satisfaction or body attitude following our definitions of these dimensions (see introduction), and (2) deemed to match the inner experience of individuals with MID-BIF.

Additional items on body awareness were taken from the MAIA-2, the BSQ and the Somatic Awareness Questionnaire (SAQ; Gijbbers van Wijk & Kolk, 1996), on body satisfaction from the BCS, and on body attitude from the DBIQ and the Body Investment Scale (BIS; Orbach & Mikulincer, 1998).

Subsequently, all items were clustered in themes. Furthermore, recommendations for developing questionnaires and formulating items specifically for individuals with MID-BIF were followed: simple language, items in first-person perspective, no double-barrelled items, no negative wording, no items requiring quantitative judgements, direct comparisons and generalisations, limited number (three to five) of response alternatives, and, if feasible, pictorial representatives for response alternatives (Finlay & Lyons, 2001; Hartley & Maclean, 2006).

Stage 2 Focus group

A focus group (Krueger & Casey, 2009) of six psychomotor therapists working with individuals with MID-BIF was formed to evaluate and improve the selected test items. The focus group evaluated these items in terms of usability, language, terminology, instructions, response alternatives and face validity. The discussions in, and recommendations from, the focus group were recorded and transcribed verbatim. Furthermore, two assistants were taking notes during the focus group meetings. Three authors (MJS, MS, CE) analysed the transcripts and notes and adapted the test based on the focus group's recommendations.

Stage 3 Verbal reports

Following the adaptation of the initial test concept, five verbal reports with adults with MID-BIF were held to evaluate how participants understand, mentally process and respond to the questionnaire (Conrad et al., 2000). The following aspects were addressed: usability, language, terminology, instructions and response alternatives. The interviews were recorded and transcribed verbatim. Three authors (MJS, MS, CE) analysed the transcripts, and made further test adaptations based on the information garnered. The number of interviews held (five) was based on content saturation (Guest et al., 2006).

Stage 4 Pilot testing

After two adaptation rounds of the initial concept, a pilot study was conducted to examine the usability, comprehensibility and reliability of the BEQ-mb at this stage of development.

Participants

The pilot study was carried out in 11 care facilities for individuals with MID-BIF in the Netherlands. The participants were recruited through non-probability sampling. The inclusion criteria for potential participants were: (1) IQ between 50-85, (2) aged 18 years or older, (3) sufficient command of the Dutch language and (4) ability to read at the lowest level (A1) (Council of Europe, 2020). The exclusion criteria were: (1) severe impairments in reality testing, and (2) other symptomatology, such as visual or motor disabilities, precluding participants from filling out a questionnaire by themselves. The practitioner in charge determined whether a potential participant was eligible for inclusion in the pilot study.

In total, 85 adults with MID-BIF, 43 men (50.6%) and 42 women (49.2%), completed the BEQ-mb. Their mean age was 34.8 years ($sd = 15.2$; range 18-75). Fifty-seven participants had MID (67.1%) and 28 participants had BIF (32.9%).

Procedure

Data were collected between December 2019 and April 2020. The managers of the contacted care facilities gave permission to collect data at their organization. Bachelor students of the Windesheim University of Applied Sciences and the Vrije Universiteit Amsterdam assisted in data collection. All research assistants were trained to administer the BEQ-mb by the first author (MJS).

The research assistants invited potential participants for a one-on-one meeting to inform them about the aim of the study, the voluntary nature of participation and the anonymous processing of data. They also received an information letter, which they read together with the research assistant to ensure that they fully understood what participation entailed. If interested in participation, the potential participants were asked to sign an informed consent form. Data from non-responders were not collected.

Participants completed the BEQ-mb individually in a quiet room, where the research assistant was present as well to answer any questions and to record the time needed to complete the BEQ-mb. After completion, the research assistant asked two additional pre-structured evaluative questions regarding length and comprehensibility of the BEQ-mb.

To evaluate test-retest reliability, 65 participants completed the BEQ-mb twice within a two-week interval. Twenty participants were unable to complete the BEQ-mb for a second time due to a variety of reasons.

Outcome measures

Usability, *comprehensibility* and *reliability* of the BEQ-mb were evaluated. *Usability* was assessed in terms of the time (in minutes) required to complete the BEQ-mb, the number of missing scores and the length of the BEQ-mb. Less than 3% missing scores per item was considered acceptable (De Vet et al., 2011). The length of the questionnaire was examined by asking the participant if the questionnaire was of good length or too long or too short. The *comprehensibility* of the items was examined by asking the participants which items were difficult or incomprehensible for them. Their answers were noted per item and analysed by three authors (MJS, MS, CE). The *reliability* was determined by assessing the internal consistency and test-retest reliability of the total scale and subscales of the BEQ-mb.

Stage 5 Evaluation

Based on the results of the pilot test, three authors (MJS, MS, CE) formulated recommendations for the final version of the BEQ-mb, which were submitted for review to the six psychomotor therapists comprising the focus group of stage 2. They were asked to provide feedback on the recommendations, after which the researchers adapted the BEQ-mb, resulting in the final pilot version.

Data analysis

SPSS version 25 for Windows was used for the reliability analysis. First, the internal consistency of the BEQ-mb was measured using Cronbach's alpha for the whole scale, the subscales and if any of the items were deleted. Cronbach's alpha was considered acceptable between 0.7 and 0.8, good between 0.8 and 0.9 and excellent > 0.9 (Mohsen & Dennick, 2011). In addition, item-total and inter-item Pearson's correlations were calculated (r). If an item had an item-total correlation of less than 0.3, no indication of a strong inter-total correlation was deemed present (Field, 2009). Items having an inter-item correlation of less than 0.2 with any of the other items were deleted, while items showing inter-item correlations higher than 0.9 were considered carefully (De Vet et al., 2011). Second, test-retest reliability of the total scale and subscales was established by intraclass correlation (ICC; two way mixed model, absolute-agreement, single measurement) (Perinetti, 2018). $ICC > 0.75$ was considered excellent and an ICC between 0.40 and 0.75 acceptable (Fleis, 1986).

Results

Stage 1 Concept development

Twenty-one items of the original BEQC were identified as suitable, including 9 items measuring body awareness, 8 items measuring body satisfaction and 8 items measuring body attitude. Three items of the BEQC were deemed unsuitable because they were

found to be childish or inappropriate for the target group. Subsequent review of the six self-report questionnaires for adults with average IQ (and higher) resulted in 21 additional items for a combined test total of 42 items. For the body awareness subscale, two items were borrowed from the MAIA-2, one from the SAQ and none from the BSQ. For the body satisfaction subscale, no items were adopted from the BCS. For the body attitude subscale, 12 items were copied from the BIS and 6 from the DBIQ.

The 42 items in the pool were clustered in themes under each of the three distinguished dimensions of body experience as follows:

- Body awareness: breathing, heartbeat, warmth, cold, tiredness, hunger, illness, excitement, pain and muscle tension;
- Body satisfaction: contentment with overall physical appearance, body weight and muscle tension;
- Body attitude: touch, body aggrandizement, fitness and vitality, body care, body protection and sexuality.

Based on these themes, and the overlap between items, the researchers reformulated the 41 items into 31 items (see stage 1 in Table 1). The items had to be scored on a 4-point Likert scale comprised of Never (1), Sometimes (2), Frequently (3) and Always (4) with pictorial representations of the response alternatives. Higher scores indicated more positive levels of body experience.

Table 1. Stagewise development of the BEQ-mb: item selection and (re-)formulations

Stage 1 Concept development	Stage 2 Focus group	Stage 3 Verbal reports	Stage 4-5 Pilot testing & evaluation
<i>Body Awareness</i>			
1: I feel it in my body when I am warm	1: If I am warm, I feel in my body [reformulated]	1: I feel it in my body when I am warm [reformulated]	1: I feel it in my body when I am warm
2: I feel it in my body when I am cold	2: If I am cold, I feel it in my body [reformulated]	14: I feel it in my body when I am cold [reformulated]	14: I feel it in my body when I am cold
3: I feel it in my body when I am tired	3: If I am tired, I feel it in my body [reformulated]	2: I feel it in my body when I am tired [reformulated]	2: I feel it in my body when I am tired
4: I feel it in my body when I am hungry	4: If I am hungry, I feel it in my body [reformulated]	3: I feel it in my body when I am hungry [reformulated]	3: I feel it in my body when I am hungry
5: I feel it in my body when I am sick	5: If I am sick, I feel it in my body [reformulated]	12: I feel it in my body when I am sick [reformulated]	12: I feel it in my body when I am sick
6: I feel it in my body when I am scared	6: If I am scared, I feel it in my body [reformulated]	15: I feel it in my body when I am scared [reformulated]	15: I feel it in my body when I am scared
7: I feel it in my body when I am angry	7: If I am angry, I feel it in my body [reformulated]	13: I feel it in my body when I am angry [reformulated]	13: I feel it in my body when I am angry

Table 1. Stagewise development of the BEQ-mb: item selection and (re-)formulations (*continued*)

Stage 1 Concept development	Stage 2 Focus group	Stage 3 Verbal reports	Stage 4-5 Pilot testing & evaluation	
8: I feel it in my body when I am relaxed	9: If I am relaxed, I feel it in my body [reformulated]	4: I feel it in my body when I am relaxed [reformulated]	4: I feel it in my body when I am relaxed	
9: I feel it in my body when I am stressed	10: If I am stressed, I feel it in my body [reformulated]	24: I feel it in my body when I am stressed [reformulated]	24: I feel it in my body when I am stressed	
10: I feel my breathing	12: I feel my breathing	26: I feel my breathing	25: I feel my breathing	
11: I feel my heart beating	13: I feel my heart beating	[eliminated: too abstract and multi-interpretable]		
	11: If I do not want something, I feel it in my body [added]		25: I feel it in my body when I do not want something [reformulated]	24: I feel it in my body when I do not want something
	8: If I am happy, I feel it in my body [added]		23: I feel it in my body when I am happy [reformulated]	22: I feel it in my body when I am happy
<i>Body attitude</i>				
12: I like to be touched by someone I like	14: I like to be touched by someone I like	5: I like to be touched by someone I like	5: I like to hug [reformulated: more in line with the language and behaviour of the target group]	
13: I do not like to be touched	15: I do not like to be touched	[eliminated: too abstract and multi-interpretable]		
14: I like to touch someone I like	16: I like to touch someone I like	30: I like to touch someone I like	8: I like to touch someone I like	
15: I like to have sex	17: I like sex [reformulated]	8: I like sex	30: I like sex	
16: I like to shower	18: I like to shower	6: I like to shower	6: I like to shower	
17: I take care of my body	19: I take care of my body	16: I take care of my body	16: I take care of my body	
18: I put warm clothes on when I am cold	20: If I am cold, I put warm clothes on [reformulated]	[eliminated: measures both body awareness and body attitude]		
19: I feel bad when someone is looking at me	21: I feel bad when someone is looking at me		28: I feel bad when someone is looking at me	27: I feel bad when someone is looking at me

Table 1. Stagewise development of the BEQ-mb: item selection and (re-)formulations (*continued*)

Stage 1 Concept development	Stage 2 Focus group	Stage 3 Verbal reports	Stage 4-5 Pilot testing & evaluation
20: I like to get a compliment about how I look	22: I like to get a compliment about how I look	29: I like to get a compliment about how I look	28: I like to get a compliment about how I look
21: I like to move	23: I like to move	7: I like to move	7: I like to move
22: I hurt myself on purpose	24: I hurt myself on purpose	27: I hurt myself on purpose	26: I hurt myself on purpose
23: I get tired quickly	25: I get tired quickly	18: I get tired quickly	17: I get tired quickly
	26: I feel fit [added]	19: I feel fit	18: I feel fit
	27: I hide my body with my clothes [added]	17: I hide my body with my clothes	[eliminated: too abstract; increased internal consistency to 0.50]
<i>Body satisfaction</i>			
24: I am happy with my weight	28: I am satisfied with my weight [reformulated]	9: I am satisfied with my weight	9: I am satisfied with my weight
25: I am happy with my height	29: I think my height is all right [reformulated]	21: I am satisfied with how tall I am [reformulated]	20: I am satisfied with how tall I am
26: I am happy with how I look	30: I am satisfied with how I look [reformulated]	10: I am satisfied with how I look	10: I am satisfied with how I look
27: I am strong	31: I think my muscle tension is all right [reformulated]	11: I am satisfied with how strong I am [reformulated]	11: I am satisfied with how strong I am
28: I am agile	[eliminated: too difficult]		
29: I like to see myself in the mirror	32: I like to see myself in the mirror	31: I like to see myself in the mirror	29: I like to see myself in the mirror
30: I wish my body looked different	33: I wish my body looked different	32: I wish my body looked different	[eliminated: too abstract]
31: I like my face	34: I think my face is all right [reformulated]	22: I am satisfied with my face [reformulated]	21: I am satisfied with my face
	35: I am satisfied with what my body is capable of [added]	20: I am satisfied with what by body is capable of	19: I am satisfied with what by body is capable of

Note: changes are marked in bold; numbers refer to the place in the BEQ-mb at that stage

Stage 2 Focus group

Based on the feedback from the focus group, 16 items were reformulated, 1 item was eliminated and 5 new items were added (see stage 2 in Table 1). The focus group found the pictorial response alternatives easy to understand, but recommended changes in shape and colour for greater clarity. The focus group also recommended simplification of the instructions.

