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Challenging behavior of people with mild intellectual disabilities or borderline intellectual functioning

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CB

CHALLENGING BEHAVIOR OF PEOPLE WITH MILD INTELLECTUAL DISABILITIES OR BORDERLINE INTELLECTUAL FUNCTIONING

The perspective of clients and support staff

Kim van den Bogaard

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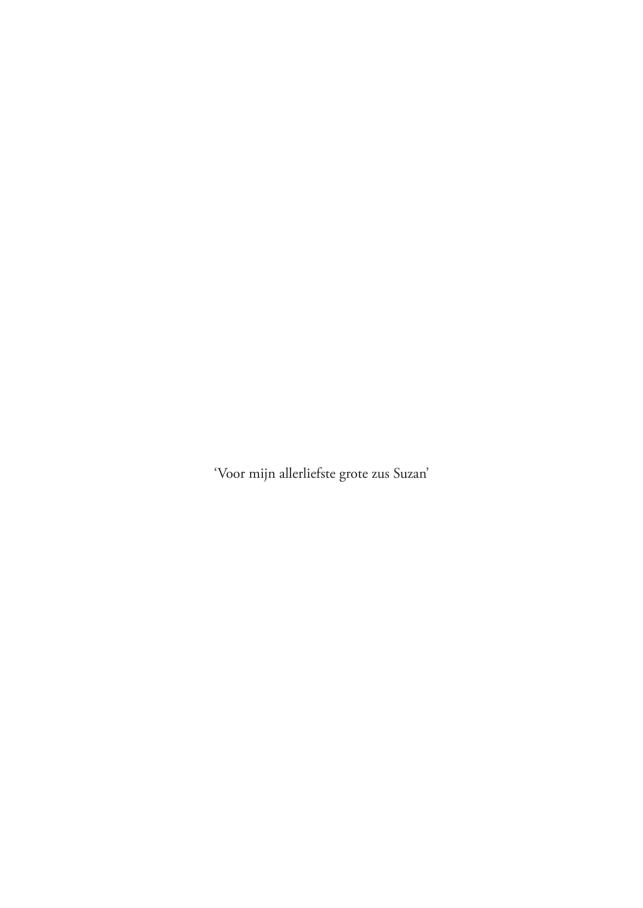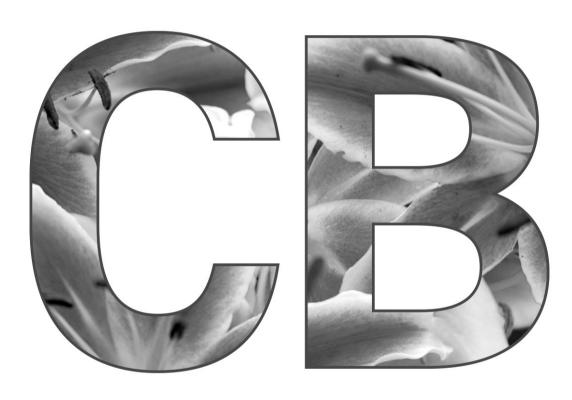Prof. dr. S. Vandevelde

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'Voor mijn allerliefste grote zus Suzan'

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Chapter 1

General introduction

People with intellectual disabilities (ID) are at higher risk of developing psychopathology compared to people without ID (Einfeld, Ellis, & Emerson, 2011; Emerson, Einfeld, & Stancliffe, 2010; Gigi et al., 2014; Matson & Shoemaker, 2011; Wieland, van den Brink, & Zitman, 2015). In addition, they relatively often display challenging behaviors (CB). Behavior can be defined as challenging when:

> *"(...) it is of such an intensity, frequency or duration as to threaten the quality*
> *of life and/or the physical safety of the individual or others and is likely to lead to responses that*
> *are restrictive, aversive or result in exclusion" (Banks et al., 2007, p. 14).*

The prevalence rates of CB reported in the literature vary, due to differences in the populations studied, the setting of the studies, the methodology used in these studies, differences in definitions, and difference in types of CB that were included by the researchers, such as aggressive behavior, self-injurious behavior (SIB), and harmful sexual behavior (HSB) (Luiselli, 2012). Some large scale epidemiological studies report rates varying between 10.0% and 18.1% of the people with ID (Bowring, Totsika, Hastings, Toogood, & Griffith, 2017; Emerson et al., 2001; Holden & Gitlesen, 2008; Lowe et al., 2007).

CB generally tends to persist over time (Einfeld et al., 2006; Kiernan et al., 1997) and people with ID who show CB often display more than one type of CB at the same time (e.g., physical aggressive behavior and SIB; Cooper et al., 2009a, 2009b; Crocker et al., 2006; Lowe et al., 2007; Nijman & à Campo, 2002; Rojahn, Zaja,Turygin, Moore, & van Ingen, 2012; Tenneij & Koot, 2008). For example, Kiernan and colleagues (1997) reported that 63% of respondents who displayed 'more demanding' forms of CB (n = 179) still displayed these 'more demanding' forms of CB in a follow-up study, seven years later. 'More demanding CB' was defined by Kiernan and colleagues as CB that is shown at least once a day, or CB that usually prevents the person from taking part in the program, or CB that usually had to be controlled with physical intervention of more than one staff member, or CB that usually results in major injuries for the person showing it or for their environment. In addition, they found that almost 40% of the people with ID (n = 93) who were identified as showing 'less demanding CB' showed also 'more demanding CB' seven years later. In other long-term follow-up studies the persistency rates of CB were comparable or higher, up to 97% (e.g., Cooper et al., 2009a, 2009b;Taylor, Oliver, & Murphy, 2011), suggesting that elimination of CB is rather difficult and CB thus requires continuous support throughout the lives of these people (Foxx, 1990).

Individuals who display CB are at risk for negative physical, psychological and social consequences due to their CB and, hence, CB can significantly impact the quality of life (Emerson & Einfeld, 2011). That is, for example, people who display CB are at risk of being physical injured, being abused by support staff, and not receiving the care and support they need. Moreover, showing CB is a predictor for out of family care (Chan & Sigafoos, 2000) and many people with ID who display CB reside in residential settings (Iemmi et al.,

2016), with CB rates of 49% of people living in institutions (Borthwick Duffy, 1994).Out placement puts a great burden on the general budget of care for people with ID, and the costs of services rise as the CB gets more severe (Knapp, Comas-Herrera, Astin, Beecham, & Pendaries, 2005) while research shows that it does not always result in the best care for people who display CB (e.g., Allen, Lowe, Moore, & Brophy, 2007).

The environment of people with ID displaying CB (e.g., professionals, family members, and other clients) can be harmed due to the CB (Griffith & Hastings, 2014; Mills & Rose, 2011; Rose, Horne, Rose, & Hastings, 2004; Smyth, Healy, & Lydon, 2015). That is, family members in the study of Griffith and Hastings (2014), for example, mentioned the loss of their own identity, loss of spare time, social isolation, physical injuries, and emotional burden as consequences of the CB of their relatives. Studies focussing on support staff reported fear of assault (Mills & Rose, 2011), helplessness (Bromley & Emerson, 1995; Mitchell & Hastings, 2001) stress, burnout, and emotional exhaustion (Mills & Rose, 2011; Smyth, Healy, & Lydon, 2015) as consequences of CB of the clients they support.

CB can be seen as a social construct that is the product of interaction between the individual and their environment (Banks et al., 2007). Support staff often play a key role in the lives of people with ID and CB. They take care of these persons (Eagar et al., 2007), but also deliver behavioral and other interventions (Allen, 1999), which can cause tension. Not only because support staff, in order to make interventions work, have to create a meaningful and good relationship with their clients who display CB, but also because support staff have to deliver, often complex, interventions (Embregts, 2011). Besides this tension, a potential lack of knowledge about the behavioral processes can make support staff a trigger or maintaining factor related to CB (Brown & Beail, 2009; Griffith, Hutchinson, & Hastings, 2013; Nijman & à Campo, 2002; Tenneij & Koot, 2008). However, it should be noted that the role of support staff regarding CB can differ per type of CB (Griffith et al., 2013; Nijman & à Campo, 2002). Nijman and à Campo (2002), for example, found that the role of the environment appeared to be more prominent in triggering aggressive behavior compared to SIB. Besides that, it has been hypothesized that reactions of support staff can be a new trigger for recurrent CB (Griffith et al., 2013; Nijman, à Campo, Ravelli, & Merckelbach, 1999).

There are three types of CB that are frequently reported in people with ID: aggressive behavior, SIB and HSB. In the following paragraphs these three types of CB will be addressed further.

Aggressive behavior

There are various definitions of aggressive behavior, incorporating one or all of the different typographies (e.g., verbal aggression, physical aggression, aggression at materials or auto-aggression; Crocker et al., 2006). Besides, in definitions of aggressive behavior there is often also a distinction based on intentionality of the behavior (Farmer & Aman, 2011). In other words, do people react aggressively with intent or not. Despite the variation, a commonly

used definition of aggression, which is also used in this thesis, was presented in a paper of Morrison (1990). She defined aggressive behavior as:

"Any verbal, non-verbal or physical behavior that was threatening, or physical behavior that actually did harm" (p. 67).

Given the great diversity of definitions, but also due to the methods used to report aggressive behavior, prevalence rates of aggressive behavior in people with ID vary widely, ranging from 30 to 60% (Cohen et al., 2010; Crocker et al., 2006; Lowe et al., 2007; Tenneij & Koot, 2008). The impact and consequences of aggressive behavior are detrimental, both for the person showing the behavior as well as for their environment. That is, aggressive behavior can lead to: 1) physical injuries, 2) higher medication use (Matson & Neal, 2009; Robertson et al., 2005), 3) being restrained (Robertson et al., 2005), 4) not receiving appropriate care (Cowley, Newton, Sturmey, Bouras, & Holt, 2005), 5) interference with educational and social activities (Emerson, Felce, McGill, & Mansell, 1994), and 6) an increased risk for physical and emotional abuse and neglect by support staff (Cambridge, 1999; Cooper et al., 2009b; Emerson & Einfeld, 2011; Emerson et al., 1994; Matson & Kozlowski, 2012). For example, physical interventions provided after a person becomes aggressive, can make the person even more aggressive, as the interventions often are aversive and support staff are sometimes not aware of this (Fish & Culshaw, 2005).

For the social environment (e.g., support staff, family members and care organizations), the aggressive behavior can also lead to physical injuries, stress, negative emotions (e.g., fear of assault), a higher risk for burn-out (Allen, Hawkins, & Cooper, 2006; Hensel, Lunsky, & Dewa, 2014; Lambrechts, Kuppens, & Maes, 2009; Mills & Rose, 2011; Mitchell & Hastings, 2001), costly services and management difficulties (Hassiotis, Parkes, Jones, Fitzgerald, & Romeo, 2008). There are various risk factors associated with aggressive behavior, including psychiatric disorders (Crocker, Prokić, Morin, & Reyes, 2014; Tsiouris, Kim, Brown, & Cohen, 2011), a low level of intellectual functioning (Cooper et al., 2009b; Crocker et al., 2014), gender (Cooper et al., 2009b; Sigafoos, Elkins, Kerr, & Attwood, 1994), genetic syndromes (Arron, Oliver, Moss, Berg, & Burbidge, 2011), negative interactions with support staff (e.g., negative communication, receiving corrective feedback, and disagreements) and task characteristics (e.g., a difficult task) or change in daily routines (e.g., Embregts, Didden, Huitink, & Schreuder, 2009; Embregts, Didden, Schreuder, Huitink, & van Nieuwenhuijzen, 2009).

Self-injurious behavior

Self-injurious behavior (SIB) is defined in many different ways varying from definitions including intentional and non-intentional behavior, actual and attempted behavior, and suicidal and non-suicidal behavior (e.g., Gratz, 2001; Sansone & Sansone, 2010). In this thesis we used the following definition of SIB:

"Behavior in which a person harms (or attempts to harm) oneself deliberately and physically"
(Nijman, Palmstierna, van den Bogaard, & Embregts, 2018, p. 719).

Typical forms of SIB are hand to head hitting, head banging, scratching, and self-biting (Folch et al., 2018; Rooker et al., 2018). However, there is a wide range of SIB and, due to different etiologies, SIB can be very heterogeneous (Symons & Kennedy, 2012). Prevalence rates vary between 4 and 23% in people with ID (Cooper et al., 2009a; Folch et al., 2018; Kahng, Iwata, & Lewin, 2002; Rojahn & Meier, 2009). Like aggressive behavior, SIB also often tends to be persistent and treatment-resistant over time (Consoli et al., 2013; Courtemanche, Lloyd, & Tapp, 2018; Emerson et al., 2001; Kiernan & Alborz, 1996; Murphy et al. 1993).

SIB can have a serious impact on the quality of life. That is, SIB can cause 1) physical injuries, for which medical treatment is necessary, or even death (Emerson, 1992; Klonsky, 2007; Nissen & Haveman, 1997), 2) higher medication use (Matson & Neal, 2009; Robertson et al., 2005), 3) being restrained (Robertson et al., 2005), 4) feelings of shame, hopelessness, and guilt (Brown & Beail, 2009), 5) interferences with developing adequate skills or taking part in activities (Richman, Barnard-Brak, Bosch, Thompson, Grubb, & Abby, 2013), 6) isolation, exclusion, and institutionalization, which can impair the psychological and social development (Banks et al., 2007; Bradley et al., 2018; Emerson & Robertson, 2008; Glaesser & Perkins, 2013), 7) neglect and abuse by their environment (e.g., support staff; Emerson et al., 1994), and 8) lack of receiving appropriate care by support staff (Cowley et al., 2005).

For the environment (e.g., families, professionals, and care organizations) SIB can also have negative consequences, like feelings of anger, inadequacy, and guilt (Fish, 2000), negative psychosocial effects (Mossman, Hastings, & Brown, 2002), costly services and management difficulties (Emerson et al., 2001; Hassiotis et al., 2008; Tureck, Matson, & Beighley, 2013).

Risk factors associated with triggering and maintaining SIB are diverse, related to genetic, biological, psychological, and environmental causes, or a combination of these (Hanley, Iwata, & McCord, 2003; Luiselli, 2012). For example, SIB has been found to be related to biological factors (e.g., dysregulation of neurtransmitters; Nock, 2009), medical conditions (e.g. eczema; Peine et al., 1995), genetic syndromes (e.g., Prader-Willi syndrome, Cri du Chat syndrome, Lesch Nyhan syndrome or Fragile X syndrome; Arron et al., 2011; Hall, Oliver, & Murphy, 2001), psychiatric conditions (e.g., autism spectrum disorder, borderline personality disorder, bipolar disorder or depressive disorder; Bradley et al., 2018; Folch et al., 2018; Haw, Hawton, Houston, & Townsend, 2001; Joyce, Light, Rowe, Cloninger, & Kennedy, 2010; Zanarini et al., 2008) and sensorial or social stimuli like pain or attention (Didden et al., 2012; Symons & Kennedy, 2012).

Harmful sexual behavior

People with ID sometimes also display harmful sexual behavior (HSB), like public masturbation or inappropriate touching of others (Lowe et al., 2007). To get an overview of all the types of HSB displayed by people with ID, we used a broad definition in this thesis. Harmful sexual behavior is:

> *"Sexual behaviour that is deemed inappropriate as a result of the nature of the behaviour or the setting in which they occur. These sexual behaviours may be self-directed or directed at others, including targeting or fixating on individuals. Where others are involved the contact may be unwanted or nonconsensual. These behaviours occur on a continuum from minor behaviours up to and including sexual assault. In addition, the behaviour may interfere with normal activity or be harmful or distressing to self or others" (Lockhart, Guerin, Shanahan, & Coyle, 2009, p. 299).*

Given the diversity of definitions of HSB and the wide range of methodologies used to obtain prevalence rates, rates are diverge and hard to determine (Lindsay, 2009). Professionals often do not report on these behaviors, as they do not know how to deal with the behavior or baggetalize the behavior (Thompson, 2010).

HSB has negative consequences for the person showing the behavior, on psychological, social, and educational domains (e.g., Lund, 1992; Thompson, 1997; Steptoe, Lindsay, Forrest, & Power, 2006), and their environment like support staff, families and victims (Byrne, 2018; McGilloway, Smith, & Galvin, 2018; Shelby, Stoddart, & Taylor, 2001; Soylu, Alpaslan, Ayaz, Essenyel, & Oruç, 2013). For example, victims report on psychological consequences, like post-traumatic stress symptoms, physical injuries, or negative emotions.

Risk factors of HSB are associated with internal and external causes (Embregts, van den Bogaard, Hendriks, Heestermans, Schuitemaker, & van Wouwe, 2010; Fortune & Lambie, 2004; Lambrick & Glaser, 2004; Lindsay, 2002; Lindsay, Olley, Baillie, & Smith, 1999; van den Bogaard, Embregts, Hendriks, & Heestermans, 2013). Internal causes are factors in the person with ID, such as physical or emotional abuse in the past (static risk factors), impulsivity, alcohol or drug abuse, or access to pornographic materials (dynamic risk factors). External causes are factors outside the person with ID, such as knowledge, skills, and attitudes of support staff, psychologists and managers related to handling HSB (dynamic risk factors).

Functional/ behavioral and cognitive perspectives on CB

To get more insight into CB, a substantial amount of research has already been conducted, using medical, functional/behavioral and cognitive perspectives. In this thesis we will focus on the functional/ behavioral and cognitive perspective. The first explains behavior as a product of interactions between the person and their environment (past and present; Chiesa, 1994; Hayes, Barnes-Holmes, & Wilson, 2012). CB is seen as a social construction and clients with ID display CB as it serves a function (Banks et al., 2007; Hastings et al., 2013).

The latter perspective explains behavior by the mental processes and representations of a person (Bechtel, 2005).

The functional/behavioral perspective

Research focusing on the functional/behavioral perspective has given a lot of attention to the causes and functions of CB. In this perspective, Functional Behavioral Assessment (FBA) is one frequently used methods to map the characteristics of CB in relation to their environment (Lloyd & Kennedy, 2014). Both descriptive assessment and experimental functional analysis provide information about the antecedents and consequences of CB, and what can trigger and maintain CB (Beavers, Iwata, & Lerman, 2013). Beavers and colleagues (2013) reviewed studies using functional analysis of CB, suggesting that the functions of various types of CB differ. That is, aggressive behavior was mostly maintained by drives to escape from demands, whereas maintaining factors of SIB were more diverse. SIB was not only maintained by wanting to escape from demands, but also by wanting to get attention and maintenance by automatic reinforcement (i.e., behavior that results in a favorable outcome without the involvement of the environment, like displaying SIB to stop the itching; Cooper, Heron, & Heward, 2007). Although FBA provides valuable information related to CB, both descriptive assessment and experimental functional analyses do not seem to be used very often in the clinical practice of care for people with ID. This is probably due to the fact that both methods are time consuming, require specific expertise to execute, are unsuitable for certain settings and types of behaviors (e.g., specific types of CB that have a low frequency; Lydon, Healy, O'Reilly, & Lang 2012).

Based on the functional/behavioral perspective, next to the FBA instruments, instruments have been developed to get more insights in (the functions of) CB. However, these instruments do not necessarily provide more insights in CB of people with ID within the context in which it occurs for various reasons. First of all, many instruments which document forms of CB do not generate information about CB in relation to its environment, and thus will not give information about the context in which it occurs (e.g., Challenging Behaviour Attribution Scale, CHABA; Hastings, 1997). Second, most of these instruments have not been developed specifically for the assessment of CB in people with ID. For example, the Staff Observation Aggression Scale-Revised (SOAS-R) was developed to report aggressive behavior on general psychiatric, forensic psychiatric, and psychogeriatric wards (Nijman et al., 1999). Third, some of these instruments are solely based on self-reports (e.g., Self-Injury Questionnaire – Treatment Related (SIQ-TR); Claes & Vandereycken, 2007). Last, information about CB is often collected in an indirect or retrospective way (Luiselli, 2012; Sansone & Sansone, 2010).

The cognitive perspective

Unlike research in the functional/behavioral perspective, research in the cognitive perspective mainly focusses on the mental processes and representations of the environment of the people showing CB, especially support staff, as they are one of the key agents in the lives of people

with ID who show CB (Eagar et al., 2007). Studies focusing on the emotions, attitudes, and attributions of support staff working with people with ID and CB are common (e.g., Randell et al., 2017; Shead, Scott, & Rose, 2016; Stoesz et al., 2016; Willems, Embregts, Hendriks, & Bosman, 2016; Williams, Dagnan, Rodgers, & Freeston, 2015; Wishart, McKenzie, Newman, & McKenzie, 2013; Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2015) and provide a lot of information about the relation between these variables and staff behavior. For example, in a study of Zijlmans and colleagues (2015), the relationship between the type of CB, attributions, emotions, and interpersonal style was examined. Support staff attributed CB aimed at the environment (e.g., aggressive or destructive behavior) to more controllable causes, they experienced fear and anxiety and had higher scores on the interpersonal styles 'control' and hostility' compared to CB that was aimed at the person him or herself (e.g., SIB or stereotyped behavior). Emotions of support staff interact with the causes support staff give for CB (i.e., attributions; Snow, Langdon, & Reynolds, 2007; Wanless & Jahoda, 2002; Willems, Embregts, Bosman, & Hendriks, 2014). In general, support staff experience CB as aversive (Mossman et al., 2002) and their natural tendency is to stop the aversive experience, and thus to use interventions aimed at stopping the CB immediately, without considering if their reaction might be maintaining the CB. According to Hastings and colleagues (2013), not adapting a reaction to the function of the behavior will likely to ensure the maintenance of CB in the long run.

Perspective of support staff. Based on the cognitive tradition, attributions and attributional styles of support staff are related to their behavior regarding CB of people with ID (Poster & Ryan, 1993; Snow, Langdon, & Reynolds, 2007; Wanless & Jahoda, 2002). Attributions are "*expressions of the way a person thinks about the relationship between a cause and an outcome*" (Munton, Silvester, Stratton, & Hanks, 1999, p.6), while attributional styles are cognitive personality characteristics which reflects the way people habitually explain the things that happen in their lives (Houston, 2016). For example, Poster and Ryan (1993) indicated that the nurses' attributions during an incident of CB (i.e., aggressive behavior), predicted their responses. As is quoted in their study: '*The nurse's interpretation, including the patient's intent and responsibility for his or her behavior, may be more important than the objective aspects of the assault (p. 32)*'.

As support staff are often key agents in the lives of people with ID and CB, their attributions and attributional styles may influence their affective, cognitive and behavioral reactions regarding CB (Dix, 1991; Harris, Allen, Cornick, Jefferson, & Mills, 1996; Snow et al., 2007; Wanless & Jahoda, 2002; Williams et al., 2015) and thus influence the quality of this relationship (Fincham, Beach, & Boucom, 1987). Attributions of support staff are studied frequently (e.g., Cudré-Mauroux, 2010; Noone, Jones, & Hastings, 2006; Rose, Gallivan, Wright, & Blake, 2014) and from these studies it becomes clear that support staff can differentiate between causes of CB (Noone et al., 2006), that it is possible to change attributions of support staff following training (Davies, Griffiths, Liddiard, Lowe,

& Stead, 2015) and that support staff hold different attributions regarding different forms of CB (e.g., Dilworth, Philips, & Rose, 2011; Hastings, Reed, & Watts, 1997; MacKinlay & Langdon, 2009; Stanley & Standen, 2000). In contrast to attributions, attributional styles are, to the best of our knowledge, not yet studied in support staff of people with ID showing CB.

Perspective of people with ID. Recent developments acknowledge the importance of incorporating the views of people with ID more often in research. However, research on the mental processes and representations of people with ID themselves, regarding their CB, is still scarce. Incorporating the views of people with ID on their mental processes and representations is valuable for a number of reasons. First, insights in their processes and representations is likely to help attune more to their wishes and needs, which may motivate them to change (Morrissey et al., 2017). Second, their processes and representations may differ from their environment (Duxbury & Whittington, 2005; Hansen, Hatling, Lidal, & Ruud, 2004). People with ID for example have different representations about the causes of their CB compared to support staff (Duxbury & Whittington, 2005). Last, a review from Bowers and colleagues (2011) indicated that support staff often are not always capable of indicating the triggering events of CB. To be more specific, in about one third of the incidents support staff were not able to provide a cause for aggressive behavior of their clients.

People with mild intellectual disabilities or borderline intellectual functioning

Within healthcare, people with mild intellectual disabilities (MID, IQ between 50 and 70) or borderline intellectual functioning (BIF, IQ between 70 and 85), hereafter designated as people with mild to borderline intellectual disability (MBID), can be seen as a special population (Salvador-Carulla et al., 2013). Although BIF is not considered a disorder or a disability, people with BIF are at a higher risk of developing mental health problems compared to people without an ID (Chen, Lawlor, Duggan, Hardy, & Eaton, 2006; Gigi et al., 2014; Hassiotis, Strydom, & Hall, 2008). Moreover, people with BIF face comparable challenges as people with mild ID regarding all areas in society (Snell et al., 2009), in particular when low intelligence is accompanied by significant limitations in adaptive functioning. Although the majority of the people with BIF do not require (mental health) care (Wieland & Zitman, 2016), a substantial part experiences problems in their adaptive functioning to a level comparable to people with mild ID. Therefore, in the Netherlands, in contrast to many other countries, people with BIF are eligible to the same specialized mental health care services as people with ID (IQ < 70).

People with MBID often attempt to hide their disability (Snell et al., 2009) and therefore their intellectual disability often goes unrecognized. A failure to recognize their MBID (Nieuwenhuis, Noorthoorn, Nijman, Naarding, & Mulder, 2017; Wieland, Haan, & Zitman, 2014) causes them to receive care in settings outside the ID settings, such as general or forensic psychiatric care, addiction services or prisons (e.g., Nouwens, Smulders, Embregts, & Van

Nieuwenhuizen, 2017; Søndenaa, Rasmussen, Palmstierna, & Nøttestad, 2008). These are settings in which professionals can lack expertise in understanding the needs of people with MBID and are not always specialized in the care and treatment of people with MBID with co-occurring psychiatric disorders (Nieuwenhuis et al., 2017). People with MBID who were admitted to regular psychiatric admissions wards had elevated risks of being confronted with coercion (e.g., being secluded during the hospitalization). Besides, this population often has higher and different clinical representations of psychiatric disorders (Diagnostic Manual-ID; Fletcher, Loschen, Stavrakaki, & First, 2007), which requires specific care and support. However, little attention has been paid to this specific population: people with MBID and co-occurring psychopathology. Getting to know more about their CB and the circumstances in which incidents are triggered, both from the perspective of support staff but also the people with MBID themselves, may help to design interventions that will best fit the wishes and needs of this specific population.

Aims of the present thesis

The overall aim of the present thesis was to contribute to a better understanding of (the potential causes of) CB in people with MBID both from a functional/behavioral and cognitive perspective. In this thesis, CB was operationalized into aggressive behavior, SIB, and HSB. The overall aim was divided into three goals. The first goal was to gain more insight into the characteristics of aggressive behavior, SIB, and HSB of people with MBID and co-occurring psychopathology, using three different observation instruments. That is, two instruments for use in people with MBID were adapted. First, regarding aggressive behavior the Staff Observation Aggression Scale- Revised (SOAS-R) was adapted. Second, regarding SIB the Self-Harm Scale (SHS) was adapted. In the case of HSB, a new instrument was developed (the Harmful Sexual Behavior Scale, HSBS) as there were no instruments available. The second goal was to gain more insight in the attributions of people with ID, by synthesizing the evidence from studies on the attributions of people with ID concerning their own or other clients' CB and by asking people with MBID about their attributions regarding their own or other clients' aggressive behavior. The third goal was to gain more insight in the attributions and attributional styles of support staff on aggressive behavior, SIB and HSB.

Outline of present thesis

This thesis consists of 8 chapters. This introduction (Chapter 1) is followed by Chapters 2, 3, and 4 in which respectively the characteristics of 236 aggressive incidents (Chapter 2), 104 incidents of SIB (Chapter 3), and 34 incidents of HSB (Chapter 4) are described and analyzed. These incidents were recorded using an adapted version of the Staff Observation Aggression Scale – Revised (SOAS-R; Nijman et al., 1999) for aggressive behavior, an adapted version of the Self-Harm Scale (SHS; Nijman & Palmstierna, 2004) for SIB, and the Harmful Sexual Behavior Scale (HSBS; van den Bogaard, Nijman & Embregts, 2013) for HSB during 9 months of data collection in a closed setting for people with MBID and co-occuring

psychopathology. In addition, in Chapter 5 the results of a systematic review of qualitative studies focusing on the attributions of people with ID regarding their own or other clients' CB are described. Next, Chapter 6 reports on the attributions of people with MBID residing in a forensic mental health setting, about their own or other client's aggressive behavior. The attributions of people with MBID (N = 20) related to causes of aggressive behavior, derived from group interviews, are reported. Furthermore, in Chapter 7, support staff (N = 20) were asked to describe both an aggressive incident, an incident concerning SIB, and an incident of HSB they had witnessed. Attributions were extracted from the transcriptions of these interviews and the frequencies of different attributional styles were calculated. In the last chapter, the results of the six studies are summarized and discussed related to the implications for clinical practice (Chapter 8). Besides that, the strengths and limitations of the six studies are addressed and recommendations for future studies are provided.

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Chapter 2

Characteristics of aggressive behavior in people with mild to borderline intellectual disability and co-occurring psychopathology

Abstract

Background

People with intellectual disabilities and co-occurring psychopathology have a relatively high likelihood to engage in aggressive behavior. Nevertheless, structured clinical assessment of aggressive behavior, including when and where it occurs, is scarce in this population.

Method

On three wards specialized in the care for people with mild to borderline intellectual disability and co-occurring psychopathology, staff members completed the Staff Observation Aggression Scale – Revised adapted for people with intellectual disabilities (SOAS-R-ID) during a 9 months period, every time they witnessed aggressive behavior.

Results

Based on 236 SOAS-R-ID forms, it was found that aggressive incidents were most common on Thursdays, and on two specific moments of the day (between 9-11 am and 7-9 pm). The aggressive behavior was often exclusively of a verbal nature and was usually targeted against staff members (77.1% of the incidents). The ICC agreement between observers on the total score of the SOAS-R-ID was 0.72. The correlation between the judgment of the severity of aggressive behavior made by the staff members and the SOAS-R-ID severity scores was moderate (r = .40), but significant.

Conclusion

Because aggressive behavior appeared to result often from interactions between the client and staff member or other clients, these interactions might be an important starting point for interventions. Structured clinical assessment of aggressive behavior can help to devise and test the effects of interventions. The SOAS-R-ID seems to be a clinical useful instrument and could therefore help to reduce the frequency of these incidents in the future.

Aggressive behavior is a common phenomenon in the care of people with intellectual disability (ID), especially in inpatient settings (Crocker et al., 2006; Tyrer et al., 2006). The prevalence rates of aggressive behavior among people with ID, however, varies drastically between studies (e.g., Crocker et al., 2006; Tyrer et al., 2006) due to methodological differences, differences in definitions of aggressive behavior, and differences in the populations studied. In this study, aggressive behavior is defined as "*any verbal, non-verbal or physical behavior that was threatening, or physical behavior that actually did harm*" (Morrison, 1990, p.67). Tenneij and Koot (2008) measured the incidence of aggressive behavior for people with mild ID in residential settings in the Netherlands. They found that about 50% of their participants had shown aggressive behavior (object destruction, verbal or physical aggressive behavior), during a 20-week observation period.

Aggressive behavior not only has negative consequences for the environment of the person, but often also for the aggressor. Physical injury, interference with social activities, and abuse are some of the detrimental consequences of aggressive behavior for the aggressors (e.g., Cooper et al., 2009; Emerson & Einfeld, 2011; Matson & Kozlowski, 2012). Staff and family members can experience negative emotions, stress, physical injuries, and fear of assault or burnout (e.g., Allen, Hawkins, & Cooper, 2006; Hensel, Lunsky, & Dewa, 2014; Mills & Rose, 2011). Research shows that aggressive behavior in persons with ID generally tends to persist over time, as is the case in other populations (Einfeld et al., 2006) and that persons with ID often display multiple forms of aggressive behavior at the same time (e.g., physical, verbal, and / or auto-aggressive behavior; Cooper et al., 2009; Crocker et al., 2006; Nijman & à Campo, 2002; Tenneij & Koot, 2008).

Factors associated with aggressive behavior in people with ID are, among others, psychiatric disorders (e.g., Crocker, Prokić, Morin, & Reyes, 2014; Tsiouris, Kim, Brown, & Cohen, 2011), a low level of intellectual functioning (e.g., Cooper et al., 2009; Crocker et al., 2014), gender (e.g., Cooper et al., 2009; Sigafoos, Elkins, Kerr, & Attwood, 1994), and genetic syndromes (e.g., Arron, Oliver, Moss, Berg, & Burbidge, 2011). Moreover, environmental factors such as negative interactions with staff members (instructions, disagreements) or wanting to escape from daily tasks (e.g., Embregts, Didden, Huitink, & Schreuder, 2009a; Embregts, Didden, Schreuder, Huitink, & van Nieuwenhuijzen, 2009b) are also associated with aggressive behavior.

There is increasing knowledge of the causes and functions of aggressive behavior and a growing recognition to use functional assessment methods to map these behaviors in relation to their environment (e.g., Lloyd & Kennedy, 2014). Descriptive assessment and experimental functional analyses of aggressive behavior provide more information about the setting and conditions (antecedents and consequences) that can trigger and maintain aggressive behavior (Beavers, Iwata, & Lerman, 2013). Beavers and colleagues (2013) showed that aggressive behavior was mostly maintained by escape, but other functions were also common (e.g., attention, maintenance by tangible reinforcers and combinations of these (multiple sources of control)).

In earlier research (e.g., Emerson, Einfeld, & Stancliffe, 2010; Wieland, van den Brink, & Zitman, 2015) it is shown that people with mild ID or borderline intellectual functioning have an increased risk of developing mental health problems. These mental health problems, as known from the Diagnostic Manual – Intellectual Disability (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007), do often have different clinical representations in people with (mild) ID and borderline intellectual functioning. Aggression is one of the often mentioned clinical representations (for example in mood disorders: "*Although more systematic investigation is needed, people with ID and Mood Disorder diagnoses do appear to present with irritability and aggression at high rates*" (DM-ID, Fletcher et al., 2007, p. 288). A recent large-scale empirical study of Nieuwenhuis, Noorthoorn, Nijman, Naarding, and Mulder (2017) showed that: 1) people with mild ID or borderline intellectual functioning often are not detected as such in general psychiatric settings, leading to unaddressed treatment needs, and 2): people with mild ID or borderline intellectual functioning that are admitted to general psychiatric wards indeed seem to have a much higher likelihood to become aggressive on these wards than people without mild ID or borderline intellectual functioning, which is illustrated by the fact that they are confronted with the use of coercive measures, such as seclusion, more often compared to clients without ID (Nieuwenhuis et al., 2017). Tenneij and Koot (2008) found that aggressive behavior was aimed at staff members in most cases. They also noticed that staff members used restrictive behavior management techniques, such as seclusion, to stop or control the aggressive behavior in almost half of the incidents. On average, Tenneij and Koot (2008) found a prevalence of 7.9 outwardly directed aggressive incidents (i.e., aggression directed against other persons or objects) per client per year.