Stage 3 Verbal reports

As a result of the verbal reports with 5 adults with MID-BIF, 14 of these 35 items were reformulated and 3 items were eliminated (see stage 3 in Table 1). The response alternatives, pictorial representations and instructions were reported as clear and easy to understand. However, the order of the items was modified since it was found to be too monotonous by the participants.

Stage 4 Pilot testing

Usability

On average, this version of the BEQ-mb, which consisted of 32 items, took 7 minutes and 43 seconds (range 1 minute and 51 seconds – 45 minutes; sd = 6 minutes and 41 seconds) to complete. Seventyone (83.5%) participants rated the length of the questionnaire as good, two (2.4%) as too long and twelve (14.1%) as too short. Item 8 “I like sex” was left unanswered by 10 (11.8%) participants. Less than 3% of all other items were left blank (see Table 2).

Table 2. Item statistics per subscale

Item	Unanswered	Marked as	Cronbach's Alpha	Item-total
	<i>n</i> (%)	difficult <i>n</i> (%)	if item deleted (α)	correlations (r)
Body awareness ($\alpha = 0.84$)				
1. I feel it in my body when I am warm	0 (0)	0 (0)	0.83	0.41
2. I feel it in my body when I am tired	0 (0)	0 (0)	0.82	0.53
3. I feel it in my body when I am hungry	1 (1.2)	0 (0)	0.83	0.44
4. I feel it in my body when I am relaxed	1 (1.2)	1 (1.2)	0.83	0.37
12. I feel it in my body when I am sick	0 (0)	2 (2.4)	0.82	0.54
13. I feel it in my body when I am angry	0 (0)	1 (1.2)	0.82	0.61
14. I feel it in my body when I am cold	1 (1.2)	0 (0)	0.82	0.57
15. I feel it in my body when I am scared	0 (0)	0 (0)	0.83	0.42
23. I feel it in my body when I am happy	0 (0)	1 (1.2)	0.83	0.46
24. I feel it in my body when I am stressed	0 (0)	1 (1.2)	0.82	0.55
25. I feel it in my body when I do not want something	0 (0)	1 (1.2)	0.82	0.59
26. I feel my breathing	0 (0)	2 (2.4)	0.83	0.48
Body satisfaction ($\alpha = 0.80$)				
9. I am satisfied my weight	1 (1.2)	0 (0)	0.79	0.48
10. I am satisfied with how I look	0 (0)	0 (0)	0.76	0.66
11. I am satisfied with how strong I am	2 (2.4)	2 (2.4)	0.80	0.39
20. I am satisfied with what my body is capable of	1 (1.2)	0 (0)	0.75	0.71
21. I am satisfied with how tall I am	0 (0)	1 (1.2)	0.80	0.35
22. I am satisfied with my face	1 (1.2)	0 (0)	0.70	0.58
31. I like to see myself in the mirror	0 (0)	1 (1.2)	0.78	0.53
32. I wish my body looked different (R)	0 (0)	5 (5.9)	0.79	0.43
Body attitude ($\alpha = 0.48$)				
5. I like to be touched by someone I like	0 (0)	6 (7)	0.46	0.18
6. I like to shower	0 (0)	0 (0)	0.46	0.17
7. I like to move	2 (2.4)	0 (0)	0.46	0.19
8. I like sex	10 (11.8)	18 (21)	0.47	0.15
16. I take care of my body	1 (1.2)	0 (0)	0.41	0.36
17. I hide my body with my clothes (R)	0 (0)	6 (7)	0.50	0.06
18. I get tired quickly (R)	0 (0)	0 (0)	0.50	0.04
19. I feel fit	0 (0)	0 (0)	0.43	0.28
27. I hurt myself on purpose (R)	0 (0)	6 (7)	0.44	0.29
28. I feel bad when someone is looking at me (R)	1 (1.2)	0 (0)	0.47	0.12
29. I like to get a compliment about how I look	0 (0)	1 (1.2)	0.43	0.27
30. I like to touch someone I like	0 (0)	2 (2.4)	0.46	0.17

R = reversed scored

Comprehensibility

Seventeen of the 32 items were evaluated by one or more participants as difficult or incomprehensible: 7 items measuring body awareness, 4 items measuring body satisfaction and 6 items measuring body attitude (see Table 2). Of these 17 items, 12 were found too difficult only once or twice and 5 items by five or more participants. Item 5 “I like to be touched by someone I like” was reported as poly-interpretable. Item 8 “I like sex” was reported as uncomfortable and too personal, while three participants reported they could not score this item because they lacked sexual experience. Item 17 “I hide my body with my clothes” and item 32 “I wish my body looked different” proved to be too abstract. Lastly, six participants evaluated item 27 “I hurt myself on purpose” as too confrontational.

The feedback of the participants was evaluated in Stage 5 Evaluation and used to adapt the BEQ-mb, resulting in the final version of the questionnaire.

Internal consistency

The internal consistency of the concept version of the BEQ-mb used in the pilot study was good (0.84) for the total scale and for the *body awareness* (0.84) and *body satisfaction* subscales (0.80), but low for the *body attitude* subscale (0.48).

Cronbach’s alpha if item deleted indicated that none of the items measuring body awareness or body satisfaction would increase the internal consistency of the *body awareness* and *body satisfaction* subscales if deleted since all values for these items were less than the overall internal consistency of 0.84 and 0.80, respectively. For two items on the subscale *body attitude*, Cronbach’s alpha if item deleted was higher than the overall internal consistency of 0.48, indicating that deleting these items would increase the internal consistency of this subscale (see Table 2).

Item-total correlations ranged from 0.38 to 0.61 for items of the *body awareness* subscale and from 0.35 to 0.71 for items of the *body satisfaction* subscale, indicating good to very good discrimination in both subscales. Item-total correlations ranged from 0.04 to 0.36, for the *body attitude* subscale, indicating poor discrimination in this subscale. More specifically, no strong item-total correlation existed among 11 out of the 12 items of the *body attitude* subscale (see Table 2). None of all the 32 items had an inter-item correlation higher than 0.9 or less than 0.2 for any of the other items, thus no items had to be deleted based on the inter-item correlations.

Test-retest reliability

ICC's on the test and retest total scores of the 32 item pilot version of the BEQ-mb were 0.87 for the total score and 0.85 for the subscale *body awareness*, 0.76 for the subscale *body satisfaction* and 0.85 for the subscale *attitude*. Thus, test-retest reliability was excellent for the total scale and the three subscales.

Stage 5 Evaluation

Three authors (MJS, MS, CE) evaluated the results of the pilot study and recommended to reformulate one item and eliminate two items (see stage 5 in Table 1). They also recommended to keep item 27 "I hurt myself on purpose" and item 8 "I like sex" because these items enable both therapists and clients to initiate conversations about these important but fraught issues, which are often circumvented (Abbott & Howarth, 2007; Bernert & Ogletree, 2013). In addition, item 8 was recommended to be the last item of the questionnaire since it may cause confusion or a strong emotional response, which may introduce error or bias in subsequent items (Finlay & Lyons, 2001). Lastly, although deleting item 18 "I get tired quickly" would improve the internal consistency of the body attitude subscale, the authors recommended to keep this item in view of its relevance for the target group.

Based on the feedback from 5 of the 6 members of the focus group of stage 2, all the recommendations of the authors were implemented in the final version of the BEQ-mb.

The final version of the BEQ-mb consisted of 30 items (see stage 5 in Table 1) to be scored on a 4-point Likert scale with pictorial representations of the response alternatives (see Figure 1). Higher scores indicated more positive levels of body experience.

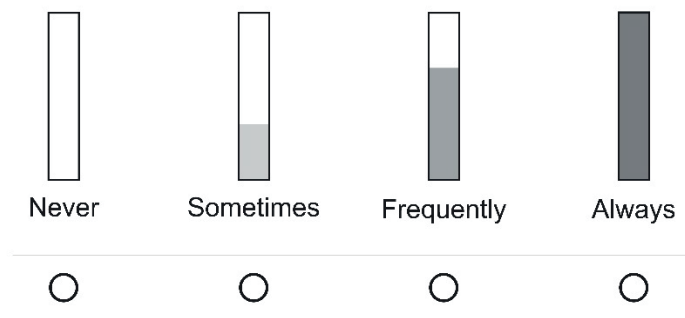


Figure 1. Pictorial representations of the response alternatives

Discussion

In this study, we developed a body experience questionnaire for adults with MID-BIF, the BEQ-mb and examined its usability, comprehensibility and reliability. The final version of the BEQ-mb consists of 30 items, to be scored on a 4-point pictorial Likert scale, measuring the three dimensions of body experience - body awareness, body satisfaction and body attitude.

The results indicated that the concept version of the BEQ-mb is applicable in adults with MID-BIF and generally comprehensible. Two items with sensitive content, both measuring aspects of body attitude, were reported as incomprehensible (i.e. “I like sex” and “I hurt myself on purpose”), possibly to avoid answering them (McNeeley, 2012). These items were deliberately preserved in the final version of the BEQ-mb to facilitate discussion about their contents between therapists and clients. In the BEQ-mb manual, we will explicitly mention that therapists and researchers need to handle these sensitive items with caution, to provide a safe therapeutic environment for discussing their contents, and to respect the client’s wish if he or she declines to answer them.

The results of this study showed excellent test-retest reliability of the concept version of the BEQ-mb and its subscales, and good internal consistency for the total scale and the body awareness and body satisfaction subscales. The body attitude subscale showed low internal consistency and low item-total correlations. An explanation for this might be that body attitude is a multifaceted concept (Röhrich et al., 2005), which is difficult to operationalise in an internally consistent manner. Also the fact that four of the twelve items of the body attitude subscale were evaluated as inappropriate may have contributed to the low internal consistency of this subscale.

We considered removing the body attitude subscale altogether, and to limit the final version of the BEQ-mb to body awareness and body satisfaction. Although this would have improved the overall reliability of the questionnaire, we decided to retain the subscale, because body attitude is potentially of great clinical relevance; removing it would imply that no information would be gathered to further explore this potential.

This study has a couple of noteworthy limitations. The first is that the criterion, structural and convergent validity of the BEQ-mb remain to be established. For its criterion validity this is hard to because no gold standard exists for measuring body experience. However, the structural validity of its three subscales may be established by conducting a factor analysis on a sufficiently large dataset. Also the convergent validity of the BEQ-mb may be established in future research, for instance by comparing the subjective outcomes

with an observation tool, like the PsyMot, a diagnostic instrument for psychomotor therapists (Emck & Bosscher, 2010; Kay et al., 2016), which is currently under development for adults with MID-BIF.

The second limitation is that no information could be provided on the internal consistency and the test-retest reliability of the final version of the BEQ-mb, since several items were reformulated in the evaluation phase. For the same reason, it is important to re-evaluate the usability and comprehensibility of the items evaluated in the fifth stage. Future research is needed to address those limitations in a new sample of participants.

Future research on, and experience with, the BEQ-mb may also lead to the further refinement of test items. For instance, on closer examination of the final adaptations of the BEQ-mb, we consider the item “I like to hug” an inappropriate replacement for the item “I like to be touched by someone I like”, since the former is much more specific than the latter. An item related to a like or dislike of touch seems highly relevant to include in relation to psychiatric symptomatology and sexual trauma (Scheffers et al., 2017), especially in individuals in whom touch has been sexualized and brought outside of their control through sexual abuse (Scheffers, 2018). Therefore, in further development of the BEQ-mb, adding an item related to a (dis)like of touch needs to be reconsidered.

To our knowledge, the BEQ-mb is the first self-report questionnaire specifically developed for adults with MID-BIF, which measures body experience, and encompasses not only body satisfaction but also body awareness and body attitude. A wide range of methods was used to develop the BEQ-mb and to test its use. Adults with MID-BIF were not only engaged as participants but also consulted in verbal reports about the content and comprehensibility of items, answer categories and instructions.

In general, the results of this study indicate that the BEQ-mb is a promising self-report questionnaire to measure body experience in adults with MID-BIF. In future research, this instrument could cast light on the specific disturbances of body experience in different psychopathological disorders, including trauma, anxiety, depression and autism. As seen in individuals with average IQ (or higher), assessing body experience is important to initiate adequate interventions in case of problematic body experience related to psychopathology (Röhrich, 2009). Adequate interventions to improve body experience are body- and movement-oriented therapies, such as PMT (Emck et al., 2021). Whereas evaluation of these interventions, especially for adults with MID-BIF, is still limited, the BEQ-mb may also be useful in the evaluation of body- and movement related interventions aimed at improving body experience.

Chapter 5

The impact of sexual abuse on body experience in adults with mild intellectual disability or borderline intellectual functioning

Smit, M. J.^{1,2}, Scheffers, M.¹, Emck, C.², van Busschbach, J. T.^{1,3}, Beek, P. J.² (2023).

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¹ School of Health, Movement & Education, Windesheim University of Applied Sciences, Zwolle, the Netherlands

² Department of Human Movement Sciences, Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

³ University Center of Psychiatry, University of Medical Center Groningen, University of Groningen, Groningen, the Netherlands

Abstract

Background: Research is lacking on body-related consequences of sexual abuse in adults with mild intellectual disability or borderline intellectual functioning (MID-BIF), although the prevalence of abuse is high and therefore body- and movement-oriented diagnostics and therapeutics seem warranted for this group.

Method: Body experience in adults with MID-BIF who were sexually abused (SA) and were not sexually abused (NSA) was compared using a self-report instrument, the Body Experience Questionnaire-mb, and an instrument to observe non-verbal psychomotor behaviour, the PsyMot-mb.