To explore the characteristics of aggressive behavior of clients residing in institutions for mental health care, the SOAS-R (Nijman et al., 1999) is an often used measure (e.g., Nijman, Palmstierna, Almvik, & Stolker, 2005). Previous studies showed that the interrater reliability of SOAS severity scores ranges between k = 0.61-0.74 (Nijman, Merkelbach, Allertz, & à Campo, 1997; Steinert, Wölfle, & Gebhardt, 2000; Steinert, Woelfle, & Gebhardt, 1999) and that the Pearson product-moment correlation between independent assessors was r = 0.87 (Nijman et al., 1997). In addition, significant correlations between the SOAS-R assessments and various other instruments measuring aggressive behavior have been found in previous studies (e.g., Kobus, Nijman, & Bulten, 2012). There seems to be a great variation between the numbers of aggressive incidents on acute admission wards (n = 38), varying from 0.4 – 33.2 incidents per patient per year (Nijman et al., 2005). The average numbers also seemed to differ between countries, with for example, the Netherlands having high rates of aggression. In order to attune the SOAS-R for people with ID, it would be beneficial to add specific triggers and consequences for this population, and as Tenneij and Koot (2008) suggested, to assess the interrater reliability of this instrument when used in this population, and explore more client characteristics (e.g., adaptive functioning) to get a clearer picture of aggressive behavior in people with mild ID or borderline intellectual functioning. Accordingly, this study has two goals. First, to examine the incidence of aggressive incidents,

the temperospatial characteristics and the circumstances under which aggressive behavior occurs using an adapted version of the SOAS-R adapted for use in persons with ID (SOAS-R-ID). The second goal was to evaluate the clinical usefulness and reliability of the SOAS-R-ID for measuring aggressive behavior of people with ID in the clinical setting.

Method

Setting and participants

This study was conducted on three closed wards at a specialized treatment centre for people with mild ID (defined as IQ between 50 and 70) and borderline intellectual functioning (IQ between 70 and 85), hereafter indicated as clients with mild to borderline ID, or MBID clients in short, and co-occurring psychiatric and/or behavior problems in the south of the Netherlands. All participating clients lived at the treatment centre and received treatment. The treatment consisted of participating in an activating day care therapy and more specific training courses (e.g., self-management training). Besides that, all clients were offered one-on-one treatment talks with support staff, psychologists and psychiatrists. Some clients received extra treatments related to their specific problems, such as EMDR. Each ward contained 10 beds. The staff members (n = 40) who completed Staff Observation Aggression Scale-Revised adapted for people with Intellectual Disabilities (SOAS-R-ID) forms were primarily women (62.5%) and had a mean age was 34.2 years (SD = 9.4). The majority of staff members had a higher vocational training (55%), and on average they had 7.1 years (SD = 6.8) of experience in working with persons with ID. Most of them (82.5%) had received some specific training in managing aggressive behavior. During the observation period of 9 months, a total of 51 clients stayed at the centre, of which a total of 33 (64.7%) were included in the study. Inclusion criteria were: a) having provided informed consent, b) being 18 years of age or older, c) having resided at the ward for a period of four weeks or more, and d) participating in the study was judged to not interfere with the personal well-being of the client according to the psychologist and psychiatrist of the treatment centre. The 33 participants with MBID (20 men) had a mean age of 31.3 years (SD = 11.4) and an average IQ-score of 73.3 (SD = 6.4). On average, they had stayed at the treatment centre for 54.0 weeks at the end of the study (SD = 38.2 weeks). Besides MBID, all included clients had co-occurring psychiatric disorders according to the Diagnostic and Statistical Manual of Mental Disorders-IV (APA, 1994). The primary diagnoses were as follow: Twelve persons (36.4%) had schizophrenia or other psychotic disorders, seven persons (21.2%) had a mood disorder, six persons (18.2%) had a pervasive developmental disorder, four persons (12.1%) had an anxiety disorder, and four persons (12.1%) had a different diagnosis (e.g., attention deficit disorder). In total, 66% of the clients were diagnosed with two or more psychiatric disorders.

Procedure

After ethical approval was given by the scientific and ethics committee of both the participating centre as well as Tilburg University, data were collected between April 2014 and January 2015 (a 41-week period). Every person with MBID that received treatment at the participating centre during the observation period (or their legal representative) as well as their staff members were asked to participate in the current study and to give informed consent prior to the data collection. After consent, demographic variables of all participants (persons with MBID and staff members) were collected. Support staff were asked to complete a short questionnaire regarding their demographics. For clients who were willing to participate in the study, the client files, with the most recent diagnostic information, were provided by their treating psychologist and psychiatrist (based on the DSM-IV). Subsequently, both clients and support staff received information about the goal of this study and the role of the researcher in their treatment centre. Support staff also received instructions during a team meeting about the use of the SOAS-R-ID; the way they had to report aggressive incidents, and the specific contents of the five SOAS-R-ID columns. Next, data collection started for the duration of 9 months. Staff members completed the SOAS-R-ID every time they witnessed aggressive behavior. The current study focused on aggression aimed at other persons and objects (outwardly directed aggression), and not on aggression aimed at oneself (auto-aggression). If two or more staff members had witnessed an aggressive incident simultaneously, each staff member was instructed to complete an SOAS-R-ID form independently. Based on these multiple SOAS-R-ID forms related to the same incidents, interrater reliability was calculated.

Measures

The SOAS-R-ID. The SOAS-R-ID (Nijman & Palmstierna, 2005; see Appendix 1) is based on the SOAS-R (Nijman et al., 1999), which in its turn originated from the SOAS of Palmstierna and Wistedt (1987). The SOAS-R report form consists of five columns. In the first column, staff members are asked to specify what apparently triggered the aggressive behavior. In the second column, the nature of the aggressive behavior is documented (e.g., exclusively verbal aggressive behavior, physical aggressive behavior, use of objects or weapons, or combinations). The target of the aggressive behavior (e.g., objects, fellow-clients, staff members) is specified in the third column. In the fourth column, the consequences of the aggressive behavior for victims and / or materials are recorded. Finally, in the fifth column, staff members are asked to describe the measures they took to stop or control the aggressive behavior. For the SOAS-R-ID, several additional potential triggers of aggressive behavior, which are specific for clients with ID and / or autism spectrum disorders, were added to the first column of the instrument. These were, among others, aggressive behavior triggered by physical proximity between people, aggression triggered by unexpected situations, or aggression triggered by changes of activity. Likewise, in the fifth column of the SOAS-R-ID, some adaptations were made in the measures taken to stop or control the aggressive behavior, such as trying to stop aggressive behavior by distracting the aggressive client, or trying to prevent escalation by sending the aggressive person to his or her room.

On the basis of completed SOAS-R-ID forms, severity scores ranging from 0 to 22 points can be assigned to the reported aggressive incidents (for the severity scoring system, see Nijman et al., 1999), with 22 points reflecting the most severe incidents in which the victim(s) of the aggressive behavior were physically injured, and the aggressive client had to be secluded or medicated against their will in response to the aggressive behavior. The rationale behind this revised severity scoring system was that the severity of aggressive behavior depends on an array of characteristics of the incidents, with some, such as the consequences for victims, being more important than others (e.g., means used by the aggressive client). With regression analyses (see Nijman et al., 1999) a validated severity scoring system was developed in which separate features are weighted in a way that they make a differential contribution to the overall aggression severity score. To be more specific, the maximum contribution to the total SOAS-R severity score of the first column is 2 points (range 0 to 2 points), the maximum contribution of the second column is 3 points (0 to 3 points), the maximum score of the third column is 4 points (0 to 4 points), the maximum severity score of the fourth column is 9 points (0 to 9 points) and the maximum severity score of the fifth column is 4 points (0 to 4 points). The overall SOAS-R severity score is calculated by adding the highest score of each of the five columns and therefore has a theoretical maximum of 22 points in case of the most severe aggression, consisting of the maximum scores of $2 + 3 + 4 + 9 + 4 = 22$ points for each of the columns. The severity scores for the adapted SOAS-R-ID, were calculated in same way as the original SOAS-R severity scores are calculated, and can only range from 0 to 22 points, as the additions, such as the extra triggers added to column 1 of the SOAS-R version for people with ID were set to 0 points (for the time being) in the calculation of the overall severity SOAS-R-ID scores.

In line with an earlier study on the psychometric properties of the SOAS-R (Nijman et al., 1999), staff members in the current study were also asked to judge the overall severity of the aggressive incident separately on a 100-mm Visual Analogue Scale (VAS) (see Appendix 2), ranging from 0 ('not severe at al') to 100 ('extremely severe').

Severity scores of every incident in this study (SOAS-R-ID form) were calculated based on the SOAS-R scoring system (Nijman et al., 1999) and compared with the 100 mm VAS-severity scores. No carryover effects from the severity scoring on the SOAS-R-ID to the VAS severity scoring were expected because the staff members participating in the current study were not familiar with the calculation of SOAS-R severity scores. Gender and working experience of staff members were included as covariates in the correlational analysis between SOAS-R-ID and VAS-severity scores, as men and women might have different perceptions of aggressive behavior, and the same is plausible for highly experienced versus less experienced staff members (Nijman, Evers, Merckelbach, & Palmstierna, 2002; Noda et al., 2012). The correlation between the SOAS-R-ID and VAS severity ratings were compared using a Pearson product-moment correlation, controlling for the effects of working experience and gender of the completing staff member (see Nijman et al., 2002; Noda et al., 2012), to determine whether the severity scoring system is also be valid for the SOAS-R-ID. The mean SOAS-

R-ID severity score was 7.7 (*SD* = 4.1, range 0-19). The mean VAS severity score was 43.4 mm (*SD* = 21.4 mm; range 4 to 90 mm). The correlation between the SOAS-R-ID and VAS severity scores, corrected for gender and years of working experience of the completing staff member, was 0.40 (*p* < .01, two-tailed).

In the current study, the interrater reliability for SOAS-R-ID forms completed by two independent observers was assessed using Cohen's kappa for each of the five columns, and for the total score using the Interclass (Pearson) Correlation Coefficient (ICC). Kappa values between 0.21 and 0.40 indicate fair agreement, kappa values between 0.41 and 0.60 indicate moderate agreement, kappa values between 0.61 and 0.80 indicate substantial agreement and kappa values >0.80 indicate almost perfect agreement (Viera & Garrett, 2005). In the current study, there were 23 incidents (out of the total of 236 reported SOAS-R-ID incidents; see results section) for which at least two SOAS-R-ID forms were completed by independent observers. Two forms were selected at random for each of these 23 incidents. The kappa-scores between the dyads of observers per column, based on the severity scores, were: column 1 (provocation) κ = 0.629; column 2 (means used) κ = 1.00; column 3 (target) κ = 0.892; column 4 (consequence for victim) κ = 0.368; column 5 (measures to stop the aggressive behavior) κ = 0.736. The ICC of the total score on SOAS-R-ID was 0.72. The absolute percentages of agreement were: 82.6% for column 1; 100% for column 2; 95.7% for column 3; 65.2% for column 4 and 82.6% for column 5.

Vineland-Z. To measure the adaptive behavior of the participants with MBID, the Dutch translation of the Vineland Adaptive Behavior Scale (VABS) survey form (the Vineland-Z; de Bildt & Kraijer, 2003) was used. This instrument contains a total of 225 items in three domains: communication (*n* = 67), daily living skills (*n* = 92) and socialisation (*n* = 66). Using an open-ended interview, staff members could indicate per item if their client usually performed in this way (score 2), sometimes or partly performed in this way (score 1), or never performed in this way (score 0). Total scores on the three domains are calculated by summing the scores of all items. A higher score on a domain represents a higher level of adaptive behavior. Reliability and validity measures of the instrument have found to be moderate to good (e.g., de Bildt & Kraijer, 2003).

Statistical analysis

The characteristics of the aggressive incidents and the clients displaying these behavior were analysed using descriptive statistics in the Statistical Package for the Social Sciences (SPSS) version 22. Univariate comparative analyses with t-tests or chi-square calculations and, if needed, Fisher exact tests were performed to investigate potential differences between aggressive versus non- aggressive persons.

Results

In the next paragraphs, the frequency of aggressive incidents as reported by means of the SOAS-R-ID, as well as the results per column of the SOAS-R-ID and temperospatial characteristics of the aggression are described.

Frequency of aggressive incidents

During the 41-weeks of data collection, a total of 236 incident forms were completed by staff members on the three wards, of which 210 concerned unique incidents of aggressive behavior. The average number of incidents was 5.1 per week or 8.9 incidents per client per year.

Triggers of aggressive behavior

In 28.6% (n = 60) of the incidents, staff members indicated that they did not understand what triggered the aggressive behavior. When staff members could specify what triggered the aggressive behavior (n = 150; 71.4%), in 28.0% (n = 42) of the 150 cases the clients became aggressive after they were denied something they wanted. In 24.0% (n = 36) of the 150 cases aggressive behavior occurred when a client was requested to execute a certain task, and in 14.0% of the incidents (n = 21) it was judged that other clients provoked the aggressive behavior. In 11.3% (n = 17) of the 150 cases, the provocation for the aggressive incident was either hearing bad news, a change of activity, staff members requiring the client to take medication, unexpected events or (help with) daily living activities. The rest of the 150 provocations (22.7%; n = 34) that staff members recorded were outside the existing categories, like losing a soccer match or fear of the dentist.

The means used by the client

The majority of the incidents (n = 120; 57.1%) consisted exclusively of verbal aggressive behavior. In 31.9% (n = 67) of the incidents, the aggressive clients engaged in physical aggressive behavior, mostly combined with verbal aggressive behavior and/or property destruction (n = 57; 85.1%). Aggressive behavior exclusively targeted against property occurred in 9.5% (n = 20) of the incidents. If there was aggressive behavior against property, clients smashed or threw with glassware, cutlery, chairs and other utensils (e.g., broom, ashtray or flower pot). In three incidents (1.4%), clients threatened someone with a knife.

The target of the aggressive behavior

Most of the aggressive incidents (n = 162; 77.1%) were aimed at staff members, of which 73.5% (n = 119) were exclusively aimed at staff members, 14.2% (n = 23) at staff members and objects, 11.7% (n = 19) at staff members and other clients. A minority of the incidents was targeted exclusively against other clients (n = 19; 9%), objects (n = 19; 9%) or both (n = 2; 1%). In 3.8% (n = 8) no person or nothing in particular was targeted, or it was unclear what the aggressive behavior was directed against.

Consequence(s) for the victim(s)

In 53.3% (n = 112) of the incidents, staff members recorded that there were no consequences of the aggressive incident for victims. If consequences were reported (n = 98, 46.7%), in more than two third (n = 78; 79.6%) of these incidents the victim had felt threatened by the client's behavior. In 8 incidents (8.2%) there was damage to objects and replacement was sometimes (n = 3; 37.5%) necessary. In 7.1% (n =7) of the incidents, victims sustained physical pain or had visible injuries.

Measures to stop aggressive behavior

Staff members usually carried out more than one measure in an attempt to stop or control the aggressive behavior. Here we only report the measures with the highest severity scores. In 55.7% (n = 117) of the incidents, the staff member spoke to the client, distracted the client, offered closeness or the contact was actively terminated by the staff member (e.g., by leaving the area). In 33 incidents (15.7%), clients were sent to their room. In 12.4% (n = 26) of the cases, the client was either manually or mechanically restrained and in 9.5% (n = 20) clients were secluded. In 3.3% (n = 7) of the incidents no measure was taken to stop the aggressive behavior (e.g., the client left the area). In seven other incidents (3.3%) the client was given medication (orally or parenterally).

Location of the incidents

Most incidents took place near or at the entrance to the staff office or in the corridors of the ward (n = 67; 31.9%). Additionally, relatively many incidents took place in the garden (n = 40; 19.0%) or in the client's room (n = 35; 16.7%). In 9.5% the incidents occurred in the living room (n = 20) and 7.1% (n = 15) of the incidents were reported in the activity center, where clients follow a daily activity program. The rest of the incidents (n = 33; 15.7%) took place in other areas (e.g., the relaxation room, in the kitchen, or dining room).

Temporal distribution

There was a significant difference on the frequency of aggressive incidents per day [χ^2(6) = 27.28, p < .001], with the highest number of incidents on Thursdays (24.3%, n = 51). Most of the incidents occurred between 09.00-11.00 am (17.6%, n = *37*) and between 19.00-21.00 pm (17.1%, n = *36*), [χ^2(8) = 40.19, p < .001].

Characteristics of the aggressive clients

Of the 33 persons with MBID included in the study, 22 (66.7%) displayed some form of aggressive behavior based on the SOAS-R incident forms. In Table 1, the characteristics of the individuals with MBID displaying aggressive behavior are summarized and compared with the persons with MBID not displaying these behaviors. Four of the 22 aggressive participants (18.2%) caused more than half of all the incidents (58.1%).

Table 1. Characteristics of aggressive and non-aggressive clients during the 9 months observation period

	Aggressive clients (n = 22)		Non-aggressive clients (n = 11)		Statistical comparison		P	ODD's ratio	Cohen's D
Gender, male: n (%)	13	(59.1)	7	(63.6)	χ2(1) =	0.06	0.80	0.92	-
IQ: M (SD)	72	(6.4)	76	(5.8)	t(28) =	-1.72	0.10	-	-0.68
Age, years: M (SD)	31.1	(13.1)	31.8	(7.1)	t(30.68) = -0.21		0.84	-	-0.07
Diagnosis, n (%)									
Schizophrenia or psychotic disorder	6	(27.3)	6	(54.5)	Fisher Exact Test		0.13	0.50	-
Pervasive developmental disorder	4	(18.2)	2	(18.2)	Fisher Exact Test		0.69	1.00	-
Mood disorder	5	(22.7)	2	(18.2)	Fisher Exact Test		0.57	1.25	-
Anxiety disorder	4	(18.2)	0	(0.0)	Fisher Exact Test		0.18	n.a.	-
Other disorder (e.g., Attention Deficit Disorder or substance-related disorder)	3	(13.6)	1	(9.1)	Fisher Exact Test		0.59	1.50	-
Involuntary admitted, n (%)	7	(31.8)	4	(36.4)	χ2(1) =	0.03	0.86	0.87	-
Length of admission in weeks: M (SD)	45	(26.5)	72	(51.8)	t (12.69) = -1.60		0.13	-	-0.65
Adaptive behavior age: M (SD)									
Communication	10.1	(2.2)	10.3	(1.8)	t (31) =	-0.27	0.79	-	-0.10
Daily activities	9.6	(2.5)	10.3	(1.9)	t (30) =	-0.83	0.42	-	-0.32
Socialisation	6.8	(2.0)	7.4	(2.2)	t (31) =	-0.72	0.48	-	-0.26
Total score on Vineland-Z	8.9	(2.3)	9.5	(1.7)	t (30) =	-0.69	0.50	-	-0.27

Discussion

The current study was aimed to gain more insight into the characteristics of aggressive behavior in people with MBID and co-occurring psychopathology. In addition the clinical usefulness and reliability of the SOAS-R-ID was assessed.

The results of this study show that aggressive behavior in people with MBID and co-occurring psychopathology is a widespread problem, with a frequency of 8.9 incidents per client per annum. This is comparable with earlier research conducted in a similar setting (7.9 incidents per client annually; treatment facility for people with mild ID and severe challenging behavior; Tenneij & Koot, 2008) and other settings (e.g., general psychiatry) in which the median value per person per year was 7.6 (Nijman et al., 2005).

The majority of the aggressive incidents consisted of verbal aggressive behavior, and the mean SOAS-R-ID severity score in this study was 7.7. This is lower than the results of studies in general psychiatric admissions wards (SOAS-R severity ranged between 9.2 and 11.0; Nijman et al., 2005).

In line with earlier studies conducted in general psychiatry, most of the incidents were caused by a minority of clients (i.e., four clients were involved in more than half of all reported incidents). This suggests that effective prevention of aggression in clients with MBID preferably consists of tailor-made interventions targeting the specific triggers of the behavior in individual clients with high aggression risks.

Aggressive behavior took place most often on a specific day of the week (Thursday) and between 9-11 am and 7-9 pm. On Thursdays staff members and clients had their weekly meeting on the three wards that participated in the current study. In these weekly meetings, clients and staff members discussed practical issues such as general tasks for the next week. Between 9-11 am most of the clients get ready for their daily program and between 7 – 9 pm most of the clients had no specific program. This could be related to the fact that in these hours staff members anticipated at stressful situations for the clients because of time pressure, the transition to (other) activities, and the interactions between clients, but further research is needed to give indications about the potential causality of these relations.

In general, the aggressive behavior was mostly aimed at staff members and almost half of the time (46.9%) negative consequences of the behavior were reported. If there were consequences reported, it mostly concerned psychological consequences, with staff members having felt threatened by the aggressor. Clearly, aggressive behavior can have an impact on staff members' feelings of safety and constitutes a psychological strain for them. However, in most of the cases, staff members used verbal interventions or sent clients to their room. In 25% of the incidents, however, more intrusive and / or restrictive measures (e.g., medication, seclusion) were used in an attempt to control the aggressive behavior. Many incidents took place close to or in front of the office, a place where many interactions between clients and staff members take place. It seems that interactions between clients and staff members can play an important role in initiating agitation and aggressive behavior (Nijman et al., 1997; Tenneij & Koot, 2008; Whittington & Wykes, 1996).

The interrater reliability of the SOAS-R-ID was satisfactory and varied for the separate columns from fair to excellent, suggesting that the SOAS-R-ID has the potential to become a reliable measure to objectively rate aggressive incidents in people with MBID. The interrater reliability was mostly modest for the SOAS-R-ID scores in the fourth column, by which the consequences for victim(s) of the aggressive behavior are recorded, with the kappa being 0.368, and the overall percentage agreement being 65.2%. The data from the 23 SOAS-R-ID incident forms that were rated by two staff members suggested that rating the psychological impact of the aggression in particular can be subjective. An incident can be experienced as being very threatening by one staff member, whereas another staff member witnessing the same incident does not have to feel threatened by the aggressive behavior at all. To further test the reliability and (convergent) validity of the SOAS-R-ID, it would be recommendable to use larger samples and other instruments which also assess aggression, like the Social Dysfunction and Aggression Scale (SDAS; Wistedt et al., 1990). For the SOAS-R, in its original form, this research has already been conducted in a maximum security forensic psychiatric institution in the Netherlands (Kobes, Nijman, & Bulten, 2012). In that study a significant correlation of *0.731* was found between SOAS-R aggression reports and SDAS-9 scores.

The correlation between the severity scores of the SOAS-R-ID and the VAS severity scores of r = 0.40 was modest but significant, and in the range of found correlations in previous studies performed in general psychiatric institutions. (i.e., in earlier studies, correlations were found between 0.387 (Noda et al., 2012) and 0.62 (Nijman et al., 2002)). The modest correlation suggests that the severity of incident as experienced by individual staff members can rather differ from the SOAS-R-ID severity scores. Staff members sometimes, for example, rated verbal aggressive behavior, with no consequences for the victim and no severe measures to stop the aggressive behavior, as very severe (i.e., a high VAS severity score). This suggests that to fully understand the impact of aggressive behavior for staff members a more subjective measure of the experience and impact of the aggressive behavior such as our single item VAS severity score, may also have to be taken into account, especially when the aggressive behavior 'only' involves verbal abuse or threats. This subjective measure may provide us more insight into the experiences of the victims of aggressive behavior and the consequences of this, as also has been reported in earlier research (e.g., Rose, Horn, Rose, & Hastings, 2004).

Limitations of the study

This study took place on three different wards of one treatment center, which limits the ability to generalise to other institutions caring for persons with ID. Despite the effort and willingness of the team to report as many incidents as possible, forgetting to report due to a high workload or not being in the place where an incident took place (e.g., incidents between clients) likely has prevented staff members from reporting all the aggressive incidents which might have led to underreporting, which is also seen in other studies (e.g., Tenneij, Goedhard, Stolker, Nijman, & Koot, 2009). Besides that, the SOAS-R-ID is an observation scale completed by staff members, which makes that the recorded incidents will have been

limited to those that were seen or noticed by the staff and particularly when verbal aggression is concerned, the used definition of aggression may leave room for interpretation on the part of the observers. Thus, the incidence of incidents is likely to be higher than that reported in the current study.

No significant differences in demographic characteristics (e.g., age, psychiatric disorders, or adaptive functioning) were found between the aggressive and non-aggressive clients in this study. Based on earlier studies (e.g., Holden & Gitlesen, 2006) it was expected that differences in, for example, adaptive functioning would be present. The small sample size and also the specific setting, with its recruitment criteria, are likely explanations for the lack of significant findings.

Relevance for clinical practice

The present study aimed at providing more insight into the characteristics of aggressive incidents. People with ID reside in many different settings, such as general psychiatry, regular care settings for people with ID, but also in prisons (e.g., Søndenaa, Rasmussen, Palmstierna, & Nøttestad, 2008) that often lack expertise in recognising people with ID and are not specialized in the care and treatment of people with ID with co-occurring psychiatric disorders. Getting to know more about their challenging behaviors (e.g., aggressive behavior) and the circumstances in which incidents are triggered may help staff members to react and intervene more appropriately.

Challenging behaviors, including aggressive behavior, are seen as the product of the interaction between different persons (e.g., staff members and clients; Banks et al., 2007). If somebody wants to know more about the aggressive behavior, it is needed to get more information about the person showing the aggressive behavior and the person witnessing the aggressive behavior. The SOAS-R-ID is an easy to use instrument, which can give an overview of the aggression that takes place on a ward, with minimal time investment. The instrument can be helpful to identify the most aggressive clients, and to get insight, albeit a rather global one, in the type and severity of aggression these clients display. Based on the results of the SOAS-R-ID, a deeper analysis of aggression of specific clients that are aggressive relatively often can take place, using for example a functional behavior assessment. In other words, the SOAS-R-ID can be a screening instrument for aggressive behavior of clients with ID, and helps determining which clients cause most incidents. Subsequently, functional analyses can be used for an in depth exploration of the functions and maintaining variables of aggressive behavior in specific clients. For evaluating the effects of interventions that are derived from the functional analyses, the SOAS-R-ID can be useful again as an outcome measure, to indicate the effects of aggression reducing interventions and treatment on the amount and types of aggression displayed. The current study contributed to this as a first step by using and testing the reliability and clinical usefulness of a structured clinical observation instrument, although more work has to be done to complete the picture of aggressive behavior in this specific population.

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Appendix 1. SOAS-R-ID

Staff Observation Aggression Scale-Revised, adapted for people with Intellectual Disabilities   **SOAS-R-ID**

Initials of the client: _____   Ward: _____

Registration no.: _____   Incident no.: _____

Other aggressive person, namely: _____   Date (dd/mm/yyyy): _____ / _____ / _____

Registrating staff member: _____   Time (hours:minutes): _____ : _____

This form is to be completed by staff members witnessing aggressive behavior of a client whereby aggression is defined as: **any verbal, non-verbal or physical behavior that was threatening (to self, others or property), or physical behavior that actually did harm (to self, others or property)** (in: *Morrison, 1990*). In the case of an aggressive incident please note the initials of the client and/or the other aggressive person, date and the time on which the incident started, and put at least one mark in each column.

1. Provocation	2. Means used by the client	3. Target of aggression	4. Consequence(s) for victim(s)	5. Measures to stop aggression
no understandable provocation ☐	verbal aggression ☐	nothing/nobody ☐	no ☐	none ☐
PROVOKED BY:	**ORDINARY OBJECTS:**	object(s) ☐	**OBJECTS:**	talk to client ☐
other client(s) ☐	chair ☐	other client(s) ☐	damaged: replacement not necessary ☐	client distracted ☐
request to perform certain task ☐	glass(ware) ☐	client self ☐	damaged: replacement necessary ☐	ended contact/ left situation ☐
client being denied something ☐	other objects, namely: _____ ☐	staff member(s) ☐	**PERSONS:**	peroral medication ☐
help with ADL ☐	**PARTS OF THE BODY:**	other persons, namely: _____ ☐	felt threatened ☐	parenteral medication ☐
physical proximity ☐	hands (e.g. hitting, punching) ☐		pain < 10 min. ☐	held with force ☐
unexpected situations ☐	hands (inappropriate physical contact) ☐		pain > 10 min. ☐	sent to room ☐
change of activity ☐	feet (e.g. kicking) ☐		visible injuries ☐	seclusion ☐
alcohol or drug abuse ☐	teeth (biting) ☐		need for treatment ☐	mechanical restraint ☐
staff requiring client to take medication ☐	other parts, namely: _____ ☐		need for treatment by a physician ☐	other measures, namely: _____ ☐
hearing bad news ☐	**DANGEROUS OBJECTS OR METHODS:**		other consequences, namely: _____ ☐	
other provocations, namely: _____ ☐	knife ☐			
	strangulation ☐			
	other means, namely: _____ ☐			

Based on: Nijman, Muris, Merckelbach, Palmstierna, Wistedt, Vos, van Rixtel & Allertz (1999).
The Staff Observation Aggression Scale – Revised (SOAS-R). *Aggressive behavior, 25,* 197-209.

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Appendix 2. The VAS

The Visual Analogue Scale (VAS)

This aggressive incident was:

|———|

Not severe at all   Extremely severe

CB

Chapter 3

Self-injurious behavior in people with intellectual disabilities and co-occurring psychopathology using the Self-Harm Scale: A pilot study

Abstract

Background

Self-injurious behavior (SIB) is one of the most detrimental behaviors for the person showing it as well as for their environment. Nevertheless, structured clinical assessments of SIB are scarce.

Method

Staff completed a Self-Harm Scale (SHS) every time they witnessed SIB in clients with an intellectual disability (ID) and co-occurring psychopathology (N = 33) during a 9 months period. Descriptive statistics were conducted to explore the nature of the incidents of SIB and the characteristics of the people involved in the incidents.

Results

In 41 weeks, 104 SIB incidents were reported for 8 out of 33 clients (24%). Incidents were most prevalent on Mondays (23%). As far as the methods of SIB concerned, cutting was the most used method (63%). Clients who showed SIB differed significantly from clients who did not on gender, having a personality disorder and communicative abilities.

Conclusions

This study was one of the first that used an incident-based record form to report SIB by direct observation. It is hoped that the SHS helps to gain more information about SIB to improve individualized interventions. Further research is necessary to determine the psychometric properties and clinical utility of the scale.

Self-injurious behavior (SIB) can be defined as *behavior in which a person harms (or attempts to harm) oneself deliberately and physically.* Typical examples are head-banging, self-biting, and self-scratching (Lowe et al., 2007), with a prevalence rates of 4.89% in a population-based cohort of adults with ID (Jones et al., 2008). SIB puts the individual at risk in a physical, psychological, and social way. It intervenes significantly with the quality of life of an individual and can lead to: 1) physical impairments or even death (Emerson, 1992; Klonsky, 2007; Nissen & Haveman, 1997), 2) increased psychotropic medication (Matson & Neal, 2009; Robertson et al., 2005), 3) mechanical restraint and protective devices (Robertson et al., 2005), 4) feelings of shame, hopelessness, and guilt (Brown & Beail, 2009), 5) diminished psychological and social development, social isolation and exclusion, and institutionalization (Emerson et al., 1994), 6) neglect and abuse (Emerson et al., 1994), and 7) obstacles in receiving adequate care (Cowley et al., 2005). SIB also has great impact on families and professionals, such as feelings of anger, inadequacy and guilt (Fish, 2000), and negative psychosocial effects (Mossman et al., 2002). Besides these personal consequences, SIB can lead to costly services and management difficulties (Emerson et al., 2001; Hassiotis et al., 2008), because of the required increased support or even one-to-one supervision (Tureck et al., 2013).

SIB is often persistent over time (Emerson et al., 2001; Kiernan & Alborz, 1996; Murphy et al., 1993) and the occurrence of specific forms is relatively stable within the group showing severe SIB (Emerson et al., 2001). Persons with ID can show multiple forms of SIB (Emerson et al., 1997) and it can have a variety of etiologies (e.g., genetic, biological, psychological, environmental, or a combination) (Luiselli, 2012). Associations have been found between SIB and several syndromes (e.g., Prader-Willi syndrome, Cri du Chat syndrome, Lesch Nyhan syndrome or Fragile X syndrome; Arron et al., 2011; Hall, Oliver, & Murphy, 2001) and psychiatric conditions (e.g., borderline personality disorder, bipolar disorder, depressive disorder; Haw et al., 2001; Joyce et al., 2010; Zanarini et al., 2008).

Estimates of the prevalence of SIB in people with ID vary, partly due to the population and setting studied (Rojahn & Esbensen, 2002) and the methodological diversity, but also due to the sometimes hidden nature of these behaviors (Nijman & à Campo, 2002). Prevalence rates range between 4% and 23% in people with ID (Cooper et al., 2009; Kahng et al., 2002; Rojahn & Meier, 2009).

There is increasing knowledge of the causes and functions of SIB and the recognition for research to guide evidence-based interventions (Gratz, 2003; Suyemoto, 1998). Descriptive assessment and experimental functional analyses of SIB give a rich source of information about the setting and conditions (antecedents and consequences) that precede and follow SIB (Beavers et al., 2013). In their review Beavers and colleagues (2013) addressed that SIB was mostly maintained by escape, attention and automatic reinforcement. Despite this relevant information, descriptive assessment and experimental functional analyses do not seem to be used often in clinical practice (Lydon, Healy, O'Reilly, & Lang, 2012). Lydon and colleagues noted that performing functional analyses is not always easy in clinical practice, because it is

time consuming, requires specific expertise to execute, and it is unsuitable for certain settings and types of behaviors. Another reason for this may be a lack of standardized and reliable ways to document incidents of SIB.

Indeed, when looking at the instruments used in research projects to assess the characteristics of SIB, it is found that most instruments are self-reports (e.g., the Self-Harm Inventory (SHI), Sansone, Wiederman, & Sansone, 1998) or informant based questionnaires (e.g., Self-Injurious Behavior Questionnaire (SIB-Q), Schroeder, Rojahn, & Reese, 1997), and collect information about SIB in an indirect or retrospective way (Luiselli, 2012; Sansone & Sansone, 2010). These instruments do not primarily focus on the relation between the behavior of an individual and potential specific situational triggers in the environment of the self-injuring client and, thus, may impede studying SIB in the context in which it occurs (place, time, direct trigger, and reactions of the environment to the behavior). To our knowledge, only Nijman and à Campo (2002) and Tenneij and Koot (2008) conducted studies using the Staff Observation Aggression Scale-Revised (SOAS-R; Nijman et al., 1999), an incident based, observer assessed instrument for aggression. Using this aggression observation instrument, SIB (auto-aggressive behavior) can also be documented as a subsequent part of the observation.