Results: The SA group showed significantly higher self-reported body awareness and more observed problems with body acceptance than the NSA group. No significant group differences were found for self-reported body satisfaction and body attitude.

Conclusions: Adults with MID-BIF who were sexually abused are more aware of their body signals, but less able to adequately attend to, tolerate, and interpret these signals. Therefore, body- and movement-oriented therapies hold promise for this group.

Keywords: sexual abuse; mild intellectual disability; borderline intellectual functioning; body awareness; body satisfaction; body attitude; body acceptance

Introduction

Sexual abuse is a worldwide problem and a violation of human rights that has far reaching consequences for human well-being and health (World Health Organization, 2013). A crucial but often overlooked impact of sexual abuse is its effect on the relationship victims have with their body (Van der Kolk, 2006, 2014). Research has shown that body experience in victims of sexual abuse is often negatively affected by the violation of the body they experience or by the threats to its physical integrity (Sack et al., 2010). Victims often experience dissatisfaction with their body or parts thereof (Jaconis et al., 2020); feelings of sexual unattractiveness (Kilimnik & Meston, 2016; Wenninger & Heiman, 1998); diminished sexual fulfilment (Scheffers et al., 2017); disgust or hate towards their body (Fallon & Ackard, 2002); and reduced vitality and health (Sack et al., 2010; Wenninger & Heiman, 1998). Furthermore, victims of sexual abuse may experience difficulties with attending to and processing body signals, such as (changes in) heartbeat, breath and feelings of hunger, pain, or temperature (Van der Kolk, 2014). They may either deny even having those body signals or may feel overwhelmed by the signals (Van der Kolk, 2006).

The afore-cited studies all based their results on the experiences of individuals with (higher) than average IQ, whereas individuals with intellectual disability (ID) are especially at risk of sexual abuse (Mailhot Amborski et al., 2021; Tomsa et al., 2021). The estimated prevalence of sexual abuse in this group is 33%, with increases in prevalence as the disability rises from mild (24%) to severe ID (67%) (Tomsa et al., 2021). Evidently the rates in ID are higher than the estimated prevalence of 24% for individuals with (higher than) average IQ (Pan et al., 2021). Two recent reviews showed that the consequences of sexual abuse are generally similar for individuals with ID and individuals with (higher than) average IQ, and cover a wide range of psychological and behavioural problems, among which includes symptoms of anxiety, depression or posttraumatic stress, and challenging or sexualized behaviour (McNally et al., 2021; Smit et al., 2019). However, body-related consequences, such as aggression and self-harm, tend to be more common in the ID population (McNally et al., 2021; Smit et al., 2019) due to limitations in their verbal communication skills and expression (Smit et al., 2019). One could therefore expect that individuals with ID who were sexually abused would have a disturbed or negative body experience, similar to or even greater than their peers with (higher than) average IQ. Although body- and movement oriented therapists, such as psychomotor therapists (Emck & Scheffers, 2019; Probst, 2017) frequently observe problems with body experience in individuals with ID who were sexually abused (Van de Kamp & Hoven, 2019), research on this topic is non-existent, as far as we could glean from the literature (Smit et al., 2019, 2022)

To obtain sufficient information about an individual's body experience, an assessment should include a combination of self-report measures and psychomotor observations (Emck & Scheffers, 2019). Self-report measures that evaluate body experience are particularly valuable because they reflect a given individual's subjective experiences (Emck & Scheffers, 2019). The Body Experience Questionnaire for adults with mild intellectual disability or borderline intellectual functioning (MID-BIF) (BEQ-mb; Smit et al., 2021) is a self-report measure that focuses on three domains of body experience: body awareness, body satisfaction and body attitude (Röhrich et al., 2005; Scheffers et al., 2017). Body awareness refers to the conscious perception of bodily states, processes, and actions based on proprioceptive and interoceptive signals (Mehling et al., 2009). Body satisfaction refers to the degree of satisfaction with the appearance or functionality of the body (Alleva et al., 2014). And body attitude refers to the cognitive (including perceptual) and affective evaluation of the body and its behavioural consequences (Pöhlmann et al., 2014; Scheffers, 2018).

Besides self-report measures, psychomotor observation may also provide valuable information about an individual's body experience (Probst, 2017). Psychomotor observation tools are particularly useful for individuals who have limitations in their verbal communication and expression, such as individuals with ID (Bellemans & Van Putten, 2021; Emck & Van Damme, 2021), as well as for individuals who are not sufficiently aware of their feelings, cognitions and behaviours associated with, for instance, post-traumatic stress (Van de Kamp et al., 2018). These tools are based on the observational assessment of a psychomotor therapist, in a clinical context, of non-verbal information such as (movement) behaviour, body posture, and facial expression (Emck & Scheffers, 2019; Van de Kamp et al., 2018). In addition, psychomotor observation tools consist of movement activities in which the client can be observed and asked about their bodily feelings as experienced in the moment. Such an approach matches the needs and cognitive capabilities of individuals with ID (Emck et al., 2012; Kay et al., 2016). The PsyMot for adults with MID-BIF (PsyMot-mb; Smit et al., 2020) is an example of an assessment tool that focuses on body acceptance, a domain of body experience that pertains to the ability to attend to, tolerate, and interpret bodily signals and the accompanying (movement) behaviour (Emck & Bosscher, 2010; Smit et al., 2020). Body acceptance includes non-verbal aspects of body experience (i.e. noticing changes in body signals, regulating breathing, and locating, relaxing, and tightening body parts). Body acceptance thus also includes behavioural responses to body awareness.

To our knowledge, the BEQ-mb and the PsyMot-mb are the only instruments presently available for measuring body experience in individuals with ID. Since these instruments measure body experience specifically in adults with MID (IQ 50-69) and BIF (IQ 70-85), this study focuses on these groups. Adults with BIF were included because, in the

Netherlands, they are accommodated in the same care facilities as adults with MID. In these care facilities, adults with BIF and MID are treated as a single group because they experience similar problems in cognitive and adaptive functioning (Wieland & Zitman, 2016b).

Research is required to document and better understand the impact of sexual abuse on body experience in adults with MID-BIF in order to improve the early recognition of sexual abuse in clinical practice. The resulting knowledge is essential for the adequate use of body- and movement-oriented therapies that target problems with body experience in adults with MID-BIF. Against this background, the aim of this study was to compare body experience in adults with MID-BIF who had and had not been sexually abused. More specifically the following questions were examined:

- (1) Do adults with MID-BIF who were sexually abused differ from those who were not sexually abused in terms of their body awareness, body satisfaction, and body attitude as measured by self-report?
- (2) Do adults with MID-BIF who were sexually abused differ from those who were not sexually abused in terms of their body acceptance as assessed by psychomotor observation?

Based on the clinical observation of individuals with MID-BIF, and the literature on individuals with (higher than) average IQ, the following general hypothesis was examined: adults with MID-BIF who were sexually abused have more problems with body awareness, body satisfaction and body attitude than adults with MID-BIF who were not sexually abused. Given the paucity of research on the impact of sexual abuse in adults with MID-BIF, we refrained from formulating more detailed hypotheses and sought instead to explore possible differences in body acceptance between the two groups.

Method

In this cross-sectional comparison study, the body experience in a group of adults with MID-BIF who were sexually abused were measured using the BEQ-mb and the PsyMot-mb and compared with those of a group of adults with MID-BIF who were not sexually abused.

Participants

Individuals with ID were recruited by 17 psychomotor therapists in 12 care facilities through non-probability convenience sampling. Inclusion criteria were: (1) IQ between 50 and 85, (2) aged 18 years or older, (3) sufficient command of the Dutch language, (4)

ability to read at least at the lowest level (A1; Council of Europe, 2020), and (5) referral to PMT. Exclusion criteria were: (1) symptoms including visual or motor disabilities that precluded participants from filling out a questionnaire and/or participating in movement activities, and/or (2) severe impairments in reality testing at the time of data collection, such as having a psychotic episode. Psychomotor therapists determined whether the potential participants were eligible for inclusion.

Based on the participant's report and information about sexual abuse in their casefile, the participant was assigned to either the sexual abuse (SA) or non-sexual abuse (NSA) group in the data analysis stage of the study (see *procedure*). We chose not to rely solely on the participant's report, because they may not have recognised the abuse, or may have been ashamed or reluctant to report the abuse (Gil-Llario et al., 2019). The SA group consisted of 24 participants (43%), including 18 participants (32%) with sexual abuse documented in their case file who reported sexual abuse by themselves, 4 participants (7%) who reported sexual abuse by themselves but for whom no sexual abuse was documented in their case file, and 2 participants (4%) who did not report sexual abuse by themselves although it was documented in their case file. The NSA group consisted of 32 participants (57%).

Table 1 summarizes the main characteristics of the SA and NSA groups. There were no significant differences between the groups in terms of age, sex, IQ, psychiatric disorder(s) according to DSM-5, or experience with psychomotor treatment before participating in the study. Only on one variable was a significant difference found: more participants in the SA group reported to have experienced traumatic events other than sexual abuse (79%) than in the NSA group (50%; $\chi^2(1) = 4.978, p = 0.026$).

Little is known about the characteristics of sexual abuse in individuals with MID-BIF. This information could be useful for diagnostic and therapeutic purposes. Although this was not an aim of the study, detailed information about the sexual abuse is provided in the supplementary material for future reference (see Table I). According to the rubrics developed by Wissink et al. (2018), the following details of sexual abuse were noted: type of abuse, frequency of abuse, evidence of abuse, and perpetrator characteristics (i.e. sex, relationship with victim).

Procedure

The study was approved by the local ethics committee of the Faculty of Behavioural and Movement Sciences of the Vrije Universiteit Amsterdam (VCWE-2020-138). Data collection took place between September 2020 and December 2021.

Table 1. Participant characteristics

	Total group (<i>n</i> = 56)	SA group (<i>n</i> = 24)	NSA group (<i>n</i> = 32)	<i>p</i>
Age (<i>M</i> , <i>sd</i>)	33 (11)	33 (11)	33 (11)	0.935
Sex (<i>n</i> , %)	27 (48)	10 (42)	17 (53)	0.396
- Male	29 (52)	14 (58)	15 (47)	
- Female				
IQ (<i>n</i> , %)				
- BIF (IQ 70-85)	23 (41)	8 (33)	15 (47)	0.308
- MID (IQ 50-69)	33 (59)	16 (67)	17 (53)	
IQ (<i>M</i> , <i>sd</i>)				
- Total IQ ¹	67 (8)	67 (8)	68 (9)	0.694
- Verbal IQ ²	71 (8)	72 (11)	71 (12)	0.824
- Performance IQ ³	69 (10)	68 (10)	70 (9)	0.696
Psychiatric disorder(s) according to DSM-5 (<i>n</i> , %)				
- Yes	45 (80)	19 (79)	26 (81)	1.000
- No	11 (20)	5 (21)	6 (19)	
Type of psychiatric disorder according to DSM-5 (<i>n</i> , %)				
- Neurodevelopmental disorders	19 (46)	6 (32)	13 (59)	
- Trauma- and stressor-related disorders	13 (32)	9 (47)	4 (18)	
- Disruptive, impulse-control- and conduct disorders	4 (10)	3 (16)	1 (5)	
- Schizophrenia spectrum and other psychotic disorders	4 (10)	2 (11)	2 (9)	
- Anxiety, depressive, bipolar and related disorders	12 (29)	8 (42)	4 (18)	
- Obsessive-compulsive and related disorders	1 (2)	1 (5)	0 (0)	
- Personality disorders	8 (20)	4 (21)	4 (18)	
- Substance-related and addictive disorders	11 (27)	6 (32)	5 (23)	
- Paraphilic disorders	2 (5)	1 (5)	1 (5)	
Traumatic experiences other than sexual abuse (<i>n</i> , %)				
- Yes	35 (63)	19 (79)	16 (50)	0.030*
- No	21 (37)	5 (21)	16 (50)	
Psychomotor treatment (<i>n</i> , %)				
- Yes	51 (91)	21 (87)	30 (94)	0.642
- No	5 (9)	3 (13)	2 (6)	

* $p < 0.05$ ¹ $n = 53, 23, 30$ (respectively total group, SA group, NSA group), ² $n = 48, 22, 25$ (respectively total group, SA group, NSA group), ³ $n = 48, 22, 26$ (respectively total group, SA group, NSA group)

Psychomotor therapists ($n = 17$) working in a care facility for individuals with ID were recruited through non-probability convenience sampling via the authors' professional networks. Recruitment took place on an individual rather than an institutional level. Therapists received an information letter about the study and were invited for an one-on-one meeting to provide more detailed information. If willing to participate, the psychomotor therapists were recommended to ask the manager of the care facility they worked for permission to invite individuals to be included in the study. If permission was given, the psychomotor therapists checked whether clients in their case load met the inclusion criteria for participating in the study (see *Participants*). If so, they invited them for a one-on-one meeting to inform them about the study. Potential participants received an information letter, which they read, together with the therapist, to ensure they fully understood what participation would entail. They were given two weeks to decide whether or not they wanted to participate in the study. If interested, the potential participants and their legal representatives (if required) were invited to sign an informed consent form.

Data for each participant were collected during two standardised PMT sessions that lasted about one hour. The first session was used for the self-report questionnaire and a semi-structured interview (first part of the PsyMot-mb). In the second session, the psychomotor observation was conducted (second part of the PsyMot-mb). All psychomotor therapists were trained by the first author (MJS) on how to administer the measurement instruments.