To increase our knowledge about the situational determinants, triggers, and consequences of SIB, research is needed in which incidents of SIB are documented directly by observation in their natural context, using an instrument specifically designed to observe SIB. In this study we therefore focus on two goals. First to assess the clinical usefulness of an incident-based assessment instrument for SIB, called the 'Self-Harm Scale' (SHS). Second to provide more insight in the characteristics of SIB of people with ID and co-occuring psychopathology as well as its frequency and severity, using an instrument focusing solely on SIB.

Method

Setting and participants

This study was carried out in collaboration with three closed units of a treatment center, specialized in care for people with mild ID or borderline intellectual functioning and co-occurring psychiatric and/or behavior problems. Each unit contained 10 beds. Of a total of 40 support staff who completed the Self-Harm Scale (SHS), 63% (*n* = 25) were women. The average age of these 40 support staff members was 34.2 years (*SD* = 9.4). On average, they worked 7.1 years (*SD* = 6.8) with persons displaying self-injurious and/or other challenging behaviors. In the 41-week period (9 months) of data collection, 51 clients stayed at the centre. A total of 33 clients (64.7%) were included in the study. Clients were not included if a) they did not gave informed consent, b) they stayed for a period shorter than four weeks or c) the responsible psychologist did not agree the client took part in the study, because informing the client about the research and asking him/her for permission would possibly

worsen the well-being of the client. Of the total participating group (*N* = 33), 20 persons (61%) were men. The mean age of the 33 participating clients was 31.3 years (*SD* = 11.4), their average IQ score was 73 (*SD* = 6.4) and the average length of stay was 54 weeks (*SD* = 38.2). Of the 33 clients, eleven persons (33%) were involuntary admitted, twelve persons (36%) were diagnosed with schizophrenia or other psychotic disorders, 7 persons (21%) with a mood disorder, 6 persons (18%) with a pervasive developmental disorder, 4 persons (12%) with an anxiety disorder and 4 persons (12%) had a different diagnosis (e.g., attention deficit disorder). In addition, 7 persons also had a personality disorder (21%).

Materials

The Self-Harm Scale. The Self-Harm Scale (SHS) was initially developed by H. Nijman and T. Palmstierna. The two authors made a first draft of this scale based on their clinical experience with clients who display SIB in general psychiatric hospitals (e.g., see Nijman & Palmstierna, 2004) and their expertise with developing incidents-based instruments regarding aggressive behavior. Following this, the first draft of the scale was presented to the members of the European Violence in Psychiatry Research Group (EViPRG), during a routine meeting of this group in Dublin several years ago, for feedback. This resulted in several revisions and additions of some commonly used self-injuring methods that are seen in clinical practice on psychiatric wards, which were added to the second column of the SHS. The current study, however, is, as far as we know, the first study in which the SHS was used to document incidents of SIB in clinical practice. The current version of the SHS consists of five columns. The SHS provides the informant with selected options in separate boxes that only have to be marked by the respondents, such as place of self-harm: arm, neck or leg. In the first column of the SHS, support staff record which people were present during the incident, the location where the incident took place and what apparently triggered the SIB. The means used to self-injure are documented in the second column (e.g., using parts of the body (e.g., nails or head) and/or materials (e.g., knife or chemicals) to self-injure). In the third column support staff indicate the part(s) of the body that were involved in the SIB. In the fourth column, support staff list the consequences of the SIB for the person him- or herself. In the fifth and last column of the SHS, support staff document in what way the SIB stopped. This could be without intervention (e.g., client stopped the SIB by him- or herself) or by an intervention of support staff (e.g., verbal intervention or held with force). The SHS form is presented in the appendix of this article. Subsequently, support staff had to judge the overall severity of the SIB on a 100-mm Visual Analogue Scale (VAS), ranging from 0 ('not severe at all') to 100 ('extremely severe'). Each support staff who witnessed SIB or was informed the client had injured him or herself was asked to complete a SHS.

The Vineland-Z. The Dutch translation of the Vineland Adaptive Behavior Scales-Survey Form (VABS; de Bildt & Kraijer, 2003), the Vineland-Z, was used to measure the adaptive behavior of the participants with ID. On the VABS, 225 items divided in three domains have

to be completed, which concern: communication (n = 67), daily living skills (n = 92), and socialisation (n = 66). In an interview, support staff indicate for each VABS-item whether their client usually performs in this way (score 2), sometimes or partly performs in this way (score 1), or never performs in this way (score 0). The total score of the list is the sum of all item scores, in which high scores represent higher levels of adaptive behavior. The instrument has a good reliability and validity in a population of people with ID (de Bildt & Kraijer, 2005).

Procedure

Ethical approval to conduct the study was obtained both by the ethical committee of Tilburg University (EC-2013.30) and the participating treatment facility in the south-east of the Netherlands (2013016.wk), in compliance with the Helsinki Declaration. Data collection took place between April 2014 and January 2015 (a 41-week period). Before data collection started, each person with ID (or their legal representative) that received treatment at the participating center during the observation period, as well as their support staff, were asked to join the study. Of all participants (i.e., persons with ID and support staff) who gave informed consent demographic variables were collected. Following this, the data collection with the SHS started. Support staff completed the SHS every time they witnessed or were informed about SIB of a client within the 41-week period. Finally, the two clients who showed most SIB and their psychologists were asked about their views on the SIB.

Analysis

The characteristics of the people with ID and support staff and the characteristics of the incidents were analysed using descriptive statistics in the Statistical Package for the Social Sciences (SPSS) version 22. A univariate comparative analyses with t-tests or chi-square calculation and, if needed, Fisher Exact tests (when the sample size was too small to perform a chi-square test), were conducted to investigate the potential differences between persons who had engaged in SIB and those who had not. Next, because two clients displayed the majority of the incidents, these two cases were analysed in detail, looking at all different variables (e.g., time of the incidents of SIB, triggers, consequences, and location of SIB). Besides using statistical analyses, we screened the interviews of the psychologist and client on qualitative information related to the SIB. Quotes about the preceding events, the SIB, the consequences and measures that typified the SIB of the clients were subsequently extracted from the interviews, and added to result section.

Results

Overall characteristics of SIB

Eight of the 33 persons with ID included in the study (24%) displayed some form of SIB based on the SHS forms. During the 41-weeks of data collection, a total of 104 incident forms were completed by support staff of the three wards. The average number of SIB incidents was 2.5 per week, which would equal 4.0 incidents per participating client per year. In Table 1, the characteristics of the persons with ID who display SIB are summarized and compared with the persons with ID who did not show any form of SIB. Clients who did show SIB were a) more often female; b) more often diagnosed with a borderline personality disorder (BPD), and c) had better communication skills compared to the clients without SIB.

The eight clients displaying SIB used various methods to injure themselves of which cutting was the most used method (n = 65, 63%), followed by head banging (n = 47, 45%), taking chemicals or medication (n = 12, 12%), injuring themselves by hitting against objects (n = 10, 10%), and strangulation (n = 8, 8%). In 33% (n = 34) of the incidents of SIB, clients used more methods at the same time. In 31% (n = 32) of the incidents of SIB support staff indicated that they did not understand what triggered the SIB. In case support staff could specify what triggered SIB, stress inducing interactions (e.g., interactions between client and support staff, hearing bad news; n = 31, 30%) and a psychological state (e.g., dissociative state, traumatic flashbacks; n = 34, 33%) were the most frequently mentioned triggers. In 64 incidents of SIB (62%), no or only 'minor' consequences were registered, which are defined as a (physical) consequence that did not require medical assistance, like scratches. In 38% of the incidents (n = 40), however, the SIB resulted in more severe injuries, where medical assistance was required, like skin burns or unconsciousness.

The average severity score (VAS) for the total group of participants who displayed SIB was 4.9 (SD 1.9, range 0.4 – 9.9). The severity scoring of support staff differed significantly between no or minor injuries and severe injuries (t (101) = -2.844, p = .005). That is, support staff experienced incidents of SIB as more severe (M = 56.1, SD = 16.2) if the consequences were also more severe according to the SHS, compared to incidents of SIB with no or minor consequences (M = 45.5, SD = 19.5). When intervening (83%), support staff used manual restraints most often (56%; n = 49), such as holding the arms of the clients to prevent the client from (further) cutting. In 36% (n = 31) support staff used verbal techniques or approached the client to stop the behavior, such as asking the client to stop immediately with SIB. In 17% (n = 18) of the incidents, the SIB stopped without an intervention.

Temperospatial characteristics of SIB

In line with an earlier study of Nijman and à Campo (2002), SIB most often took place in the bedroom of the client (93%, n = 97). The frequency of SIB differed significantly over the days [χ^2 (6) = 19.2, p = .004], with the highest number of incidents on Mondays (23%, n = 24). Most of the incidents occurred between 6.30 and 10.30 PM (57%, n = 59) [χ^2 (3) = 68.3, p < .001].

Table 1. Characteristics of persons with and without self-injurious behavior

	Self-injuring clients (*n* = 8)		Non-self-injuring clients (*n* = 25)		Statistical comparison	P
Gender, male: *n* (%)	1	(12.5)	19	(76.0)	Fisher Exact test	.003
IQ: mean (*SD*)	73.1	(7.7)	73.4	(6.1)	*t*(28) = -0.105	.917
Age, years: mean (*SD*)	30.9	(15.3)	31.5	(10.2)	*t*(9.083)= -0.107	.917
Diagnosis axis I, *n* (%)						
Schizophrenia or psychotic disorder	1	(12.5)	11	(44.0)	Fisher Exact test	.206
Pervasive developmental disorder	3	(37.5)	3	(12.0)	Fisher Exact test	.137
Mood disorder	2	(25.0)	5	(20.0)	Fisher Exact test	1.000
Anxiety disorder	2	(25.0)	2	(8.0)	Fisher Exact test	.241
Other disorder (e.g., Attention Deficit Disorder or substance-related disorder)	0	(0.0)	4	(16.0)	Fisher Exact test	.550
Diagnosis axis II, *n* (%)						
Personality disorder	4	(50.0)	3	(12.0)	Fisher Exact test	.042
Involuntary admitted, *n* (%)	3	(37.5)	8	(32.0)	Fisher Exact test	1.000
Length of admission: mean (*SD*)	52.7	(37.9)	54.4	(39.1)	*t*(31) = -0.110	.913
Adaptive behavior age: mean (*SD*)						
Communication	11.5	(1.1)	9.8	(2.1)	*t*(23.312)= 3.107	.005
Daily living skills	10.1	(1.9)	9.8	(2.5)	*t*(30) = 0.322	.750
Socialisation	8.0	(2.2)	6.6	(1.9)	*t*(31) = 1.714	.097
Total score on Vineland-Z	10.0	(2.0)	8.9	(2.1)	*t*(30) = 1.313	.199

SIB illustrated by two cases

Two of the eight clients who displayed SIB, which will be called Ms. M. and Ms. L., caused more than eighty percent of the incidents (85%). The characteristics of these two clients are described in the next paragraph, completed with quotations from the interviews with M., the psychologist of M. and the psychologist of L.

Description of SIB of M. M. is a 20-year-old woman (full-scale IQ = 67) diagnosed with a dissociative disorder, post-traumatic stress disorder and borderline personality disorder. She stayed at the treatment center for 77-weeks. In the 41-week of data collection, a total of 55 unique incidents of SIB were recorded, consisting mostly of head-banging (*n* = 35; 64%) and cutting (*n* = 33; 60%). Most of M.'s incidents of SIB took place in the evening, between 6.30 and 10.30 PM (80%; χ^2 (3) = 89.1, *p* < .001), and were performed in her own room (96%). In 31% (*n* = 17) of the incidents support staff reported that the reason for the SIB was unclear to them. In the case support staff could indicate potential triggers that led to SIB, they often (*n* = 19, 50%) gave psychological reasons (e.g., emotions, dissociation, traumatic flashbacks) and three times (8%) the SIB was reported to follow an EMDR-treatment session. As the psychologist stated:

"We saw her glance changing, we could not make any contact any more, she (M.) did not response to her name….. Stress was the greatest trigger between not hurting and hurting herself".

In 42% (*n = 16)* of the incidents, support staff indicated that a specific interaction appeared to have led to SIB. M.'s psychologist:

"Most of the time it was a longer course, during which you could see the tension rising. Conflicts with other clients, or trouble with support staff, when they had different opinions or when plans changed, disappointments, stuff with parents….eventually led to M. hurting herself".

In 78% of the incidents, SIB resulted in injuries, of which 40% were mild injuries (i.e., injuries for which no medical treatment was necessary such as scratches and bruises) and 60% major injuries (i.e., injuries for which medical assistance was necessary such as unconsciousness, vomiting and deep cuts). In 18% (*n* = 10) of the incidents, support staff did not need to intervene to stop the SIB. In the other incidents intervening was required. In the majority of the incidents of SIB (80.0%), support staff manually restrained the client to stop the SIB. As the psychologist said:

"The only thing that you could do….literally…was to overpower her and prevent her from hurting herself further".

In four of the incidents (9%) support staff also offered an alternate sensory stimulus (i.e., lemon juice) next to the interventions. That M.'s SIB at times was very severe, both for M. and the support staff, is illustrated by quotes from M.'s psychologist:

"It is a miracle that she is not…., that she did not decease, while she was doing this. She did a great appeal on the entire support staff, it continued 24-hours a day. Sometimes I felt truly powerless. I believe there was a lot of shame, and also fear for M. when she hurts herself".

The view of M. on her behavior:
"Most of the time it happened in the evening, because I have a trauma about something that happened in the evening. I did it to get out of the traumatic flashbacks, it helped me to avoid thinking about the periods I have been through. Sometimes I just walked up and down, did not know what to do, and then I took a knife and cut myself. If I did not have anything, like in seclusion, I banged with my head. I often felt that a kind of ease came over me, which brought me to a normal level, so to say. Distractions helped me. Playing games, hitting a punching bag, sometimes just a hug and staying next to me, smoking cigarettes did help, but the best was just to offer closeness and seek distraction".

Description of SIB of L. L. is a 19-year-old woman (full-scale IQ = 79) diagnosed with a dysthymic disorder. She stayed at the treatment center for 29 weeks. In the 29-week of her stay, 33 incidents of SIB were recorded, of which 85% (*n* = 28) included cutting and 21% (*n* = 7) included head-banging. Most of the incidents occurred between 10.30 AM - 2.30 PM (61%; χ^2 (3) = 24.3, *p* < .001) and were performed in her own room (91%). As her psychologist said:

> *"It most often happened in the beginning of the afternoon; …and during unoccupied moments [with no activities and distractions]….these moments were also a problem for her".*

In 33% (*n* = 11) of the incidents support staff reported that the reason for the SIB was unclear to them. In the incidents support staff could identify potential triggers leading to SIB, they often (55%) indicated that a specific interaction led to SIB and in 41% they gave a psychological reason (e.g., being overwhelmed by emotions). In some cases, a trigger could be the sound of a train passing by. The psychologist of L.:

> *"If she saw a train, she thought about the train she once stood in front of when she wanted to commit suicide or she thought about… apparently there was a situation in which she was bullied…and some boys told her: 'You are worthless, jump in front of a train'. It often was a kind of social situation or memory or flashback of a situation that triggered her, which got her out of balance and got her extreme tensioned, and it seemed she could not do anything else to regulate this tension than hurting herself.*

In all but one of the SIB incidents of L. (97%), the SIB resulted in injuries, of which 75% concerned minor injuries and 25% more severe injuries. When support staff felt they had to intervene, in 69% (*n* = 20) of the incidents the behavior stopped after verbal intervention or approaching of support staff. In 31% (*n* = 9) SIB was stopped by manually restraining L.

Comparison of the two cases. M. and L. differed in several aspects regarding their SIB. Most markedly where the differences in the time of the day on which the SIB took place (see figure 1) and the forms of SIB, consequences of and measures to stop SIB. There is a significant difference between M. and L. regarding the time of SIB. More specifically, L's SIB occurred more often between 10.30 AM and 2.30 PM and that of M's between 6.30 – 10.30 PM (χ^2 (3) = 36.8, *p* < .001). The nature of SIB, mostly head-banging for M. and cutting for L., also impact the injuries and ways support staff tried to stop SIB. The injuries of M. were more often severe and support staff used more severe interventions to stop the SIB of M. compared to the SIB of L.

Figure 1. Frequency of incidents distributed over time

Discussion

The goal of this study was twofold: 1) to assess the clinical usefulness of the Self-Harm Scale, and 2) to explore the characteristics, frequency, and severity of SIB of people with MBID and co-occurring psychopathology. The results of this study indicated that SIB is a common problem in people with mild to borderline ID with 4.0 incidents per participating client annually, although a minority of clients were involved in engaging in SIB in the current study. This mean number of incidents per client per year is higher compared to earlier studies conducted with the same population (2.3 incidents per participating client per annum; Tenneij & Koot, 2008) as well as with other populations (e.g., psychiatric patients; 0.3 per participating client annually; Nijman & à Campo, 2002). In line with these earlier studies, our research showed that the majority of the incidents were caused by a minority of people, and that the SIB incidents relatively often happened in the evenings. However, the two cases presented in the current study showed that the times on which clients engage in SIB can differ substantially. Furthermore, almost all incidents happened in the clients own room, which confirms earlier research stating that SIB often takes place in private places (Nijman & à Campo, 2002). For support staff it was sometimes hard to determine what triggered the SIB, but most of the times interpersonal and intrapersonal motivations for the client were the trigger for SIB, as also becomes clear in other studies relating to SIB (Walsh, 2006). As can be seen in the description of the cases, it is important to consider both functions, as this can differ between clients but also within a client. Support staff most often used manual restraint to stop the SIB. This seems to be partly contrary to the findings of earlier research of for example Tenneij and Koot (2008), in which staff most often talked to the client to stop

the SIB, and manual restraint was only used in 5% of the SIB-incidents. The SHS scale in our study is more purely focussed on physical self-injuring acts that have the aim to injure one's own body, compared to the SOAS-R used by Tenneij and Koot, which is also used to document verbal (auto)-aggressive acts. The physical nature of the self-injuring acts that are documented with the SHS will make a direct physical response including manual restraints by staff more often necessary to prevent clients from further injuring themselves.

Comparison between clients with and without SIB revealed three significant differences. To the best of our knowledge, the association between female gender and SIB has not been reported in earlier studies with people with ID (e.g., McClintock et al., 2003), though it was found in a psychiatric sample showing SIB (Nijman & à Campo, 2002). The association between SIB and BPD is also found in earlier research regarding psychiatric patients (Nijman & à Campo, 2002; Zanarini et al., 2008). The association between communication skills and SIB is not in line with previous research, which reported that SIB is related to poor communication skills (Lowe et al., 2007). There are several reasons that might explain these differences between our findings and earlier research, such as the small sample size and the collection of data in only one treatment facility in the current study as well as the differences in target population. The respondents in our study who displayed SIB were all people with ID and co-occuring psychopathology. There was a significant difference between the self-injuring and non-self-injuring group related to having a personality disorder. The group who displayed SIB was more often diagnosed with a personality disorder. In our clinical experience, clients with personality disorder socially interact and communicate with their environment much more than for example people with autism or psychotic disorders, who relatively often withdraw themselves from social interactions. As such, communication skills seem to be related to SIB, and as such may be an important variable to consider in the assessment and treatment of SIB. Further research on a larger scale, within multiple treatment centers, with the SHS may help to increase our knowledge about SIB.

In our opinion, the cases of M. and L. strongly suggest that it is important to analyse and translate the results of the structured clinical assessments of SIB incidents into an individualized approach and treatment. In line with earlier research (Tenneij & Koot, 2008), a minority of clients (8 out of 33 clients; 24%) were involved in all of the 104 reported incidents of SIB. Learning more about the specific characteristics of their repetitive SIB, and the circumstances under which the SIB occurs, may help to intervene more appropriately at the client level, which in turn can help to reduce the danger and devastating effects of these behaviors. In the cases of M. and L. the striking difference in when the SIB occurs (in the evening versus the morning), and the differences in what support staff noted on the SHS forms as the potential triggers of the SIB of M. and L., suggests that the causes and triggers for the SIB are different and urge different preventive strategies for these two clients. In line with earlier findings from Nijman and à Campo (2002), the risk of engaging in SIB in M. seems to be increased when she is at her room alone at night, without much distracting stimuli, which possibly gives room for memories and intrusions about earlier traumatic

experiences. In the case of L., it appears that other conditions play a role in triggering her SIB. Especially when there is a lot of interaction and activities in the morning, she seems to become vulnerable for engaging in SIB. For intervening, this may imply that M. needs to be kept in contact and have some (distracting) activities or interactions during the evening to prevent SIB, whereas for L. overstimulation and unexpected situations during the daytime may need to be reduced. Moreover, the results of the current study illustrate in our opinion the importance of structured clinical assessment of SIB in getting to know more about this behavior, its client-specific triggers and consequences.

The present study can be seen as a first step towards gaining more insight in SIB of people with ID using an incident based SIB scale, such as the SHS. In line with clinical screening instruments for aggressive behavior of clients with ID (van den Bogaard, Nijman, Palmstierna, & Embregts, 2018), the SHS is an easy to use instrument for structured clinical assessment of SIB by support staff. Data of the SHS gives an overall picture of the SIB that takes place on a ward, with minimal time investment. The instrument identifies which clients perform SIB, and gives insight in the types and severity of SIB these clients display. Based on the data of the SHS, an in-depth analysis of the SIB of specific clients can be executed, using for example a functional behavior assessment, in which variables like setting events, duration and onset of the behavior can also be taken into account. In other words, the SHS can be seen as a screening instrument for SIB of clients with ID, and helps determining which clients cause most incidents and the main characteristics of their SIB. A functional analysis can be conducted to explore the functions, setting events and maintaining variables of SIB in specific clients. Subsequently, the SHS can then be used again as a useful outcome measure, to evaluate the effects of interventions that are derived from the functional analyses, and to indicate the effects of the chosen interventions on the amount of SIB displayed.

Further research is needed to study SIB, using the SHS, in larger samples from different populations and settings and to study the psychometric aspects of the SHS (e.g., the inter-observer agreement of the SHS) and to compare the results of the SHS with other measures of auto-aggressive behavior. Further research should also be conducted to give an indication of the clinical utility and the way this scale can be used together with functional assessment instruments. It is hoped that the SHS will help to gain more information about SIB and to design and test individualized intervention strategies for clients who repeatedly engage in SIB.

3

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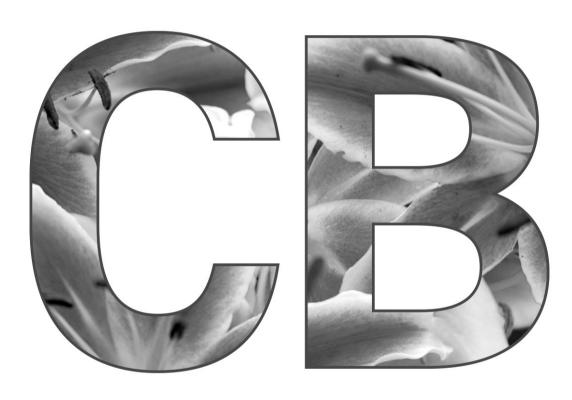
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3

Appendix 1. The Self-Harm Scale

Self-Harm Scale				SHS

Initials of the client: _____ Ward: _____

Registration number: _____ Incident number: _____

Registrating staff member: _____ Date (dd/mm/yyyy): _____ / _____ / _____

Time (hours:minutes): _____ : _____

This form is to be completed each time a client harms (or attempts to harm) oneself deliberately and physically.

1. Circumstances of self-harm	2. Mean(s) used during self-harm	3. Place(s) of the self-harm	4. Consequence(s) for victim	5. Measure(s) to stop self-harm
PEOPLE PRESENT DURING SELF-HARM?	**BODILY FORCE**	Arm ☐	No (apparent) consequence(s) ☐	**STOPPED WITHOUT INTERVENING**
Client was alone ☐	Nails (scratching) ☐	Leg ☐	**IMMEDIATE / VISIBLE CONSEQUENCE(S)**	Stopped by client him / herself ☐
In the presence of staff member(s) ☐	Teeth (biting) ☐	Neck ☐	Scratches ☐	Deliberately ignoring client's behavior ☐
In the presence of other client(s) ☐	Arms (self-hitting) ☐	Head ☐	Injuries *(not requiring somatic treatment)* ☐	Client stopped due to fainting ☐
In the presence of family / visitor(s) ☐	Head (banging) ☐	Stomach ☐	Injuries *(requiring somatic treatment)* ☐	**STOPPED BY INTERVENING**
In the presence of other people, namely: ☐	Swallowing, namely: ☐	Other place(s), namely: ☐	Burns ☐	Client stopped when staff arrived ☐
WHERE DID THE SELF-HARM TAKE PLACE?	**OBJECT(S) USED**		Vomiting ☐	Verbal intervention ☐
In own room ☐	Pills / medication ☐		Unconsciousness ☐	'Disarmed' client ☐
Bathroom ☐	(Chemical) fluids ☐		Other consequence(s), namely: ☐	Held with force ☐
Kitchen ☐	Scissors ☐		**(POTENTIAL) LONG TERM CONSEQUENCE(S)**	Mechanical restraint ☐
Ward living room ☐	Knife / razor blade ☐		Scars ☐	Other measure(s), namely: ☐
Other location, namely: ☐	Glass ☐		Lasting disabilities / handicaps ☐	
POTENTIAL TRIGGER(S)	Ligatures / rope ☐		Death ☐	
No understandable trigger ☐	Plastic bag ☐		Other consequence(s), namely: ☐	
Interaction with staff member(s) ☐	Cigarette (burning) ☐			
Interaction with other client(s) ☐	Fire ☐			
Interaction with family / visitor(s) ☐	Other mean(s) used, namely: ☐			
Hearing bad news ☐				
Other potential trigger(s), namely: ☐				

3

Chapter 4

Structured clinical assessment of harmful sexual behavior in people with intellectual disabilities

Abstract

Background

Within the framework of Positive Behavioral Support (PBS) it is important to develop an understanding of individuals' challenging behavior (CB) within the context in which this behavior occurs. To assess various forms of CB (e.g., aggressive behavior and self-injurious behavior (SIB)) structured observation instruments are used, while standardized instruments for documenting incidents of harmful sexual behavior (HSB) do not seem to be in use. The aim of the current study was twofold: 1) exploring the usefulness in clinical practice of a newly designed instrument for documenting incidents of HSB, and 2) based on this, exploring the kind of HSBs support staff of people with mild ID or borderline intellectual functioning, encounter.

Method

Support staff of three wards were asked to record HSB during a nine months period, using the newly designed Harmful Sexual Behavior Scale (HSBS).

Results

A total of 34 HSB incidents were reported by support staff. Most of the reported incidents of HSB had no physical or psychological consequences (71%). To intervene, staff often changed the situation or used verbal interventions to stop the behavior.

Conclusion

The results indicate that support staff mostly focus on stopping the HSB immediately, but don't seem to invest much in the prevention of the behavior in the future. Clients and support staff might benefit from reporting HSB more systematically and discussing sexuality more pro-actively with their clients. Using structured clinical assessment instruments will give more insight in CB within its context, which allows for getting a better evidence base for PBS.

Harmful sexual behavior (HSB), like public masturbation or inappropriate touching of others, are displayed by people with intellectual disabilities (ID) (Lowe et al., 2007), though often underreported (Thompson, 2010). Little systematic research has been done on this subject, while HSB can result in serious negative consequences for both the person showing this behavior (Lund, 1992; Thompson, 1997) as well as their environment (Byrne, 2018; Shelby, Stoddart, & Taylor, 2001; Soylu, Alpaslan, Ayaz, Esenyel, & Oruç, 2013). The definition of HSB of Lockhart, Guerin, Shanahan and Coyle (2009, p. 299) emphasizes the social nature of these behaviors and the importance of the context in which the behavior is displayed. The definition also makes clear that HSB encompasses various types of behavior; sexual offending behaviors, but also sexual behaviors that can be harmful and challenging for the person showing it and their environment, without it being sexual offending. As such, support staff sometimes have difficulties to determine which sexual behaviors are appropriate and which are not (Swango-Wilson, 2008) and to determine how to be supportive and not controlling or overprotecting (Bates, Terry, & Popple, 2017; Whittle & Butler, 2018).

It is clear that sexual behaviors of their clients can give support staff and other caregivers of clients with ID feelings of uncertainty and discomfort (Rushbrooke, Murray, & Townsend, 2014). A study of Wilson and Frawley (2016) revealed that support staff can feel incompetent to react appropriately to the sexual behaviors of their clients with ID, possibly caused by a lack of knowledge and skills. These feelings of incompetence of support staff might result in two negative pathways for people with ID. First, it can lead to an increased risk that sexual expressions of clients with ID are interpreted and labelled as inappropriate, deviant and/ or offending, whereas other explanations for the behavior may be more beneficiary. This phenomenon is described in the theory of 'counterfeit deviance' (Griffiths, Hingsburger, Hoath, & Ioannou, 2013; Hingsburger, Griffiths, & Quinsey, 1991), which stresses eleven alternative hypotheses to explain HSB. Second, negative attitudes and reactions of support staff on sexual expressions (e.g., expressing disapproval) can lead to restrictive practices, which may limit the opportunities for people with ID to develop and express healthy sexuality instead of HSB (McGuire & Bayley, 2011; Swango-Wilson, 2008).

To our knowledge, no structured clinical assessment instruments are available to assess HSB of people with ID in relation to their environment, which are comparable to valid and reliable instruments focussing on for example aggressive behavior (e.g., the Staff Observation Aggression Scale – Revised, SOAS-R; Nijman et al., 1999) or self-injurious behavior (e.g., the Self-Harm Scale, SHS; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018). As becomes clear from literature on the multicomponent framework of Positive Behavioral Support (PBS; Dunlap & Carr, 2007; Hastings et al., 2013), an important part in intervening adequately and improving the quality of live for people with ID who display CB, is to increase our understanding of the CB of an individual, based on the assessment of the behavior, along with the context in which it occurs (Gore et al., 2013)

We developed the Harmful Sexual Behavior Scale (HSBS), to facilitate adequate interpreting of HSB, including reports of the setting in which it occurs, and its antecedents

and consequences. In the current study, the HSBS, was used to explore the nature of sexual behaviors among people with ID that are judged to be challenging by their support staff.

Method

Participants and setting

This study was carried out in a treatment centre within a closed setting, specialized in treatment in people with mild intellectual disabilities (IQ between 50-70) or borderline intellectual functioning (IQ between 70 – 85), hereafter designated as people with mild to borderline intellectual disability (MBID), and co-occurring psychiatric and/or behavioral problems. In each ward (N = 3) ten participants lived together and received treatment for their specific problems. Some clients followed a day-care program at the treatment facility; other clients had a paid job for some hours a week outside of the ward. During leisure time some participants could go home, some had activities with or without support staff outside of the treatment centre and some stayed at the treatment centre, dependent on the conditions of their treatment (e.g., being involuntary admitted or not) and their psychological well-being. Treatment consisted in following activating day care therapies and specific training courses (e.g., self-management training). Besides, participants received one-on-one treatment talks with support staff, psychologists, and psychiatrists and if necessary additional treatment (e.g., eye movement desensitization and reprocessing) related to their specific problems.

Forty support staff, of which 62.5% (n = 25) were women, with a mean age of 34.2 (SD = 9.4) were asked to complete HSBS every time they witnessed some form of HSB. The level of education of support staff ranged from secondary education to a master degree in psychology, with the majority of the support staff having higher vocational training (55%). Support staff on average had 7.1 years (SD = 6.8) working experience in this sector. Almost one third (32.5%) had received training related to harmful sexual behaviors. In the 41-weeks of data collection, 51 clients stayed at the centre, of which 33 clients (65%) were included in the study after written consent. Inclusion criteria were: a) 18 years of age or above, b) staying for a period longer than four weeks at the treatment centre, and c) informing the client about the research and asking for permission to collect the data would not worsen the well-being or psychiatric condition of the client according to the responsible psychologist and psychiatrist.

Measures

The HSBS (see Appendix 1) was developed by the authors in line with instruments measuring other forms of CB in clients with MBID (e.g., the Staff Observation Aggression Scale-Revised – Intellectual Disability (SOAS-R-ID), van den Bogaard, Nijman, Palmstierna, & Embregts, 2018a); the Self-Harm Scale (SHS; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018b). HSB was defined according to the definition of Lockhart and colleagues (2009, p. 299). Based on the structure of the SOAS-R (Nijman et al., 1999), the HSBS consists of five

columns: 1) the apparent trigger of the HSB (e.g., a verbal interaction or bodily contact), 2) the HSB of the client (e.g., verbal sexual comments or inappropriately touching other persons), based on the checklist of Heestermans, van den Bogaard, Embregts, and Hendriks (2013). In this checklist all criminal acts concerned with sexuality under the Dutch Law were included. One additional item was included, verbal sexual comments, as this is not a criminal act in the Dutch Law. 3) the target of the HSB (e.g., support staff or other clients), based on the persons or subjects mentioned in the Dutch criminal acts related to these behaviors, 4) the consequences of the HSB (e.g., feeling threatened or physical consequences), and 5) the interventions of support staff to stop the HSB (e.g., distracting the client or sending the client to his room). Subsequently support staff was asked to judge the overall severity of the HSB on a 100-mm Visual Analogue Scale (VAS), ranging from 0 ('not severe at all') to 100 ('extremely severe'). The VAS is a subjective measure that can give more insight in the experiences and impact of HSB on the person reporting it.

Procedure

Ethical approval to conduct the study was obtained both by the ethical committee of Tilburg University (EC-2013.30) and the participating treatment facility. Data were collected between April 2014 and January 2015. After informed consent of both the client and, if necessary, their legal representatives, as well as from the support staff, demographic variables of clients and support staff were collected. Following this, support staff were asked to complete the HSBS every time they witnessed incidents of HSB. In order to describe the characteristics of the people with MBID and support staff as well as the characteristics of the incidents, descriptive and comparative statistics from SPSS were used.

Results

Characteristics of participants reporting and showing HSB

In total 19 staff members (47.5%) reported 34 incidents of HSB. The reporting staff members were mostly women (78.9%), and significantly more women reported an incident of HSB ($\chi (1) = 4.18$, $p = 0.042$). The mean age of the reporting staff members was 31.7 ($SD = 7.4$) and this did not significantly differ from their colleagues who did not report ($t (38) = -1.59$, $p = 0.12$). Characteristics of the clients who showed HSB are displayed in Table 1. None of the included participants were diagnosed with sexual or gender identity disorders, according to the DSM-IV (APA, 1994).