During the first session, the therapists asked the participant whether they had been sexually abused². The participant could answer "yes" or "no" and was not obliged to further discuss the abuse, but was allowed to do so if feeling sufficiently safe. Independent of this answer, reports of sexual abuse were searched for in the participant's case file. The SA group consisted of participants who reported the sexual abuse by themselves (answered "yes") and/or for whom the sexual abuse was documented in their case file. If the sexual abuse was not documented in the participant's case file and they answered "no" to the question about sexual abuse, the participant was categorized in the NSA group.

2 Sexual abuse refers to "any sexual activity that a victim does not fully comprehend, is unable to give informed consent to, or for which the victim is not developmentally prepared, or that violate the laws or social taboos of society" (World Health Organization, 1999, p. 15).

Measures

Registration form

A registration form for recording the participant characteristics was developed by the authors (MJS, CE, MS). The characteristics in question were extracted from the participant's case file. The participant characteristics included age, sex, IQ levels (total, verbal, and performance), psychiatric disorders according to DSM-5, traumatic experiences other than sexual abuse, and experience with psychomotor treatment prior to participating in the study.

BEQ-mb

The BEQ-mb, a 30-item self-report questionnaire, was used to measure three distinct domains of body experience: body awareness (e.g., "I feel it in my body when I am cold"), body satisfaction (e.g., "I am satisfied with how I look"), and body attitude (e.g., "I like to hug") (Smit et al., 2022). The items were scored on a 4-point Likert scale ranging from never (1) to always (4) with pictorial representations of the response alternatives, and a higher score respectively indicating higher awareness, a more positive attitude and greater satisfaction. Internal consistency of the pilot version of the BEQ-mb was found to be good for the total scale ($\alpha = 0.84$) and the body awareness ($\alpha = 0.84$) and body satisfaction subscales ($\alpha = 0.80$), but low for the body attitude subscale ($\alpha = 0.43$). Test-retest reliability of the pilot version of the BEQ was found to be excellent for the total scale ($ICC = 0.87$), and for the body awareness ($ICC = 0.85$), body satisfaction ($ICC = 0.76$), and body attitude ($ICC = 0.85$) subscales (Smit et al., 2022). Based on the results of the pilot test, the BEQ-mb was adapted in order to improve the internal consistency of the body attitude subscale, resulting in the BEQ-mb used in this study. The reliability and validity of this adapted version remain to be established (Smit et al., 2022).

PsyMot-mb

The PsyMot-mb, a standardized tool for the psychomotor assessment of adults with MID-BIF, was used to measure body acceptance, defined as the ability to attend to, tolerate, and interpret body signals (Smit et al., 2020). Besides the measurement of body acceptance itself, the PsyMot-mb focusses on the (behavioural) problems arising from disturbances in the aforementioned aspects of body acceptance. The PsyMot-mb is based on a combination of the subscale 'body acceptance' of the PsyMot for children (Emck & Bosscher, 2010) and the PsyMot for individuals with intellectual disabilities and challenging behaviour (PsyMot-ID) (Kay et al., 2016).

The PsyMot-mb consists of 13 items (e.g., "sensation of pain", "breathing", "managing body signals") scored on a 5-point Likert scale ranging from no problems (0) to extremely severe problems (4). The items are scored based on a semi-structured interview and an

observation session. Examples of questions posed during the semi-structured interview are “Do you feel tense sometimes?”, “If so, how do you notice?”, “If so, where in your body do you notice?”, and “If so, what do you do when you feel tense?”. The observation session consisted of three movement activities: running, a free choice movement activity, and a relaxation exercise. During those activities, participants become physically active and thereby enabled the psychomotor therapist to observe the participants, and ask them, for example, if they noticed any change in their body signals, such as breathing, heart rate, sweating or warmth. The relaxation exercise was introduced to assess whether, for example, the participants were able to regulate their breathing, to focus on and locate body parts, and to tighten and relax muscle groups. The PsyMot-ID was shown to be a useful instrument in clinical practice with good inter-rater reliability on all subscales (kappa range: 0.71-1; Kay et al., 2016).

Data analysis

All analyses were conducted using IBM SPSS Statistics software version 28. Mean (sub) scale scores were not computed for participants who had more than two missing item scores. Two participants in the SA group scored more than two standard deviations (*sd*) below the mean of the subscale body satisfaction, and one participant in the SA group scored more than two *sd* above the mean of the PsyMot-mb. However, since these scores seemed legitimate observations, reflecting a degree of variation that is to be expected in a heterogeneous clinical sample such as the present one, we decided to keep their scores in the analyses (Laurikkala et al., 2000). Normal distribution of the variables was checked using the Shapiro-Wilk test.

Chi-squares (χ^2) were used to analyse group differences in sex and IQ (MID or BIF) because expected cell frequencies of these variables were greater than 5 (Field, 2009). Group differences in experience with psychomotor treatment before participating in the study, psychiatric disorders according to DSM-5, and traumatic experiences other than sexual abuse, were analysed by applying Fisher’s exact tests because expected frequencies of these variables were 5 or lower (Field, 2009). Group differences in age and IQ levels (total, verbal, and performance) were analysed using independent t-tests.

Independent t-tests were conducted to compare mean values between the two groups in BEQ-mb scores and PsyMot-mb scores. Significant mean differences were expressed in Cohen’s *d* and considered large if > 0.80 , moderate between 0.79 and 0.50 , and small between 0.49 and 0.20 (Cohen, 1988). Although we conducted multiple t-tests, we refrained from applying the Bonferroni correction because this correction increases the risk of type II errors and missing true positive results that could be further investigated

in future research (Feise, 2002; Perneger, 1998). Instead, effect sizes and confidence intervals (CI) were reported to assess the magnitude of the differences and the extent of any uncertainty (Cumming, 2014; Sullivan & Feinn, 2012).

Additionally, to control for differences between the two groups on variables independent of sexual abuse, hierarchical regression analyses were conducted to predict the BEQ-mb scores and PsyMot-mb scores based on a model with only the group variable (step 1), and a model with both the group and a dummy for the presence of traumatic experiences other than sexual abuse (step 2). All statistical analyses were performed two sided, using a significance level of 0.05.

Results

Table 2 shows the mean differences in BEQ-mb total and subscale scores, as well as the PsyMot-mb scores, between the participants in the SA and NSA groups. Differences in body experience between both groups were significant and moderate for the subscale body awareness on the BEQ-mb and for the PsyMot-mb. The participants in the SA group scored higher on the subscale body awareness on the BEQ-mb and the PsyMot-mb than the participants in the NSA group.

Table 2. Mean differences in BEQ-mb total- and subscale scores and PsyMot-mb scores between the SA and NSA groups

	SA group (<i>n</i> = 24)	NSA group (<i>n</i> = 32)	<i>df</i>	<i>t</i>	<i>p</i>	95% <i>CI</i>	Cohen's <i>d</i>
BEQ-mb (<i>M, sd</i>)	2.89 (0.44)	2.89 (0.43) ¹	52	0.004	0.996	-0.24, 0.24	
Subscales BEQ-mb (<i>M, sd</i>)							
- Body awareness	3.19 (0.48)	2.90 (0.52) ²	53	2.079	0.042*	-0.56, -0.01	0.57
- Body satisfaction	2.55 (0.82)	2.89 (0.66)	54	-1.704	0.094	-0.06, 0.74	
- Body attitude	2.79 (0.47)	2.89 (0.38)	54	-0.888	0.379	-0.13, 0.33	
PsyMot-mb (<i>M, sd</i>)	1.47 (0.72)	1.05 (0.59)	54	2.400	0.020*	-0.77, -0.06	0.65

¹*n* = 30, ²*n* = 31

Additional multivariate analyses were performed to examine whether the significant differences between the groups could also be explained by the difference in traumatic experiences other than sexual abuse (see Table II in the supplementary material). In step 1, results indicated that sexual abuse significantly predicted scores on the subscale body awareness and the PsyMot-mb, explaining respectively 5.8% and 9.6% of the variation. Both regression models were significant.

In step 2, the variable traumatic experiences other than sexual abuse was included in all models. However, adding this variable accounted for only an additional 1.8% and 1.1% of the variation in the scores on the subscale body awareness and the PsyMot-mb. Both regression models were not significant.

Discussion

The main aim of this study was to compare body experience in adults with MID-BIF who were and were not sexually abused. Differences between the SA and NSA groups on three domains of body experience, i.e. body awareness, body satisfaction and body attitude, were measured by self-report, and differences between the SA and NSA groups on the body acceptance domain were measured using psychomotor observation. Both groups were comparable in terms of the participant characteristics, except for the variable traumatic events other than sexual abuse, with significantly more traumatic events reported in the SA group. An additional analysis showed that the higher prevalence of trauma other than sexual trauma in the SA group provided no explanation for the group differences observed using the self-report and psychomotor observation instruments. Nevertheless, the higher prevalence of trauma other than sexual trauma in the SA group is an important finding in its own right, because it illustrates both the vulnerability of the target group and the complexity of their problems.

The participants in the SA group scored significantly higher on self-reported body awareness than the participants in the NSA group. This indicates that participants in the SA group were more aware of their body signals (e.g., change in breath, feelings of hunger, pain, or temperature) than those in the NSA group. Possibly, this higher body awareness indicates that the participants in the SA group may have felt overwhelmed by their body signals; they may have been hyperalert or overly aware of their body signals, also known as a state of hyperarousal (Ogden et al., 2006; Van der Kolk, 2006). Hyperarousal is a survival mechanism, which enables an individual to assess threat, and to (rapidly) select resources for safety. However, in victims of traumatic events, hyperarousal is often present long after the threat of the trauma has disappeared. They perceive harmless triggers as dangerous, resulting in too much arousal to process information effectively, which is not adaptive over time. This makes it difficult for victims of traumatic events to adequately interpret and rely on their body signals, which in turn may lead to inadequate behavioural decisions (Ogden et al., 2006; Van der Kolk, 2014). Heightened awareness of body signals is thus not particularly helpful in adults with MID-BIF who were sexually abused. This insight is in line with the study by Mehling et al. (2009), who considered heightened body awareness as potentially distressing and

maladaptive, and is also in alignment with our hypothesis that participants in the SA group would experience more problems with body awareness than those in the NSA group.

In contrast with our hypothesis, participants in the SA and NSA groups did not differ in their self-reported body satisfaction or body attitude. With respect to body satisfaction, this might be related to the fact that, in general, individuals with ID have positive beliefs about their body and tend to underestimate their body size (Eden & Randle-Phillips, 2017). Moreover, their image of the ideal body may be different to individuals with (higher than) average IQ because individuals with ID might be protected by their environment from negative discussions about (their) appearance. As such, they are less susceptible to societal pressures about the ideal body image and may lack the ability to generalize to themselves concepts such as the ideal image of the body in society (Eden & Randle-Phillips, 2017). The fact that no significant differences were found in body attitude between the groups may be related to the low internal consistency of the subscale body attitude of the BEQ-mb. Body attitude is a multifaceted concept (Röhrich et al., 2005), which includes behavioural responses to body awareness. It is therefore difficult to operationalise in an internally consistent manner using questionnaires (Smit et al., 2022). As a result, this subscale might not be robust enough to detect differences and might thus be less suitable for investigating problems in body attitude as a singular concept. Therefore, the results of the body attitude subscale should be interpreted with caution. Further research is needed to substantiate these explanations and suggestions.

Based on the findings of the psychomotor observations, the participants in the SA group had significantly more problems with body acceptance than those in the NSA group. More specifically, the participants who were sexually abused were less able to adequately attend to, tolerate, and interpret body signals, resulting in more problematic (movement) behaviour, compared to those without sexual abuse. These findings are in line with the conceptual framework of Price and Hooven (2018) according to whom trauma affects the ability to access (i.e. to pay attention to and perceive) body signals and to appraise (i.e. interpret and make behavioural decisions based on) these body signals. Moreover, the problems with body acceptance reported in the PsyMot-mb by the therapists possibly reflect the behavioural responses to hyperarousal in the SA group.

In general, our study provides an indication of the impact of sexual abuse on the victims' relationship with their body. Although differences in group means on our measures of body awareness and body acceptance were clearly present, proper diagnostics are required to determine the impact on an individual level. From this perspective, it is advisable to include an evaluation of body experience in the treatment of sexual abuse, making use of body- and movement-oriented interventions such as psychomotor

therapy (PMT). Since evidence for these interventions in individuals with MID-BIF who were sexually abused are scarce (Stobbe et al., 2021), the development of effective body- and movement-oriented interventions that target problems in body experience in this group is highly warranted. Furthermore, it is advisable to include the assessment of body experience in the standard assessment and admission procedures for individuals with MID-BIF, especially in light of the high prevalence of sexual abuse in this group. This may improve the early recognition of sexual abuse and related problems in this group. Additionally, to gain a more encompassing understanding of body experience, different types of instruments need to be used for its assessment, in particular self-report questionnaires and psychomotor observation tools (Emck & Scheffers, 2019).

To our knowledge, this is the first study examining body experience in adults with MID-BIF who were sexually abused which used a combination of self-report and psychomotor observation as assessment tools. Another strength of this study, considering the sensitivity of the topic, and the vulnerable population, is the relatively large sample consisting of participants from 12 different care facilities throughout the Netherlands. This contributes to the generalisability of the findings to individuals with MID-BIF accommodated in Dutch care facilities.