Overall characteristics of HSB

The reported HSB incidents ($N = 34$) consisted mostly of inappropriate (non-directed) communication (e.g., 'Come and sleep in my bed with me', staring to long and making approving sounds; 47%), (non-directed) exposure (e.g., walking with t-shirt open into living

Table 1. Characteristics of clients who displayed HSB during observation period

	Clients who showed HSB (*n* = 8)	
Gender, male: *n* (%)	6	(75)
IQ: mean (s.d.)	72	(9)
Age, years: mean (s.d.)	31	(12)
Diagnosis axis I, *n* (%)		
Schizophrenia or psychotic disorder	2	(25)
Pervasive developmental disorder	2	(25)
Mood disorder	1	(13)
Anxiety disorder	1	(13)
Expressive language disorder	1	(13)
Attention Deficit Disorder	1	(13)
Involuntary admitted, *n* (%)	3	(38)
Length of admission (weeks): mean (s.d.)	43	(18)
Adaptive behavior age: mean (s.d.)		
Communication	9	(3)
Daily activities	9	(3)
Socialisation	6	(2)
Overall adaptive functioning	8	(3)

room; 26%) and inappropriate touching of support staff or fellow-clients (e.g., on hips or breast; 26%). In 62%, it was not clear according to support staff what had triggered the HSB. If support staff could indicate a trigger, expressions of support staff or fellow-clients (12%), a reference to a specific mental health state (e.g., psychosis, 9%) and bodily contact (9%) were mentioned. Support staff and fellow-clients (68%) were mainly the target of the HSB. In 29% percent support staff reported negative psychological consequences related to the HSB, such as feeling threatened or feeling uncomfortable. In 71% of the incidents, no physical or psychological consequences were reported by staff members. Staff members sometimes (24%) carried out more interventions in order to stop the behavior. Support staff changed the situation (65%), intervened verbally (32%) or distracted the client (24%). Only one time staff members did not use any intervention to stop the behavior. Severity scores ranged from 2 to 97 mm, with a mean of 38 mm (SD = 25 mm) on the 100 mm VAS. There was no significant difference in the mean severity scores between non-physical (M = 3.63, SD = 2.56) and physical HSB (M = 4.32, SD = 2.44) (t (32) = -0.730, p = 0.471).

Cases

Three clients were responsible for almost 80 percent (n = 27) of the reported HSB incidents. The characteristics of the behavior of these three clients are described below in more detail. Some background information about the clients was omitted or changed for reasons of anonymity. The three clients were admitted for reasons not related to the HSB they showed (e.g., stabilization related to their psychiatric disorder or clarifying their clinical symptoms). Their treatment trajectory did not focus on the HSB they displayed.

Q. is a 26-years-old man (full-scale IQ: 64, mean level of adaptive functioning: 4.9 years). He stayed at the treatment center for 41 weeks and showed HSB and aggressive behavior. The HSB (n = 12) consisted mostly of inappropriate touching of others (e.g., hips or legs; n = 4) and making inappropriate sexual comments (n = 3) or a combination of touching and sexual comments (n = 3), mostly aimed at support staff and fellow clients. Most of the time support staff could not indicate the direct trigger (n = 7), three times the trigger was bodily contact. The majority of the behavior did not have psychological consequences according to the reporting staff members (n = 10), and support staff mostly used a combination of techniques (n = 5) (change situation, distraction and speaking to the client) or a change of situation (n = 4) to stop the behavior.

K. is a 56-years-old man (borderline intellectual functioning (disharmonic profile), mean level of adaptive functioning: 9.9 years). He stayed at the treatment center for 47 weeks and displayed HSB and aggressive behavior. The HSB (n = 8) consisted of inappropriate sexual comments, one time combined with inappropriate touching, aimed mostly at support staff (n = 5). Four times support staff did not know what triggered the behavior, three times the antecedent of the HSB was a reaction towards the comments of another person and one time it was the appearance of support staff. Most of the times (n = 7) there were no psychological consequences mentioned by support staff following the HSB. Support staff spoke to the client (n = 5) or distracted the client (n = 3) to stop the behavior.

G. is a 34-years-old woman (full-scale IQ: 61, mean level of adaptive functioning: 7.6 years). She stayed at the treatment center for 49 weeks and displayed different types of CB (e.g., aggressive, self-injurious and harmful sexual behaviors). The HSB (n = 7) always consisted of walking around with her upper body uncovered or t-shirt open, not aimed at a specific person (n = 5). Support staff could not specify the trigger most of the times (n = 4) and otherwise related the behavior to her disorder (psychosis, n = 3). Staff always changed the situation to stop the behavior. If there were consequences (n = 3), they were related to feelings of discomfort off staff.

4

Discussion

The Harmful Sexual Behavior Scale (HSBS) was developed to get a better understanding of the nature and prevalence of incidents of harmful sexual behavior (HSB), as well as the conditions under which HSB occurs in people with MBID. The results show that HSB seems to be less common than other forms of CB, like aggression. The rate of aggression, in similar settings (e.g., 7.9 incidents per client annually; treatment facility for people with mild ID and severe CB; Tenneij & Koot, 2008) is more than 6 times higher compared to the rate of HSB (1.3 incidents per client per annum).

Besides, a minority of the people with MBID were involved in HSB incidents (i.e., 24%), but the persons who did display HSB often did so on multiple occasions (i.e., three clients were involved in almost 80% of the reported HSB incidents). The data show that the three persons displaying HSB all had their own profile, with specific personal characteristics and types of HSB. This confirms the suggestion from a review of Keller (2016) that a more individualized approach in risk assessment and intervention planning could enhance opportunities for change with intervention. The data also shows the relation between the antecedents and maintaining variables of HSB and the environment, which is in accordance with the research of Schalock, Luckasson, and Shogren (2007). In this study the importance of considering individual functioning in the light of community environments, age and culture is highlighted.

Data of the three cases show that most of the behaviors displayed by the participants are non-assaultive and non-contact behaviors. This is in line with earlier research (Almond & Giles, 2008; Lindsay, Michie, Steptoe, Moore, & Haut, 2011; Malovic, 2016). In the review of Malovic (2016) focusing on youth with ID, the most frequently reported behaviors were non-assaultive behaviors and 'nuisance' offences. Besides, some of the data reveals the counterfeit deviance (Griffiths et al., 2013), in which the behavior of the participant (e.g., masturbating) in itself is appropriate, but is labeled by support staff as inappropriate, because for example a lack of private space. The HSBs displayed by the participants were very diverse and different people were victimized. This seems in line with earlier research (e.g., Lindsay, 2002) in which is stipulated that people with ID are less discriminating in their victims and types of offenses they commit. Although the people in this study were not convicted for the behavior they had shown, they also displayed different types of sometimes offending and harmful sexual behavior, aimed at a variety of people.

In PBS, CB, including HSB, is seen as functional (Hastings et al., 2013) and as a product of interaction between the individual and its context (e.g., support staff and clients; Banks et al., 2007). Using structured clinical assessment instruments, including the HSBS, are helpful in getting a better understanding of HSB within its context. It can be seen, within the PBS framework, as a first step in the functional assessment of HSB, as it gives a global picture of the HSB of a person within its context (e.g., who is showing HSB, what kind of HSB are shown, how severe is the HSB according to support staff). The results of the HSB can be a

starting point for a deeper analysis of HSB of specific clients and its influencing factors (e.g., examining a person's communicative abilities, physical or mental well-being). Following this, the HSBS again can be used to evaluate the process of PBS, as it gives indications about the effect of interventions and the management of the behavior and thus helps to monitor and evaluate interventions and support in the long run (Gore et al., 2013).

This suggests that tailor made interventions for the relatively small proportion of people with MBID who do display HSB frequently may be most effective, and should be based on the analyses of the causes and triggers of these incidents. In line with the study of Rushbrooke, Murray, and Townsend (2014), support staff in the current study often did not know the cause of the behavior, though reacted by changing the situation or distracting the client instead of having conversations with the clients involved afterwards. These results are in line with previous studies and our clinical experience that support staff find it hard to react appropriately to HSB, possible due to a lack of policy, knowledge and skills (Abbott & Howarth, 2007; Rushbrooke, Murray, & Townsend, 2014; Travers, Tincani, Whitby, & Boutot, 2014; Wilson & Frawley, 2016). Training and coaching of support staff to develop these skills is however of great importance, as ignoring HSB can eventually reinforce HSB, and will not help clients to adapt sexual behavior to societal norms and values (Wilson & Frawley, 2016).

This study is one of the first studies that assess HSB using a structured clinical assessment tool. Using structured clinical assessment can be useful in getting more information about different types of CB. The small sample size and the small amount of data based on one setting should be taken into account when interpreting the results.

Future research will be necessary to explore the psychometric properties of the HSBS in more detail. However, our study supports the idea that more knowledge about the prevalence and nature of HSB among people with MBID is needed.

There is a great diversity in the HSB people with MBID did show, from sexual offending behaviors to sexual behaviors that were challenging for support staff, but not offending as such (e.g., making an inappropriate comment or staring to long and making approving sounds). It is important that staff is supported to (learn to) react in an appropriate manner and to get to know more about the underlying causes and triggers of these HSB. Training support staff on reacting pro-active to repeated HSB, providing psycho-education, formulating policies regarding sexuality, and creating awareness about the sexual behavior of the client and their reactions are necessary in order to see sexuality and sexual expressions of people with MBID not solely as a problem (Thompson, 2010), though as a normal aspect of life.

4

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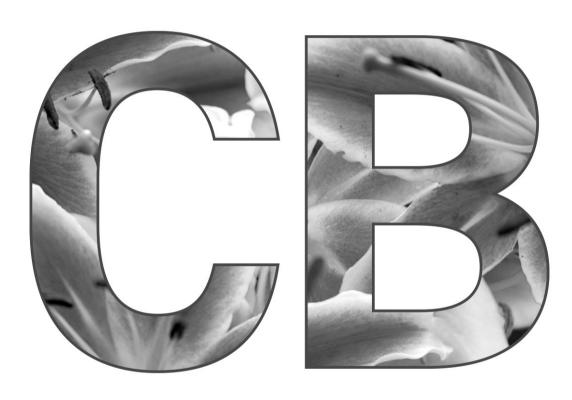
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Appendix 1. Harmful Sexual Behaviour Scale

Harmful Sexual Behaviour Scale	HSBS

Van den Bogaard, Nijman, & Embregts, 2013 ©

Initials of the client:	Ward: ....
Registration no.:	Incident no.: ....
Other person, namely:	Date (dd/mm/yyyy): ..../................./...................
Registrating staff member:	Time (hours:minutes): ....

This form is to be completed by staff members witnessing harmful sexual behaviour (HSB) of a client whereby HSB is defined as: 'Any sexual behaviour that is experienced as inappropriate, undesirable or threatening by the person witnessing or experiencing the behaviour'.
In the case of harmful sexual behaviour please note the initials of the client and/or the other person, date and the time on which the incident started, and put at least one mark in each column.

1. Trigger	2. Behaviour of client	3. Target of HSB	4. Consequence(s) for victim(s)	5. Measures to stop the HSB
No understandable provocation ☐	**NON-CONTACT**	Client self ☐	**PHYSICAL**	None ☐
Change of activity ☐	Inappropriate sexually oriented comments ☐	Staff member(s) ☐	no physical consequence ☐	Client distracted: changing subject ☐
Physical proximity, by: _____ ☐	Forcing people to see pornographic materials or actions ☐	Other client(s) ☐	Visible injuries, place: _____ ☐	Client distracted: changing situation ☐
Watching porn ☐	Possessing illicit pornographic materials ☐	Environment, no specific person ☐	Pain < 10 min ☐	Victim left situation/was removed from situation ☐
Other person saying something, namely: _____ _____ ☐	Grooming: approaching/getting in contact with potential victim(s) to perform inappropriate sexual behaviour ☐	Child(ren), age: _____ ☐	Pain > 10. min ☐	Held with force ☐
Action of other person, namely: _____ ☐	Performing sexual behaviour or exposing genitals at public places ☐	Animals ☐	Treatment necessary, by: _____ ☐	Sent to room ☐
Other provocation(s), namely: _____ ☐	**CONTACT**	Other person(s), namely: _____ ☐	Other physical consequence(s), namely: _____ ☐	Seclusion ☐
	Unwanted touching the body of another person. Place of the body that was touched: _____ ☐		**PSYCHOLOGICAL**	Mechanical restraint ☐
	Sexual actions (no penetration) ☐		No psychological consequence ☐	Other measure(s), namely: _____ ☐
	Sexual penetration ☐		Feeling threatened ☐	
	Other sexual behaviour(s), namely: _____ ☐		Other psychological consequence(s), namely: _____ ☐	

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Chapter 5

Attributions of people with intellectual disabilities of their own or other clients' challenging behavior: A systematic review of qualitative studies

Abstract

Background

As opposed to studies focusing on staffs' attributions of challenging behavior (CB), relatively few studies have looked at how people with intellectual disabilities (ID) attribute such behaviors themselves, and a systematic overview is currently lacking. The aim of this review was to synthesize the evidence from qualitative studies on the attributions people with ID have concerning their own or other clients' CB.

Method

A systematic literature search was conducted in Embase, Medline Ovid, Web of science, Cochrane CENTRAL, PsychINFO Ovid, and Google Scholar. Studies were included if they focused on people with ID who report on attributions of their own or other clients' actual CB. The methodological quality of the studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist.

Result

A total of 10 studies were included. Three main types of factors subdivided in 13 sub-types were reported by clients as potential causes of CB: interpersonal factors (1 support staff, 2 other clients, 3 general, 4 life history), environmental factors (1 ward, 2 social exclusion, 3 situational factors) and intrapersonal factors (1 syndrome or diagnosis, 2 medical or physical symptoms, 3 psychological reasons, 4 emotions and feelings, 5 coping, 6 other).

Conclusion

This thematic synthesis shows that clients with ID report a diverse range of attributions regarding their own or other clients' CB. This spectrum can be used as a framework for interpreting CB and for the development of appropriate support systems for people with ID demonstrating CB.

People with intellectual disabilities (ID) relatively often present challenging behavior (CB), such as aggressive behavior, self-injurious behavior (SIB), and stereotypic behavior (Emerson et al., 2001; Jones et al., 2008), with prevalence rates in population-based cohorts between 10 to 25% (e.g., Emerson et al., 2001; Jones et al., 2008; Sheenan et al., 2015). This behavior tends to persist over time (Totsika, Toogood, Hastings, & Lewis, 2008) and may have a negative impact on the aggressors themselves (e.g., physical injury or high medication use to reduce aggression; Deb, Unwin, & Deb, 2015; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018a) as well as on support staff or families supporting the person (e.g., negative emotions, stress, injuries and burn out; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018b; Griffith & Hastings, 2014; Meppelder, Hodes, Kef, & Schuengel, 2015; Mills & Rose, 2011).

Behavior in general and more specifically CB can be considered as a product of interaction between the individual and his or her environment (Banks et al., 2007). In explaining and managing CB, it may be helpful not only to look at the environment of the client demonstrating the CB, but also to take the view of the client into account. In research the role of the environment, and especially support staff, related to CB has often been studied (e.g., Griffith & Hastings, 2014; van Oorsouw, Embregts, Bosman, & Jahoda, 2010). Support staff can have an important role in managing, but also in triggering and maintaining CB. Intrapersonal variables (e.g., emotions, attitude or attributions), interpersonal variables (e.g., behavior of clients) and environmental variables (e.g., team climate) influence the behavior of support staff (Randell et al., 2017; Shead, Scott, & Rose, 2016; Stoesz et al., 2016; Willems, Embregts, Hendriks, & Bosman, 2016; Williams, Dagnan, Rodgers, & Freeston, 2015; Wishart, McKenzie, Newman, & McKenzie, 2013; Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2015).

Support staff mostly are the key agent in the lives of people with ID and CB, as they have a supporting role for clients (e.g., Eagar et al., 2007) and often are key in delivering behavioral interventions (e.g., Allen, 1999). Attributions about behavior or events may influence the affective and behavioral reactions within these close relationships of support staff and people with ID and CB (Snow, Langdon, & Reynolds, 2007; Wanless & Jahoda, 2002), as well as the quality of the relationship (Willems, Embregts, Bosman, & Hendriks, 2014). Attributions of support staff about CB of clients with ID are often studied (e.g., Davies, Griffiths, Liddiard, Lowe, & Stead, 2015; Noone, Jones, & Hastings, 2006; Snow, Langdon, & Reynolds, 2007; Wanless & Jahoda, 2002; Williams, Dagnan, Rodgers, & Freeston, 2015). Support staff are able to differentiate between causes of CB (Noone et al., 2006), and their attributions about CB are linked with and affected by their cognitive and emotional responses (Snow et al., 2007; Wanless & Jahoda, 2002; Williams et al., 2015). The results of Davies and colleagues (2015) show that it is possible to change attributions of support staff if they follow a specific training.