Besides these strengths there are also a few noteworthy limitations and recommendations for future research. First, from a statistical perspective, the sample size was too small to comply with the standard power level of 0.80 recommended by Cohen (1988). This might account for the lack of significant differences between the SA and NSA groups on body satisfaction and body attitude. Also, the heterogeneity within the sample in terms of participant characteristics and characteristics of the sexual abuse may have led to a relatively small level of variance explained by the effect.

Second, the possibility of observer bias exists for the PsyMot-mb, a bias that may have influenced the observations in two ways. Prior to the interview- and observation session, the psychomotor therapists knew whether the participant was categorized in the SA or NSA group, and this may have led to under- or overreporting during the psychomotor observation and, therefore, could have affected especially the information where problems in body acceptance were concerned (Jager et al., 2020). Moreover, the risk of diagnostic overshadowing is present in individuals with ID (Mevissen & de Jongh, 2010), which may have led to attributing problems in body experience to the ID, instead of the sexual abuse, resulting in a possible underreport of problems in the broad domains of body experience.

Third, the sample in the present study was a selective group of clients who had a referral to PMT and of whom the majority had experience with PMT prior to participating in the study. Since body experience is a primary focus of PMT (Bellemans & Van Putten, 2021; Emck & Scheffers, 2019; Probst, 2017), it could be that problems in body experience had already been reduced or treated through the PMT. Moreover, no conclusion could be drawn on the severity of the problems in body experience, because norm scores for the BEQ-mb and PsyMot-mb from adults with MID-BIF in a non-clinical setting were not yet available.

Finally, it is known that psychiatric disorders, such as neurodevelopmental disorders, trauma- and stressor-related disorders, and depressive disorders, are often related to problems in body experience (e.g., Emck et al., 2012; Garfinkel et al., 2016; Scheffers et al., 2017, 2019). However, the role of psychiatric disorder(s) as a third concurrent variable was not investigated due to the heterogeneity and small sample sizes of the specific psychiatric diagnoses made according to the DSM-5.

Acknowledging these limitations, we recommend future studies on body experience in sexually abused adults with MID-BIF to preferably not inform the therapists about the group to which the participant belongs (i.e. SA or NSA). Future studies should also be longitudinal, use non-clinical comparison groups, and take into account the role of third variables such as psychiatric disorders. Furthermore, norm-scores on the BEQ-mb and PsyMot-mb from adults with MID-BIF in a non-clinical setting need to be established.

Conclusion

This study aimed to examine body experience in adults with MID-BIF who were sexually abused by comparing self-reported and observational measures of body experience in adults with MID-BIF who had and had not experienced sexual abuse. The group with experiences of sexual abuse was found to be characterised by higher self-reported body awareness in combination with problematic body acceptance as reported by the therapist on the basis of structured psychomotor observations. No significant differences were found for the scores of self-reported body satisfaction and body attitude. However, due to the small sample size, the heterogeneity of the group, and the possibility of observer bias, the present results need to be interpreted with caution and used as a basis for further research on body experience in individuals with MID-BIF. Nevertheless, the findings of the study demonstrate that the development and evaluation of interventions that target problems in body experience in the treatment of individuals with MID-BIF who were sexually abused are highly warranted.

Acknowledgement

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Appendices

Table 1. Characteristics of sexual abuse in the group of individuals with MID-BIF who were sexually abused as reported in their casefile

Characteristics of sexual abuse	n (%)
<i>Type of sexual abuse¹</i>	
Penetration	11 (46)
Touching of genitals of the perpetrator	11 (46)
Touching of genitals of victim by themselves or perpetrator	10 (42)
Touching, but not of genitals of the perpetrator	2 (8)
Touching, but not of genitals of the victim, by themselves or perpetrator	3 (13)
Online-abuse	0 (0)
Other types of abuse	2 (8)
Unknown	9 (38)
<i>Frequency of abuse</i>	
Repeatedly (by the same or different perpetrator)	14 (58)
Single occasion	5 (21)
Unknown	5 (21)
<i>Evidence of the abuse</i>	
Proven	6 (25)
Clear signs	11 (46)
Indistinct signs	7 (29)
<i>Perpetrator's sex</i>	
Male	21 (88)
Female	0 (0)
No information on perpetrator(s)	3 (13)
<i>Relation of perpetrator to victim¹</i>	
Partner	3 (13)
(Step/foster)parent or sibling	6 (25)
Second-degree family member	2 (8)
Group mate/peer	2 (8)
Employee of the care facility	1 (4)
Acquaintance of the victim (other than a group mate/peer of employee of the care facility)	8 (33)
Unknown individuals	2 (8)
No information on perpetrator(s)	4 (17)

¹more answers possible

Table II. Hierarchical regression analysis predicting the BEQ-mb scores and PsyMot-mb scores (n = 56)

Dependent variable	Step	Independent variable	β	F	df	t	p	R^2	ΔR^2
BEQ-mb ¹	I	Sexual abuse	0.001	0.000	1, 52	0.004	0.996	0.000	0.000
	II	Sexual abuse	0.034	0.402	2, 51	0.273	0.786	0.016	0.016
		Traumatic events other than sexual abuse	-0.115			-0.897	0.374		
Subscales BEQ-mb									
- Body awareness ²	I	Sexual abuse	0.284	4.324	1, 53	2.079	0.042*	0.058	0.058*
	II	Sexual abuse	0.280	2.125	2, 52	1.950	0.057	0.076	0.018
		Traumatic events other than sexual abuse	0.013			0.087	0.931		
- Body satisfaction	I	Sexual abuse	-0.338	2.902	1, 54	-1.704	0.094	0.051	0.051
	II	Sexual abuse	-0.277	1.931	2, 53	-1.333	0.188	0.068	0.017
		Traumatic events other than sexual abuse	-0.209			-0.981	0.331		
- Body attitude	I	Sexual abuse	-0.101	0.788	1, 54	-0.888	0.379	0.014	0.014
	II	Sexual abuse	-0.060	1.066	2, 53	-0.505	0.616	0.039	0.025
		Traumatic events other than sexual abuse	-0.140			-1.157	0.252		
PsyMot-mb	I	Sexual abuse	0.419	5.759	1, 54	2.400	0.020*	0.096	0.096*
	II	Sexual abuse	0.376	3.161	2, 53	2.050	0.045*	0.107	0.011
		Traumatic events other than sexual abuse	0.146			0.778	0.440		

* $p < 0.50$, ¹ $n = 54$, ² $n = 55$

Chapter 6

Summary and general discussion

Summary and general discussion

Introduction

Sexual abuse is a worldwide problem that has far reaching consequences for health and psychosocial functioning (World Health Organization, 2013). Research has demonstrated that individuals with intellectual disability (ID) are at greater risk of sexual abuse than individuals with (higher than) average IQ (Mailhot Amborski et al., 2021; Tomsa et al., 2021). To mitigate the consequences of sexual abuse, prevent re-victimization and improve quality of life, early detection and adequate assessment and treatment of sexual abuse are indispensable. Two requirements in particular stand out to achieve this. First, a clear policy and protocol to identify and handle sexual abuse and their effective implementation within a care facility is a prerequisite. This is crucial for care professionals, including body- and movement-oriented therapists, to know how to act if they suspect or detect sexual abuse. In addition, such a protocol should provide information about which assessment tools and treatments are recommended. Second, care professionals should have knowledge about the consequences of sexual abuse in individuals with ID. For body- and movement-oriented therapists, knowledge about the impact of sexual abuse on body experience is of specific value as this is the main focus of their treatment approach. However, hardly any studies are available on sexual abuse in individuals with ID, as a result of which the knowledge basis to fulfil these requirements is largely lacking.

The studies in this thesis aimed at and contributed to improving this situation with the following achievements:

- The state of affairs regarding policies on sexual abuse and their implementation in care facilities for individuals with ID was assessed. In addition, the potential areas of improvement regarding policies on sexual abuse and their implementation in care facilities for individuals with ID were investigated.
- An overview of the literature on the clinical characteristics of individuals with ID who have been sexually abused was provided.
- A new instrument, the Body Experience Questionnaire for individuals with MID-BIF (BEQ-mb) was presented to measure body experience in individuals with MID-BIF.
- Differences in body experience were demonstrated between adults with MID-BIF who have and have not been sexually abused.

In this final chapter, first a summary of Chapter 2 through 5 is provided. Second, the key findings of the chapters are discussed, followed by the most important strengths and limitations of this thesis. This chapter concludes with a discussion of the implications of the present work for clinical practice and future research.

Summary of the chapters

In **Chapter 2**, the state of affairs regarding policies on sexual abuse and their implementation in Dutch care facilities for individuals with ID was evaluated. Additionally, areas of improvement in this regard were identified. An online survey was completed by 69 managers working in care facilities for individuals with ID. The findings showed that most care facilities comply with the national legal requirements on sexual abuse, which demand the availability of a protocol on sexual and mandatory reporting to the Health and Youth Care Inspectorate (in Dutch 'Inspectie Gezondheidszorg en Jeugd', IGJ). However, the care facilities varied widely in the extent to which the protocols on sexual abuse are brought to the staff's attention and used in practice. About half of the care facilities provided no staff training on the protocol on sexual abuse, while nearly one-third of them provided no organizational protective measures, such as a special-task official on sexual abuse, a sexuality or sexual abuse department or cooperation with the vice squad. Most areas of improvement reported by the managers were related to staff training and the practical use of policies and protocols on sexual abuse. Thus, the availability of policies and protocols on sexual abuse does not guarantee a caring culture in which these policies and protocols are effectively implemented, and in which sexual abuse is prevented, detected early, and addressed in a timely and adequate manner.

Chapter 3 provides a review of the literature on the clinical characteristics of individuals with ID who have been sexually abused. Whether this group experiences clinical characteristics similar to those with (higher than) average IQ was also explored. In the seven studies included, a wide range of behavioural and psychological characteristics were reported. Higher levels of aggression, self-injury, inappropriate sexualized behaviour and posttraumatic stress, anxiety or depressive symptoms were among the most frequently mentioned. New information came to the fore regarding the question whether individuals with ID experience similar clinical characteristics as those with (higher than) average IQ. More specifically, several behavioural characteristics, namely self-injury, conduct disorder and inappropriate sexualized behaviour, seem to be more prominent in individuals with ID who have been sexually abused. Although body-related characteristics, such as negative or disturbed body experience have been reported in studies on sexual abuse in individuals with (higher than) average IQ recently, none of the included studies mentioned these characteristics. Given the results of this study, clinicians should be aware of the broad range of behavioural and psychological problems associated with sexual abuse.

Chapter 4 describes the development and initial evaluation of the BEQ-mb, a Dutch self-report questionnaire for adults with MID-BIF, which measures three dimensions of body experience, namely body awareness, body satisfaction and body attitude. The BEQ-mb was developed in five stages: (1) concept development, (2) focus group, (3) verbal

reports, (4) pilot testing and (5) evaluation. The initial version of the BEQ-mb was based on existing self-report questionnaires for individuals with (higher than) average IQ. To properly adapt the items, recommendations for developing questionnaires specifically for individuals with MID-BIF were followed (stage 1). This new version was evaluated in a focus group consisting of six psychomotor therapists and subsequently modified based on the focus group's recommendations (stage 2). Next, five verbal reports were held with adults with MID-BIF to evaluate how they understand, mentally process and respond to the BEQ-mb at this stage of development, and further adaptations were made (stage 3). This resulted in the pilot version of the BEQ-mb, which was tested in 85 adults with MID-BIF (stage 4). The pilot test showed that the BEQ-mb is applicable in, and comprehensible by, adults with MID-BIF. Also, the internal consistency turned out to be good for the total scale and the subscales body awareness and body satisfaction, but low for the subscale body attitude, while the test-retest reliability was excellent for both the total scale and the subscales. Based on the pilot test, recommendations for the final version of the BEQ-mb were formulated and presented for review to the six psychomotor therapists comprising the focus group (stage 5), which resulted in some final adaptations. The definitive version of the BEQ-mb consists of three subscales (i.e. body awareness, body satisfaction and body attitude) and 30 items to be scored on a 4-point Likert scale. The results of this study indicate that the BEQ-mb is a promising self-report questionnaire measuring body experience in adults with MID-BIF that could cast light on the specific disturbances of body experience in different psychopathological disorders, including (sexual) trauma. Nevertheless, further research should establish the structural validity of the scales by conducting factor analysis on a sufficiently large dataset. Also, the convergent validity of the BEQ-mb needs to be established by comparing the subjective outcomes with an observation tool, such as the PsyMot-mb (Smit et al., 2020).

Chapter 5 presents a study that compared the body experience in adults with MID-BIF who have and those who have not been sexually abused. Body awareness, body satisfaction and body attitude were assessed using the BEQ-mb, a newly developed self-report questionnaire. Another aspect of body experience, namely body acceptance, was assessed using an instrument to observe non-verbal psychomotor behaviour, the PsyMot for adults with MID-BIF (PsyMot-mb). Body acceptance is the ability to attend to, tolerate and interpret body signals, and includes also the behaviour that follows. The sexual abuse group and non-sexual abuse group included in this study were comparable in terms of participant characteristics, except for the variable traumatic events other than sexual abuse, with significantly more other traumatic events reported in the sexual abuse group. The findings from questionnaires and observations showed that the sexual abuse group had significantly higher self-reported body awareness and more observed problems with body acceptance than the non-sexual abuse group. No significant

group differences were found for self-reported body satisfaction and body attitude. The variable traumatic events other than sexual abuse provided no explanation for the group differences on body awareness and body acceptance. In conclusion, adults with MID-BIF who were sexually abused seemed more aware of their body signals, but less able to adequately attend to, tolerate, and interpret these signals. Therefore, body- and movement-oriented therapies, such as psychomotor therapy (PMT) hold promise for this group, because in these therapies body experience is a central theme.

Discussion of the findings

Policies and protocols on sexual abuse and its implementation

The study presented in Chapter 2 showed that the availability of policies and protocols on sexual abuse in care facilities for individuals with ID does not guarantee a caring culture in which these policies are implemented effectively, both of which are required for the prevention and early detection of sexual abuse. In 2023, in the Netherlands, this key finding has been acknowledged in the revised IGJ brochure about sexual abuse within a healthcare facility (IGJ, 2023). In the previous version of this brochure (IGJ, 2016), the main focus was on the formal aspects in cases of (suspicion of) sexual abuse, such as laws, guidelines and professional codes. The revised version focuses in particular on the safe care relationship between staff members and clients or between clients (IGJ, 2023). The IGJ recognizes that the availability of policies and protocols is not sufficient to prevent and detect sexual abuse within a care facility. They emphasize that staff need to be aware of the frequent occurrence of sexual abuse within a care facility (IGJ, 2023). Staff training, appointing a special-task official and a clear step-by-step plan in cases of sexual abuse or suspicion thereof are also reported in the brochure as factors that might have a preventive effect (IGJ, 2023). This renewed focus in the brochure is in line with the points of improvement reported by the managers in Chapter 2 of this thesis. Although the brochure of the IGJ and the knowledge about the points of improvement reflect a positive development for Dutch clinical practice, their implementation might still leave to be desired.

A broad range of psychological and behavioural consequences

Pertinent literature suggests that individuals with ID who have been sexually abused suffer from similar psychological and behavioural consequences as those with (higher than) average IQ (Byrne, 2018; Sequeira & Hollins, 2003). Although both groups experience a broad and common range of psychological and behavioural consequences, some interesting findings came to the fore in the literature study presented in Chapter 3. It was found that behavioural consequences, such as developing a conduct disorder, self-injury and sexualized behaviour, are more prevalent in individuals with ID who have

been sexually abused than those with (higher than) average IQ. This finding corresponds with the Diagnostic Manual – Intellectual Disability 2 (DM-ID-2), which states that psychiatric problems, such as symptoms of PTSD, anxiety or depression, can manifest in various behavioural ways, including challenging behaviour (Fletcher et al., 2017).

Rittmannsberger et al. (2020) investigated the interrelations between trauma exposure, PTSD and challenging behaviour in individuals with ID. They found that trauma exposure is not directly associated with challenging behaviour, but mediated by PTSD symptoms (Rittmannsberger et al., 2020). It is likely that the inability of individuals with ID to regulate and cope with emotional distress plays an important role in this relationship (Melville et al., 2016; Rittmannsberger et al., 2020; Wolkorte et al., 2019). This means that during re-experience of trauma, for instance through flashbacks, challenging behaviour might occur in response to the emotional distress of the perceived threat (Rittmannsberger et al., 2020).

A crucial element in the regulation of emotional (traumatic) stress and its relationship with challenging behaviour is body awareness (Price & Hooven, 2018; Zamariola et al., 2019). How one perceives internal body signals directly influences one's emotional experiences and thereby affects the process of emotion regulation (Gross, 1998). Being aware of and adequately interpreting body signals is a prerequisite for emotional regulation strategies that influence the emotional and behavioural response to a desired end (Price & Hooven, 2018). Adequate body awareness might prevent challenging behaviour, such as aggression, since it enables an individual to intervene before the actual response takes place (Bellemans, 2021). Specifically, while an individual is feeling tensed, the body can be used as an information source. Increased tension can be recognized through changes in body signals (e.g., sweating, increasing heart rate of breathing). While one is aware of feeling tensed, the body can in turn also be used as a tool to down-regulate this (e.g., by relaxation or breathing exercises), and thus prevent the expression of challenging behaviour (Anderson et al., 2019; Bellemans, 2021). However, to my knowledge, research on the role of body awareness in emotion regulation and challenging behaviour in individuals who have been sexually abused is non-existing as for now.

Body-related consequences of sexual abuse

In the literature study presented in Chapter 3, no studies on body-related consequences, such as a disturbed or negative body experience, of sexual abuse in individuals with ID were found. Since our literature study, three new studies, one of them part of this thesis, have been published exploring the body-related consequences of sexual abuse in this group (Gil-Llario et al., 2019; Hughes et al., 2018; Smit et al., 2023). First, the study by Gil-Llario et al. (2019) focused on the attitude towards sexuality, an aspect of body-attitude.

They found that individuals with mild to moderate ID who have been sexually abused have significantly more negative attitudes towards sexuality than individuals with mild to moderate ID who have not been sexually abused. Second, the study by Hughes et al. (2018) examined the relation of abuse with physical health outcomes of a group of individuals with developmental disabilities (defined as lifelong disabilities that originate before the age of 22 and result in at least three major functional limitations). Of this group, 65% was diagnosed with an ID, but no information was provided about the severity of the ID. Physical health outcomes were measured with an adapted version of the Patient Health Questionnaire – Physical Symptom Scale (PHQ-14). Several items of this questionnaire can be related to body awareness or body attitude, for instance the items on feelings of pain, change in heartbeat and breath, sexuality and fitness and vitality (Kroenke et al., 2002). They found that childhood sexual abuse and adult sexual abuse were significantly related to the scores of the PHQ-14. However, regression analysis showed that both types of sexual abuse did not significantly predict the scores of the PHQ-14. Although interesting findings came to light in both studies, the study of Gil-Llario et al. (2019) did not use an assessment instrument specifically developed or adapted for individuals with ID, which might have rendered its results less reliable. The study of Hughes et al. (2018) did not specifically focus on individuals with ID, which is detrimental to the generalizability of the results to the ID population. Conversely, in the study presented in Chapter 5 two assessment instruments specifically developed for individuals with ID, the PsyMot-mb and BEQ-mb, were used to assess body experience individuals with MID-BIF, which favours the reliability and generalizability of the obtained results.

The BEQ-mb as an promising self-report measure to assess body experience

The BEQ-mb is the first self-report questionnaire focusing on body experience specifically developed for adults with MID-BIF, that measures body awareness, body satisfaction and body attitude. This instrument could cast light on the specific disturbances of body experience in individuals with MID-BIF who have been sexually abused. Additionally, it can be assumed that the BEQ-mb can be used in a broad range of other psychopathological problems, since these problems are often accompanied by a disturbed body experience. Specifically, body experience is often negatively affected in anxiety disorders (Aderka et al., 2014), depressive disorders (Scheffers et al., 2019), somatoform disorders (Scheffers et al., 2018), autism spectrum disorders (Garfinkel et al., 2016) and externalizing disorders (Emck et al., 2012). The BEQ-mb could be used to shape and develop body- and movement-oriented interventions and set up specific treatment goals related to body experience. Furthermore, the BEQ-mb may also prove useful in the evaluation of body- and movement-oriented therapies, which is still limited in individuals with MID-BIF.

Subscale body awareness

Unlike the subscales measuring satisfaction and attitude, a higher score on the subscale body awareness does not necessarily indicate a more positive body awareness. A higher score on this subscale indicates higher awareness of proprioceptive and interoceptive bodily signals, which can be either adaptive or maladaptive. This depends on the ability to interpret and make behavioural decisions based on these signals (Mehling et al., 2009; Price & Hooven, 2018). Heightened awareness is maladaptive when an individual is overwhelmed by their body signals, as is often the case in individuals with high anxiety or a history of (sexual) trauma (Mehling et al., 2009). Thus, when using the BEQ-mb, it should be taken into account that differentiating between adaptive and maladaptive body awareness is not possible. Therefore, assessment of body awareness should include a combination of self-report and psychomotor observation. In psychomotor observation the client can be observed and asked about their bodily feelings (i.e. noticing changes, regulating breathing, and locating, relaxing and tightening body parts) and their behavioural responses to body awareness (Kay et al., 2016).

Subscale body satisfaction

Measuring body satisfaction with the corresponding subscale of the BEQ-mb is of value since it focuses on body appearance as well as on body functionality. Until the publication of the studies reported in this thesis, no research has been conducted on body functionality in individuals with ID. Previously published studies focus on body satisfaction specifically in relation to body weight and shape (Eden & Randle-Phillips, 2017; Napolitano et al., 2010). However, it might be important to assess body functionality as part of body satisfaction since this affects an individual's overall functioning (Alleva et al., 2014). Additionally, positive feelings about body functionality were found to be associated with positive feelings towards the body and greater satisfaction with body appearance in individuals with (higher than) average IQ (Alleva et al., 2014). There is no reason to assume that this is any different in the ID-population.

Subscale body attitude

The pilot test revealed a low internal consistency of the subscale body attitude ($\alpha = 0.48$). In this stage of development of the BEQ-mb, we decided to retain the body attitude subscale because it was deemed to be of great potential clinical interest. The items on sexuality and self-injury enable both therapists and clients to initiate conversations about these crucial but potentially unsettling themes, which are often circumvented in clinical practice (Abbott & Howarth, 2007; Bernert & Ogletree, 2013). Since research has shown that individuals with ID often experience problems with sexuality (Borawska-Charko et al., 2017) and injure themselves (Cooper et al., 2009), there is a particular need to address these issues in this group.

It should be noted that the subscale body attitude of the latest version of the BEQ-mb is less suitable for investigating problems in body attitude as a singular concept. In clinical practice, results of the subscale body attitude should therefore be interpreted on item level, and always discussed with the client and/or their system (e.g., parents, family, care workers).

Problems in body awareness

The results reported in Chapter 5 indicated that individuals with ID who have been sexually abused are more aware of their body signals compared to individuals with ID without sexual abuse. As mentioned, this higher body awareness may indicate that individuals with ID who have been sexually abused feel overwhelmed by their body signals (Ogden et al., 2006; Van der Kolk, 2006). They may be hyperalert or overly aware of their body signals, a phenomenon known as hyperarousal (Ogden et al., 2006; Van der Kolk, 2006). In a threatening situation, the sympathetic nervous system will be activated, which increases arousal and mobilizes survival mechanisms, such as flight or fight reactions, in response to the ensuing threat. In such a state of hyperarousal, blood pressure, muscle tension and heart rate increase, while cognitive processes become disorganized and vigilance, alertness and emotional reactivity become more intense (Ogden et al., 2006; Van der Kolk, 2014). Hyperarousal allows an individuals to perform powerful fight and flight responses to the prevailing threat and gives a maximum chance of survival (Levine, 1997). However, in victims of traumatic events, hyperarousal is often present long after the threat of the trauma has disappeared. They perceive harmless triggers as dangerous, resulting in too much arousal to process information effectively, which is not adaptive over time. This makes it difficult for victims of traumatic events to adequately interpret and rely on their body signals, which in turn may lead to inadequate behavioural decisions (Ogden et al., 2006; Van der Kolk, 2014). A heightened awareness of body signals in individuals with ID, as found in Chapter 5, might thus not be particularly helpful in adults with ID who have been sexually abused. This is in line with the other results of Chapter 5 that individuals with ID who have been sexually abused are less able to adequately attend to, tolerate and interpret body signals, resulting in more problematic behaviour, compared to individuals with ID who have not been sexually abused.

Body satisfaction and body attitude: not affected?

Contrary to our expectations, the findings in Chapter 5 showed that individuals with ID who have been sexually abused do not experience more negative body satisfaction and body attitude than those without sexual abuse. The absence of a difference in body satisfaction could be explained by the fact that individuals with ID, both males and females, generally have overall positive beliefs about their body and, for instance, females tend to underestimate their body size (Eden & Randle-Phillips, 2017). Their perception of the ideal body may differ from individuals with (higher than) average IQ as they are

shielded from negative discussions about their appearance by their environment (Eden & Randle-Phillips, 2017). In line with this, they may not be affected by societal pressures about the ideal body image. Also, they may lack the ability to relate the concept of the ideal body image to themselves (Eden & Randle-Phillips, 2017).

The absence of a difference in body attitude between individuals with ID who have and have not been sexually abused may be related to the low internal consistency of the body attitude subscale. Body attitude is a multifaceted concept (Scheffers, 2018) and therefore difficult to operationalize in an internally consistent manner. Furthermore, the results of the body attitude subscale are inconsistent with recent studies about sexuality and self-injury in individuals with ID who have been sexually abused. These studies found that attitude towards sexuality is negatively affected in this group (Gil-Llario et al., 2019) and that self-injury is more common in this group compared to individuals with ID without sexual abuse (Chapter 3). It might thus be that the body attitude subscale we used is less suitable for investigating problems in body attitude as a singular concept. It is in any case evident that the results of the subscale body attitude should be interpreted with caution.

Strengths and limitations

The research reported in this thesis has a few noteworthy strengths and limitations. A strength of this thesis as a whole is that it contributes to building of a body of knowledge regarding sexual abuse in individuals with an ID from a psychomotor perspective. Although in the past three decades or so sexual abuse in individuals with ID has begun to receive attention in the literature, it is still an overlooked and underrepresented theme in both scientific research and clinical practice. Moreover, prior to this thesis, no research was available on the impact of sexual abuse on body experience in this group and no self-report instruments were available to assess body experience in individuals with ID.

Another strength is that clients were actively involved in two of the four studies. Active involvement of individuals with ID is needed to align research outcomes with client needs (Frankena et al., 2015). This is also in accordance with the democratic right for individuals with ID to be involved in everything that affects their lives, including scientific research (United Nations, 2015). As discussed in Chapter 4, individuals with ID were involved in the development of the BEQ-mb. Based on five verbal reports with individuals with ID, several items were reformulated or eliminated: these items were found too abstract or multi-interpretable. Also, during the pilot-test, individuals with ID were asked additional evaluative questions regarding length and comprehensibility of the BEQ-mb. In Chapter 5, individuals with ID were engaged as participants, and asked to fill out a self-report questionnaire, and participate in an interview, in order to gain

information about their subjective body experience. In clinical practice, assessing the subjective body experience of an individual with ID is often unusual. This is remarkable since body experience is pre-eminently a subjective theme (Scheffers, 2018). It is therefore essential to involve individuals with ID in the assessment of body experience, especially by using the BEQ-mb and the interview of the PsyMot-mb (Smit et al., 2020). Additionally, information given by individuals with ID themselves might be more accurate than information gathered from proxies (Kooijmans et al., 2022). In sum, both the involvement of individuals with ID in the development of the BEQ-mb and the use of self-report to assess the subjective body experience in individuals with ID can be seen as strengths of this study.

A third strength of this thesis is that in Chapter 5 two sources of information were used to determine whether or not clients were sexually abused, namely the participants' report and information about sexual abuse in their case file. We did not solely rely on the verbal reports of the participants, because they might not have recognized the abuse, or might have been ashamed or reluctant to report the abuse (Gil-Llario et al., 2019). In some of these cases, the sexual abuse was documented in the participants casefile by a professional, based on earlier disclosure of the client or their relatives (Gil-Llario et al., 2019). In other cases, the abuse was not documented in the casefile, but reported by the client themselves. In these cases, it is possible that the client has never been asked about their experiences of sexual abuse or that the sexual abuse was a long time ago or, on the contrary, very recent. Moreover, the growing attention to sexual abuse within this target group (Borawska-Charko et al., 2017) might have resulted in a reduced level of fear when it comes to sharing experiences of sexual abuse.

Several limitations should also be noted. The results in the studies presented in this thesis may have been influenced by different kinds of bias. In Chapter 2 and 5, the possibility of non-response bias exists (Berg, 2010). In Chapter 2, care facilities without a formal policy on sexual abuse may have been underrepresented in the sample, because the managers of these facilities may have refrained from filling out the survey in view of reputational concerns (Solarino & Aguinis, 2021). In Chapter 5, potential participants who have been sexually abused might have refused participating in the study due to avoidance or shame associated with the sexual abuse. Another kind of bias, publication bias, may have played a role in the systematic review presented in Chapter 3. Studies that report significant positive effects are more likely to be published than studies with negative, nonsignificant or inclusive findings (Sutton, 2009). This may result in underrepresentation of studies that did not report any significant differences between individuals who have and have not been sexually abused, as they may not have passed the peer review process. Indeed, in the selection on which the review was based, studies that did not show significant differences between groups were in the minority.

Lastly, in Chapter 5, there is a potential for observer bias that may have influenced the psychomotor observation used as an outcome in two ways. Prior to the psychomotor observation, the psychomotor therapists knew whether or not the participant had been sexually abused, which could have resulted in an under- or over-reporting of problems in body experience (Jager et al., 2020). Additionally, there is a risk of diagnostic overshadowing in individuals with ID, which may have resulted in professionals observing problems in body experience but attributing them to the intellectual disability instead of the sexual abuse. This could have led to a possible underreporting of problems in body experience (Jager et al., 2020; Mevissen & de Jongh, 2010).

Both a limitation and strength of this thesis is that the Dutch definition of mild ID, which refers both to individuals with mild intellectual disability (MID, IQ 50-70) and borderline intellectual functioning (BIF, IQ 70-85), has been used. This definition is not in line with the Anglo Saxon definition of mild ID including only individuals with an IQ between 50 and 70. On the one hand, the findings of the literature study (Chapter 3) are therefore not straightforwardly generalizable to the Dutch clinical situation because few of the included studies focus on individuals with BIF. On the other hand, the findings of Chapter 2, 4 and 5 pertain specifically to the Dutch situation, and may thus be implemented in Dutch care facilities for individuals with ID. These results are also generalizable to Dutch mental health care facilities not specifically focusing on individuals with ID, since, on average, 41% of the clients in these facilities might have a MID or BIF (Nieuwenhuis et al., 2021). Moreover, on average, 44% of these clients have been sexually abused (Nieuwenhuis et al., 2019). It is thus important to include individuals with BIF in research in individuals with ID, because this group also experience problems in adaptive functioning and need professional support (Nouwens et al., 2017). Also, the symptom profile of individuals with BIF and PTSS seems to be very similar to that of individuals with MID and PTSS (Wieland & Zitman, 2016a).

Implications for future research

There are a few noteworthy recommendations for future research. First, further research on the perspective of staff regarding policy, prevention and detection of sexual abuse is needed. By listening to the needs of staff and clients with ID, policies, protocols and preventive factors will be better aligned with the daily work practice, which will improve their implementation (Dew et al., 2014; Grin & Van de Graaf, 1996). It is therefore essential to know whether or not staff is familiar with the policy and protocols of the care facility and to what extent they make use of them. Also, potential areas of improvement regarding policy, prevention and detection of sexual abuse, according to the staff, must be established. As body- and movement-oriented therapists have an important role in the prevention and detection of sexual abuse since body experience is often affected in individuals with ID who have been sexually abused, they need to be included in future

studies on this topic. Furthermore, the implementation of policy, protocols and points of improvement needs to be monitored and evaluated in flanking research. By monitoring and evaluating policy and protocols in consultation with stakeholders (i.e. managers, staff, clients), direct attention is paid to familiarity and awareness of the policy and protocols on sexual abuse, and reflection is stimulated on one's own standing practice (Forrest et al., 1996).

Second, the results of this thesis show that individuals with ID who have been sexually abused are characterized by a broad range of challenging behaviours, including problems with body awareness. Since body awareness is related to emotion regulation (Price & Hooven, 2018), which in turn is related to challenging behaviour (Wolkorte et al., 2019), it is interesting to investigate the interactions amongst sexual abuse, body awareness, emotion regulation and challenging behaviour in greater depth in this specific group.

Third, further research should re-evaluate the internal consistency and test-retest reliability of the latest version of the BEQ-mb. Also, the structural validity of the scales needs to be established by conducting a factor analysis on a sufficiently large data set.

Lastly, the PsyMot-mb, the psychomotor observation tool used in the study presented in Chapter 5, is still in its infancy. Although the English version of the PsyMot for individuals with ID showed usability and good inter-rater reliability of all subscales (Kay et al., 2016), the psychometric qualities of the PsyMot-mb are only currently under investigation. To date, one unpublished thesis showed good inter-rater reliability of the PsyMot-mb (IBB: 86,5%; Clark & Marijnissen, 2022). Further studies into the psychometric qualities and its usefulness for guiding (psychomotor) therapists in selecting appropriate interventions are required.

Implications for clinical practice

Given the high prevalence of sexual abuse in individuals with ID, it is essential for clinicians to be aware that behavioural, psychological and body-related problems may well be related to sexual abuse. Considering the possibility of sexual abuse should therefore be a part of standard assessment and admission procedures. This will contribute to the early detection of sexual abuse and the provision of adequate treatment of sexual abuse in individuals with ID. It is important to mention that there is no standard developmental trajectory of the consequences after an experience of sexual abuse. This complicates the detection of sexual abuse and makes it difficult to label psychological, behavioural and body-related problems as specific consequences of sexual abuse. Most of the consequences studied in the literature, such as anxiety or depressive symptoms, are general and may also have other causes than sexual abuse (Totsika et al., 2022).

Given that individuals with ID who have been sexually abused experience problems with body experience, which adversely affect psychosocial functioning, it is recommended that assessment of body experience becomes part of standard assessment procedures in individuals with ID. This may be achieved by giving body- and movement-oriented therapists a fixed position in the multidisciplinary teams, which is not yet the case in Dutch care facilities for individuals with ID; they may or may not be present in such teams. Body- and movement-oriented therapists are often called upon after the diagnostic procedure has been completed; in such cases assessment of body experience takes place at a later stage during body- and movement-oriented therapy. The BEQ-mb is a promising self-report questionnaire that should be used during the standard assessment procedures to assess body experience. Although the BEQ-mb does not specifically need to be administered by body- and movement-oriented therapists, they should be involved when interpreting the scores of the BEQ-mb. In case of abnormalities or deviating scores they should further investigate body experience during body- and movement-oriented therapy. To provide additional information about an individual's body experience, these therapists should use the PsyMot-mb, a psychomotor observation tool to assess body experience (Kay et al., 2016; Smit et al., 2020).

Overall, the relationship with the body remains vastly overlooked, not only in diagnostic procedures but also in therapy. To date, cognitive-behavioural therapy (CBT) and Eye Movement Desensitization and Reprocessing therapy (EMDR) are still regarded as the most effective treatments in this group (Byrne, 2022; McNally et al., 2021; Stobbe et al., 2021). One simple explanation for this is that CBT and EMDR are by far the most investigated treatments, thus having accumulated the largest "evidence base" for their effectiveness (Byrne, 2022; McNally et al., 2021; Stobbe et al., 2021). Although these treatments may certainly be helpful in treating psychological and behavioural characteristics of sexual abuse, it should be recognized that sexual abuse has significant adverse consequences on a bodily level, and that a more body- and movement-oriented approach is needed. Recently, more neurobiological support has emerged for body- and movement-oriented therapies. Research suggests that the evolutionarily older brain systems that are central to processing overwhelming stress may not be adequately reached through verbal and cognitive interventions, such as CGT and EMDR (Ogden et al., 2006; Van der Kolk, 2006). These interventions primarily target the prefrontal cortex, the evolutionary youngest part of the human brain, which is unable to influence the lower brain areas in individuals with trauma (Van der Kolk, 2014). A bottom-up approach, starting with bodily sensations, as provided by body- and movement-oriented interventions, may be a more suitable form of treatment for regulating arousal and emotions (Ogden et al., 2006; Van de Kamp et al., 2019; Van der Kolk, 2014). Therefore, body- and movement-oriented therapies, such as PMT, should be a part of broad multidisciplinary treatment in individuals with ID who have been sexually abused. PMT also matches the needs and

learning styles of individuals with ID, as it places less emphasis on the clients' verbal skills and focuses on the immediate bodily experiences and concrete behaviour of the client (Bellemans, 2021; Bellemans & Van Putten, 2021; Kay et al., 2016; McDonnell et al., 2015). Especially individuals with ID who have been sexually abused will thus benefit from reducing the emphasis in treatment on their cognitive and verbal skills, and need a more balanced treatment approach that addresses subjective body experience through body- and movement-oriented interventions.

Chapter 7

Samenvatting

References

Author contributions

Dankwoord

List of publications

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Samenvatting

Introductie

Seksueel misbruik is een wereldwijd probleem dat verregaande gevolgen heeft voor de gezondheid en het psychosociaal functioneren (World Health Organization, 2013). Onderzoek heeft aangetoond dat mensen met een verstandelijke beperking een hoger risico hebben om seksueel misbruikt te worden dan mensen met een (boven)gemiddeld IQ (Mailhot Amborski et al., 2021; Tomsa et al., 2021). Om de gevolgen van seksueel misbruik te beperken, herhaald slachtofferschap te voorkomen en de kwaliteit van leven te verbeteren, zijn vroegtijdige signalering en adequate diagnostiek en behandeling van seksueel misbruik essentieel. Om dit te bereiken zijn twee zaken in het bijzonder van belang. Ten eerste zijn een duidelijk beleid en een protocol voor het signaleren van en het omgaan met seksueel misbruik een vereiste. De effectieve implementatie van zo'n beleid en protocol binnen een zorginstelling voor mensen met een verstandelijke beperking is daarbij ook van belang. Het is cruciaal voor zorgprofessionals, waaronder lichaams- en bewegingsgerichte therapeuten om te weten hoe ze moeten handelen als er sprake is van (een vermoeden van) seksueel misbruik. Ten tweede moeten zorgprofessionals kennis hebben van de gevolgen van seksueel misbruik bij mensen met een verstandelijke beperking. Voor lichaams- en bewegingsgerichte therapeuten is kennis over de gevolgen van seksueel misbruik voor de lichaamsbeleving van specifieke waarde, aangezien lichaamsbeleving een belangrijk thema is binnen hun therapie. Er zijn echter weinig studies gepubliceerd over seksueel misbruik bij mensen met een verstandelijke beperking, waardoor kennis ten aanzien van bovengenoemde twee zaken grotendeels ontbreekt.

De studies in dit proefschrift hadden als doel deze situatie te verbeteren met behulp van de volgende resultaten:

- De stand van zaken met betrekking tot het beleid rondom seksueel misbruik en de implementatie ervan in zorginstellingen voor mensen met een verstandelijke beperking werd geëvalueerd. Daarbij werden mogelijke verbeterpunten gerapporteerd met betrekking tot het beleid rond seksueel misbruik en de implementatie ervan in zorginstellingen voor deze doelgroep.
- Er werd een overzicht gegeven van de literatuur over de gevolgen van seksueel misbruik bij mensen met een verstandelijke beperking.
- Er werd een nieuw instrument, de Lichaamsbelevingslijst LVB (LBL-lvb), ontwikkeld voor mensen met een lichte verstandelijke beperking om de lichaamsbeleving bij deze doelgroep te meten.
- Er werden verschillen aangetoond in lichaamsbeleving tussen volwassenen met een lichte verstandelijke beperking die wel en geen seksueel misbruik hebben meemaakt.

Samenvatting van de hoofdstukken

In **Hoofdstuk 2** wordt de stand van zaken met betrekking tot het beleid rond seksueel misbruik en de implementatie ervan in Nederlandse zorginstellingen voor mensen met een verstandelijke beperking geëvalueerd. Ook worden verbeterpunten op dit vlak gerapporteerd. Een online survey werd ingevuld door 69 managers werkzaam in zorginstellingen voor mensen met een verstandelijke beperking. Uit de resultaten blijkt dat de meeste zorginstellingen voldoen aan de nationale wettelijke vereisten op het gebied van seksueel misbruik, namelijk de aanwezigheid van een protocol voor seksueel misbruik en verplichte melding van seksueel misbruik aan de Inspectie Gezondheidszorg en Jeugd (IGJ). De zorginstellingen verschillen echter sterk in de mate waarin het protocol voor seksueel misbruik onder de aandacht wordt gebracht van hun zorgmedewerkers en daadwerkelijk in de praktijk wordt gebruikt. Ongeveer de helft van de zorginstellingen biedt geen training aan over het protocol voor seksueel misbruik. Bovendien zet een derde van de zorginstellingen geen organisatorische beschermende maatregelen in, zoals een aandachtsfunctionaris seksueel misbruik, een afdeling seksualiteit of seksueel misbruik of samenwerking met de zedenpolitie. De meeste verbeterpunten die door de managers zijn genoemd, hebben betrekking op training over het protocol seksueel misbruik en het verbeteren van de gebruiksvriendelijkheid van het protocol voor seksueel misbruik. Kortom, de aanwezigheid van beleid en een protocol seksueel misbruik garanderen geen zorgcultuur waarin beleidsmaatregelen effectief worden geïmplementeerd, en waarin seksueel misbruik wordt voorkomen en vroegtijdig wordt gesignaleerd en behandeld.

Hoofdstuk 3 biedt een overzicht van de literatuur over de klinische kenmerken van seksueel misbruik bij mensen met een verstandelijke beperking die seksueel misbruik hebben meegemaakt. Er werd ook onderzocht of deze groep vergelijkbare kenmerken vertoont als mensen met een (boven)gemiddeld IQ. In de zeven geïnccludeerde studies werden gedragsmatige en psychologische kenmerken gerapporteerd. Agressief gedrag, zelfverwonding, ongepast geseksualiseerd gedrag en symptomen van post-traumatische stress, angst of depressie werden het vaakst genoemd. Nieuwe kennis kwam naar voren met betrekking tot de vraag of mensen met een verstandelijke beperking vergelijkbare kenmerken laten zien als mensen met een (boven)gemiddeld IQ. Sommige gedragsmatige kenmerken lijken vaker voor te komen bij mensen met een verstandelijke beperking die seksueel misbruik hebben meegemaakt, waaronder zelfverwonding, een gedragsstoornis en ongepast geseksualiseerd gedrag. Hoewel lichaamsgerelateerde gevolgen kenmerken van seksueel misbruik, zoals een negatieve of verstoorde lichaamsbeleving, worden gerapporteerd in studies bij mensen met een (boven)gemiddeld IQ, werden deze kenmerken niet genoemd in één van de geïnccludeerde studies van het literatuuronderzoek. Op basis van de resultaten dienen

clinici zich bewust te zijn van het brede scala aan gedragsmatige en psychologische kenmerken dat mensen met een verstandelijke beperking die seksueel misbruik hebben meegemaakt mogelijk laten zien.

Hoofdstuk 4 beschrijft de ontwikkeling en initiële evaluatie van de LBL-lvb, een Nederlandse zelfrapportagelijst voor volwassenen met een lichte verstandelijke beperking, die drie dimensies van lichaamsbeleving meet, namelijk lichaamsbewustzijn, lichaamswaardering en lichaamsattitude. De LBL-lvb is ontwikkeld in vijf fasen: 1) conceptontwikkeling, 2) focusgroep, 3) cognitieve interviews, 4) pilotonderzoek, en 5) evaluatie. De initiële versie van de LBL-lvb is gebaseerd op bestaande zelfrapportagelijsten gericht op lichaamsbeleving voor mensen met (boven)gemiddeld IQ. Om de items goed af te stemmen op de doelgroep, werden aanbevelingen gevolgd voor het ontwikkelen van zelfrapportagelijsten specifiek voor mensen met een lichte verstandelijke beperking (fase 1). De initiële versie van de LBL-lvb werd geëvalueerd in een focusgroep met zes psychomotorisch therapeuten en aangepast op basis van de resultaten van de focusgroep (fase 2). Vervolgens werden vijf cognitieve interviews gehouden met volwassenen met een lichte verstandelijke beperking om te evalueren in hoeverre zij de items van de aangepaste versie van de LBL-lvb begrepen en wat zij van de zelfrapportagelijst vonden, waarna verdere aanpassingen werden gemaakt (fase 3). Dit resulteerde in de pilotversie van de LBL-lvb, die werd getest bij 85 volwassenen met een lichte verstandelijke beperking. Het pilotonderzoek toonde aan dat de LBL-lvb bruikbaar en begrijpelijk is voor volwassenen met een lichte verstandelijke beperking. De interne consistente bleek goed te zijn voor de subschalen lichaamsbewustzijn en lichaamswaardering, maar laag voor de subschaal lichaamsattitude. De test-hertest betrouwbaarheid was uitstekend voor alle subschalen (fase 4). Op basis van het pilotonderzoek werden aanbevelingen geformuleerd voor de definitieve versie van de LBL-lvb, die ter beoordeling werden voorgelegd aan de zes psychomotorisch therapeuten van de focusgroep, wat resulteerde in de laatste aanpassingen (fase 5). De definitieve versie van de LBL-lvb bestaat uit drie subschalen (lichaamsbewustzijn, lichaamswaardering en lichaamsattitude) en 30 items die worden gescoord op een 4-punts Likertschaal. De resultaten van dit onderzoek wijzen erop dat de LBL-lvb een veelbelovende zelfrapportagelijst is die de lichaamsbeleving meet bij volwassenen met een lichte verstandelijke beperking en inzicht kan bieden in verstoringen in lichaamsbeleving bij verschillende problematiek, waaronder (seksueel) trauma. Desalniettemin moet toekomstig onderzoek de structurele validiteit van de subschalen vaststellen door middel van een factoranalyse met een grote dataset. Ook moet de convergente validiteit van de LBL-lvb worden vastgesteld bijvoorbeeld door de subjectieve resultaten op de LBL-lvb te vergelijken met een observatietool, zoals de PsyMot-lvb (Smit et al., 2020).

In **Hoofdstuk 5** wordt de lichaamsbeleving van volwassenen met een lichte verstandelijke beperking die wel en geen seksueel misbruik hebben meegemaakt met elkaar vergeleken. Lichaamsbewustzijn, lichaamswaardering en lichaamsattitude werden gemeten met behulp van de LBL-lvb. Een ander aspect van lichaamsbeleving, namelijk lichaamsacceptatie, werd gemeten met een psychomotorisch observatie instrument, de PsyMot-lvb. Lichaamsacceptatie is het vermogen van een individu om lichaamssignalen waar te nemen, te tolereren en te verdragen, en omvat ook het gedrag dat daarop volgt. De groep mensen met seksueel misbruik en de groep mensen zonder seksueel misbruik vertoonden vergelijkbare kenmerken, behalve wat betreft traumatische gebeurtenissen anders dan seksueel misbruik, waarbij significant meer andere traumatische gebeurtenissen werden gerapporteerd in de groep mensen met seksueel misbruik. De resultaten van de zelfrapportagelijst en de psychomotorisch observatie toonden aan dat de groep mensen met seksueel misbruik een hoger zelf gerapporteerd lichaamsbewustzijn had en meer problemen met lichaamsacceptatie dan de groep mensen zonder seksueel misbruik. Er werden geen significante groepsverschillen gevonden voor zelf gerapporteerde lichaamswaardering en lichaamsattitude. De variabele traumatische gebeurtenissen anders dan seksueel misbruik gaf geen verklaring voor de groepsverschillen op het gebied van lichaamsbewustzijn en lichaamsacceptatie. Concluderend lijken volwassenen met een lichte verstandelijke beperking die seksueel misbruik hebben meegemaakt zich meer bewust te zijn van hun lichaamssignalen, maar zijn ze minder goed in staat om deze signalen adequaat waar te nemen, te tolereren en te interpreteren. Daarom zijn lichaamsgerichte- en bewegingsgerichte therapieën, zoals psychomotorische therapie, veelbelovend voor deze doelgroep, aangezien lichaamsbeleving een centraal thema is in deze therapieën.

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Author contributions

Chapter 2: Policy on sexual abuse: a survey study amongst managers of care facilities for individuals with intellectual disability.

Study conception and design (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek), data collection (M. J. Smit, L. Engelsman); analysis (M. J. Smit, L. Engelsman), writing - review and editing (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek).

Chapter 3: Clinical characteristics of individuals with intellectual disability who have experienced sexual abuse. An overview of the literature.

Study conception and design (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek), literature search (M. J. Smit); analysis (M. J. Smit, M. Scheffers), writing - review and editing (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek).

Chapter 4: The Body Experience Questionnaire for adults with mild intellectual disability or borderline intellectual functioning (BEQ-mb): development and initial evaluation.

Study conception and design (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek), data collection (M. J. Smit), analysis (M. J. Smit, M. Scheffers, C. Emck), writing – review and editing (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek).

Chapter 5: The impact of sexual abuse on body experience in adults with mild intellectual disability or borderline intellectual functioning.

Study conception and design (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek), data collection (M. J. Smit), analysis (M. J. Smit), writing – review and editing (M. J. Smit, C. Emck, M. Scheffers, J. T. van Busschbach, P. J. Beek).

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Publication list

- Leeflang, M., Smit, M. J., Scheffers, M., & Van Busschbach, J. T. (2021). Seksueel misbruik bij mensen met een lichte verstandelijke beperking: de inzet van psychomotorische diagnostiek en therapie. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen*, 47, 27-31.
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About the author

Manon Smit was born on November 4th 1993 in Meppel and grew up in Vledder. After obtaining her pre-university diploma, she started studying Pedagogical Sciences at the University of Groningen in 2013. Her interest in the target group was sparked during her internship at Vanboeijen, a care facility for individuals with intellectual disability. Her enthusiasm for research developed while writing her Bachelor's thesis on abuse among individuals with intellectual disability, and during her participation in the Honours College, a two-year university program focused on research. In 2016, Manon enrolled in the Master's program in Orthopedagogy at the same university, specializing in individuals with disabilities. She wrote her Master's thesis on the alertness of children with severe intellectual disability. After completing her Master's degree, Manon began her doctoral research in December 2017, focusing on sexual abuse in individuals with intellectual disability and the use of psychomotor diagnostics. During her doctoral research, she worked as a behavioural therapist at Uw Psychiater in Zwolle from 2018 to 2020, a small treatment setting for individuals with psychiatric problems. Starting from the academic year 2020-2021, Manon combined her doctoral research with a position as a lecturer in the Master's program in Psychomotor Therapy at Windesheim University of Applied Sciences. She is currently involved in the research courses of this Master's program. In January 2023, Manon joined Viveon, the academic workplace of 's Heeren Loo and the Vrije Universiteit Amsterdam, as a project leader for the project 'Kwaliteit van zorg bij psychotrauma bij mensen met een verstandelijke beperking'. Within this project, the development of a guideline for psychotrauma in individuals with intellectual disability is central.

Over de auteur

Manon Smit werd geboren op 4 november 1993 in Meppel en woonde gedurende haar jeugd in Vledder. Na het behalen van haar VWO-diploma begon zij in 2013 aan de studie Pedagogische Wetenschappen aan de Rijksuniversiteit Groningen. Tijdens haar stage bij Vanboeijen, een instelling voor mensen met een verstandelijke beperking, werd haar interesse voor de doelgroep gewekt. Haar enthousiasme voor onderzoek ontstond tijdens het schrijven van haar bachelorthesis over misbruik bij mensen met een verstandelijke beperking, maar ook tijdens het volgen van het Honours College, een tweejarig programma naast de reguliere opleiding gericht op het doen van onderzoek. In 2016 startte Manon aan dezelfde universiteit met de master Orthopedagogiek met als afstudeerrichting Personen met beperkingen. Zij schreef haar masterthesis over de alertheid van kinderen met een zeer ernstige meervoudige beperking. Na het behalen van de master startte Manon in december 2017 met haar promotieonderzoek naar seksueel misbruik bij mensen met een verstandelijke beperking en de inzet van psychomotorische diagnostiek. Tijdens haar promotieonderzoek werkte zij van 2018 tot 2020 als orthopedagoog bij Uw Psychiater in Zwolle, een kleinschalige behandelsetting voor mensen met psychiatrische problematiek. Vanaf het studiejaar 2020-2021 combineerde Manon haar promotieonderzoek met een baan als docent bij de master Psychomotorische Therapie van hogeschool Windesheim. Hier is zij tot op heden betrokken bij de onderzoeksvakken. Daarnaast startte Manon in januari 2023 bij Viveon, de academische werkplaats van 's Heeren Loo en de Vrije Universiteit Amsterdam, als projectleider van het project "Kwaliteit van zorg bij psychotrauma bij mensen met een verstandelijke beperking". Binnen dit project wordt toegewerkt naar een richtlijn psychotrauma bij mensen met een verstandelijke beperking.