Although the perspective of support staff already gives us useful information about causes of CB in clients with ID, there are a number of reasons why the perspective of people with ID should be taken into account. First, incorporating the views of people with ID, and thus increasing their involvement and engagement in services and therapies is a precursor for progress related to their CB and clinical symptoms (Morrissey et al., 2017). It might help them to become more motivated to change their behavior. Second, studies in other settings (i.e., psychiatric settings) show that support staff and clients differ in their opinion regarding the causes of aggressive behavior (Duxbury & Whittington, 2005). It is thus plausible that this also accounts for people with ID. Third, based on for example the review of Bowers and colleagues (2011) or the study of van den Bogaard and colleagues (2018b) focusing on the triggers of CB, support staff are not able to provide the direct cause of the CB in about 1/3 of the incidents. It is therefore helpful to take the view of people with ID into account, as they can explain what is the cause of their CB. However, a comprehensive overview of attributions of people with ID drawn from studies explicitly focusing on CB is currently lacking. The aim of this qualitative review was therefore to synthesize the evidence from studies on the attributions people with ID have concerning their own or other clients' actual CB. We focused on actual behavior rather than fictitious situations of CB (e.g., studies using vignettes or questionnaires related to attributions), as this may elicit different patterns of attributions (Allen, 1999; Dagnan & Weston, 2006). We therefore only included qualitative studies in our synthesis.

Method

Concepts and definitions

In this systematic literature review both CB and attributions are defined and conceptualized. CB was defined as behavior of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Banks et al., 2007, p10). Following Sheehan and colleagues (2015), the National Institute for Health and Care Excellence's (NICE, 2015) conceptualization of the term challenging behavior was used. This conceptualization includes the following behaviors: aggression, SIB, stereotypic behavior, agitation, disruptive or destructive acts, withdrawn behavior, arson, and sexual misconduct.

Attributions were defined as "expressions of the way a person thinks about the relationship between a cause and an outcome" (Munton et al., 1999, p.6) and were any answer to the question 'Why did a person display CB?' (Munton et al., 1999).

Search Strategy

In June 2018 a literature search was conducted in Embase, Medline Ovid, Web of science, Cochrane CENTRAL, PsychINFO Ovid, and Google Scholar using several combinations of the following key words; intellectual disability, challenging behavior, and attributions. Peer-

reviewed journal articles available in English were included in the search. The specific search terms used for each database are presented in Appendix 1.

Inclusion/Exclusion criteria

The following inclusion criteria were used: (1) the study focuses on people with ID who report on attributions of either their own or other clients' actual CB, (2) the study sample includes (>50%) adult clients (>18 years of age), (3) the study concerns an empirical study.

Studies were excluded if: (1) the study reports on prior events and subsequent CB, but the link is not explicitly acknowledged by the participants; (2) the results of the study in terms of attributions of people with ID versus the attributions of other participants (e.g., support staff) could not be distinguished.

Selection process

First, the titles and abstracts of all studies were screened independently by two authors (2nd and 3rd) to identify potentially relevant papers. The search results were supplemented by screening the references cited in reviews. Disagreements were discussed with the other two authors until consensus was achieved. Next, the full texts of the remaining papers were obtained and independently assessed for eligibility by the same two authors (2nd and 3rd). In both rounds the inclusion and exclusion criteria listed above were used. This resulted in the final selection of studies to be included in the review.

Data Extraction and Analysis

Extraction of data: The following data were extracted from each paper: first author and year of publication, country of study, topic, sample, setting, type of CB, design of study, and method of data analysis. All data were extracted by one author (2nd) and completely checked by a second author (3rd). Any discrepancies were discussed until consensus was reached.

Quality assessment: To assess the methodological quality of the included studies the Critical Appraisal Skills Programme (CASP) checklist (Critical Appraisal Skills Programme, 2018) was used, a 10-question checklist specifically designed for qualitative studies. This checklist covers various methodological aspects such as validity, recruitment strategy, data collection method, rigorousness of data and ethical issues. Two authors (2nd and 3rd) each assessed the quality of half of the studies by answering the ten questions (yes, no or unclear), while checking the provided answers of the other author for the other half of the studies. In case of discrepancy between the first and second reviewing author, the two other authors were consulted until consensus was achieved.

Data synthesis

To synthesize the evidence on the attributions of people with ID concerning their own or other clients' actual CB, a thematic synthesis was applied (Thomas & Harden, 2008). A thematic synthesis was chosen to generate new insights rather than presenting a summary of the findings of the various studies. The following procedure was followed:

First, all sentences referring to an attribution of a person with ID concerning their own or other clients' actual CB were extracted by two authors (2nd and 3rd): each author extracted the attributions of half of the studies, while checking the attributions selected by the other author. Disagreements were discussed until consensus was reached. The final extracts were then entered verbatim in AtlasTi, a software program for qualitative data analysis.

Second, the verbatim findings of each study were line-by-line coded by the same two authors (2nd and 3rd) independently by use of AtlasTi. During this process we stayed as closely to the results as they are presented in the original studies. Codes were created inductively to capture the meaning and content of each sentence. Results of the two authors were compared and discrepancies resolved. This process created a total of 147 initial codes without a hierarchical structure.

Third, the two authors (2nd and 3rd) looked for similarities and differences between the initial list of codes in order to start grouping them in a hierarchical tree structure. This resulted in a tree-structure with main and sub-types of attributions (descriptive themes). All codes and related text were checked for consistency of interpretation and changed if needed. A draft summary of the findings across the 10 studies was then written by two of the author (2nd and 3rd) and checked and rewritten by the other two authors (1st and 4th).

The final stage consists of generating analytical themes. It this step new interpretive constructs, explanations and hypotheses are generated. This stage was achieved by several group discussions of the draft findings across the 10 studies to infer relations about clients' attributions of different types of CB and the relationship between different factors. Through these group discussions more analytical or abstract themes emerged.

Results

Selection of the studies

A total of 22.423 papers were identified in our initial search of six databases. After duplicates were removed 12.882 papers remained. Reference lists of relevant review articles were screened, resulting in one additional article. A total of 12.883 papers were thus further screened and selected. The selection process, the number of excluded papers, and the reasons for exclusion are summarized in Figure 1 based on the Prisma flow chart (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2010). A total of 10 studies met the inclusion criteria and were included in the review (see Table 1).

Description of Studies

Detailed characteristics of the included studies are provided in Table 1. The studies were published between 2002 and 2017. The vast majority of the studies (90%) were conducted in the United Kingdom, and one study originated in the Netherlands. The sample size ranged from 1 to 26 people. The majority of the studies (50%) focused on people with ID, in which

Figure 1. Prisma flow chart of the study selection process

the level of ID was not specified, three studies focused on people with mild ID, in one study the participant group consisted of people functioning in the mild to borderline range of intellectual disability, and one study included persons with either mild or moderate ID. Although in half of the studies the level of ID of the target population is not specified, it is feasible participants were people with moderate, mild or borderline ID as people with severe or profound ID are not capable in giving a meta-view of their own or other people's behavior (Bellamy, Croot, Bush, Berry, & Smith, 2010; Griffiths & Smith, 2016; Hostyn, Daelman, Janssen, & Maes, 2010).

Most studies (70%) took place in (low or medium) secure services; four of these studies took place in a forensic setting. Of the three studies taking place in non-secured settings,

Table 1. Characteristics of the Included Studies (*n* = 10) in the Thematic Synthesis

	Author/ year	Country	Topic	Sample	Setting	Type of CB	Design of study	Data analysis method
1	Harker-Longton (2002)	UK	Subjective experience of SIB of clients	One woman with mild ID	Medium secure unit for adults with intellectual and associated disabilities	SIB	Qualitative case-study; multiple interviews	Phenomenological approach
2	Fish (2005)	UK	Clients' and staff accounts of aggressive incidents and the consequences of physical intervention	Nine client with LD (seven men and two women)	Medium secure LD forensic service	Aggressive behavior	Qualitative interview study	Phenomenological analysis
3	Jones (2006)	UK	Views of service users towards physical restraint procedures	Ten service users with mild LD (seven men and three women)	Secure residential units for people with LD	CB (not specified)[1]	Qualitative interview study	Not stated (themes and words that are powerful in meaning were highlighted)
4	Stevens (2006)	UK	Service user experience of CB	Twenty-six people with LD (thirteen men and thirteen women)	Residential respite (short break) and day services (living with parents) of social services for people with LD	Several types of CB: upsetting verbal behavior; physical aggression; SIB; stereotypical behavior	Qualitative study consisting of interviews, group discussions and observations	(Elements of) grounded theory
5	Isher-wood (2007)	UK	Clients' understanding of the history, experience and offending behavior	Six men with ID	Medium or low security services for people with LD who had been detained	Offending behavior: arson and sexual offending behavior	Qualitative interview study	Interpretative phenomenological analysis (IPA)

6	Didden (2008)	NL	Impact and perception of skin-picking behavior of people with Prader-Willi Syndrome (PWS)	Ten people with PWS who functioned in the mild to borderline range of ID (five men and five women)	Various settings (group home in community, residential facility, at home with parents, independent living in community with daily support)	Skin-picking	Qualitative interview study	Grounded theory (open coding (n = 5) and axial coding (n = 5), grouping and categorizing the interviews)
7	Brown (2009)	UK	Client experiences and understanding of SIB and client experiences of interventions associated with SIB	Nine people with mild ID (five men and four women)	Special secure service for people with ID and CB	SIB	Qualitative interview study	Interpretative phenomenological analysis (IPA)
8	Dupe-rouzel (2010)	UK	Understanding of client experiences of SIB and impact of this on lives within medium secure unit	Nine people with mild or moderate ID (four men and five women)	A medium secure unit (forensic service)	SIB or repeated SIB (currently or in the past), without sole intent to commit suicide	Qualitative interview study (with repeated face to face interviews)	Phenomenological approach
9	Haydon-Laurelut (2017)	UK	Clients views about CB and CB services	Five participants with LD (three men and two women)	Community-based CB services	CB (not specified)[2]	Qualitative focus group study	Thematic analysis
10	Clarkson (2009)	UK	Perceptions and experience of adults with ID regarding direct support staff	Part 1 (focus group): ten participants with ID (eight men and 2 women) Part 2 (individual interviews): eleven people with ID (eight men and three women)	Forensic inpatient service consisting of a medium and low secure service and rehabilitation service)	CB (not specified)[3]	Qualitative interview study (derived from focus groups and individual interviews)	Interpretative phenomenological analysis (IPA)

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* Abbreviations in Table 1 (CB = Challenging behavior; SIB = self-injurious behavior; LD = learning disabilities; ID = intellectual disability; PWS = Prader-Willi Syndrome)
1) In the result section the authors of this study give examples of violence, aggressive behavior and SIB as types of CB
2) In the result section the authors of this study give different examples of aggressive behavior as types of CB
3) In the result section the authors of this study give examples of aggressive behavior and agitation as types of CB

one concerned residential and day services, one focused on various settings (e.g., living with parents or in community with support), and one concerned community-based CB services.

As for the type of CB, most studies focused on SIB (n = 4), three studies did not specify the type of CB, one study focused on aggressive behavior, one on offending behavior, and one on several types of CB (e.g., physical aggression and SIB).

All studies adopted a qualitative design consisting of either only interviews, only focus groups, interviews derived from focus groups and individual interviews or interviews combined with group discussions and observations. Most studies (60%) applied a phenomenological approach to data analysis. Two studies used (elements/principles of) Grounded Theory, one study used thematic analysis, and in one study the applied data analysis method was not explicitly stated/unclear.

Research quality

The findings of the quality appraisal are presented in Table 2. Most studies indicated general (Clarkson et al., 2009; Didden et al., 2008; Duperouzel & Fish, 2010; Fish & Culshaw, 2005), or specific (Brown & Beail, 2009; Harker-Longton & Fish, 2002; Haydon-Laurelut et al., 2017; Jones & Stenfert Kroese, 2007; Stevens, 2006) inclusion and/or exclusion criteria. The method for data collection (e.g., interviews, focus groups) was described in all studies, mostly referring to an interview schedule/guide (Brown & Beail, 2009; Clarkson et al., 2009; Didden et al., 2008; Duperouzel & Fish, 2010; Fish & Culshaw, 2005; Haydon-Laurelut et al., 2017; Isherwood et al., 2007; Jones & Stenfert Kroese, 2007; Stevens, 2006); one study (Harker-Longton & Fish, 2002) did not provide any information on the content of the interview.

Some studies applied techniques to increase the success of interviews/focus groups such as choosing an appropriate location (Brown & Beail, 2009; Duperouzel & Fish, 2010; Harker-Longton & Fish, 2002; Isherwood et al., 2007; Jones & Stenfert Kroese, 2007), spending time with the participant prior to the interview to get to know the participant (Harker-Longton & Fish, 2002) or warm-up exercises at the start of the focus group (Haydon-Laurelut et al., 2017).

Related to ethical issues of anonymity, and confidentiality one study (Brown & Beail, 2009) did not clearly discuss informed consent and three studies (Fish & Culshaw, 2005; Harker-Longton & Fish, 2002; Stevens, 2006) did not clearly state that approval from an ethic committee was obtained. In five studies the ability of participants to give informed consent was explicitly checked (Clarkson et al., 2009; Duperouzel & Fish, 2010; Jones & Stenfert Kroese, 2007; Stevens, 2006) and/or easy-read consent forms were used (Clarkson et al., 2009; Haydon-Laurelut et al., 2017).

Overall, the studies provided sufficient data to support the findings. As for the rigorousness of the data analysis, in one study (Harker-Longton & Fish, 2002) not all interviews were audiotaped (notes were taken) and one other study did not provide any information in this respect (Jones & Stenfert Kroese, 2007). All but one study (Jones & Stenfert Kroese, 2007)

Table 2. Quality Appraisal of the Included Articles using the CASP

	1	2	3	4	5	6	7	8	9	10
Was there a clear statement of the aims of the research?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Has the relationship between researcher and participants been adequately considered?	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Unclear	No	Yes
Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Was the data analysis sufficiently rigorous?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research?	v	v	v	v	v	v	v	v	v	v

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provided a clear statement of findings, discussed in relation to the original research question. All studies provided valuable qualitative research contributing to existing knowledge and understanding as well as highlighting their findings in relation to other studies and most discussed new areas for research and/or practice (Brown & Beail, 2009; Clarkson et al., 2009; Duperouzel & Fish, 2010; Fish & Culshaw, 2005; Harker-Longton & Fish, 2002; Haydon-Laurelut et al., 2017; Isherwood et al., 2007; Stevens, 2006).

Thematic synthesis of attributions of challenging behavior

Three main types of attributions divided further in 13 sub-types of attributions emerged from the data (Table 3). The three main types were: (1) interpersonal factors; (2) environmental factors and (3) intrapersonal factors. Within these main and sub-types of attributions analytical themes emerged from the synthesis, which are described below.

Interpersonal factors leading to challenging behavior. Clients described interpersonal attributions for every type of CB. Interpersonal attributions refer to the individual related to

Table 3. A Summary of Main and Subtypes of Attributions of Clients regarding (Different Types of) CB of Clients

Main- and subtypes of attributions	AGG	SIB	OFF	CB-NS
Interpersonal factors	X	X	X	X
1.1 Staff	X	X		
1.2 Other clients	X	X		X
1.3 General	X	X	X	X
1.4 Life history		X	X	x
Environmental factors	X	X	X	
2.1 Ward	X	X		
2.2 Social exclusion		X	X	
2.3 Situational factors		X	X	
Intrapersonal factors		X	X	X
3.1 Syndrome or diagnosis		X	X	X
3.2 Medical or physical symptoms		X		
3.3 Psychological reasons		X		
3.4 Emotions and feelings		X	X	X
3.5 Coping		X		
3.6 Other		X		

Note. CB NS: Challenging behavior not specified; SIB: Self-injurious behavior; AGG: Aggression; OFF: Offending behavior

others within their environment (Isherwood et al., 2007). In the studies it became clear that the attitude of support staff, their reactions but also the lack of their reactions were triggers for CB of clients. More specifically, interpersonal factors related to support staff (*subtype* 1.1) may cause aggressive behavior or SIB according to clients. Clients reported that interactions with support staff in general may contribute to aggressive behavior (Clarkson et al., 2009; Jones & Stenfert Kroese, 2007). Clients indicated that they experienced various negative feelings related to the behavior of support staff, such as feeling rejected (Brown & Beail, 2009; Fish & Culshaw, 2005; Harker-Longton & Fish, 2002; Jones & Stenfert Kroese, 2007).

They also felt a disbalance of power between themselves and support staff, in which support staff controlled or overpowered them and made decisions for them, which causes clients to display aggressive behavior and SIB (Brown & Beail, 2009; Jones & Stenfert Kroese, 2007). As a client stated:

> *"I wanted a glass of milk and they said 'no' so I kicked off. They said there wasn't enough, but there was" (p1; Jones & Stenfert Kroese, 2007, p. 53).*

Staff reactions or interventions (or the lack of it) may lead to (further) SIB and aggressive behavior. Staff reactions or interventions, particularly observation and restraining, were reported to lead to further SIB (Duperouzel & Fish, 2010) or aggressive behavior (Fish & Culshaw, 2005; Jones & Stenfert Kroese, 2007). In addition, support staff failing to react or intervene was also reported to contribute CB (not specified) or continuing SIB (Duperouzel & Fish, 2010; Jones & Stenfert Kroese, 2007).

Next, also interpersonal factors related to other clients (*subtype* 1.2) were reported to either passively or actively contribute to aggressive behavior, SIB or CB (not specified) (Fish & Culshaw, 2005; Harker-Longton & Fish, 2002; Stevens, 2006). Passively being around other clients who are unhappy or stressed contributed to SIB according to clients (Brown & Beail, 2009). Active confrontations with other clients, for example calling names, personality clashes or getting angry at the client for their behavior, contributed to aggressive behavior and CB (not specified) (Fish & Culshaw, 2005; Stevens, 2006). In the study of Harker-Longton and Fish (2002) clients indicated that SIB can also be provoked by getting tools to injure yourself with.

Interpersonal factors in which the person is not specified (*subtype* 1.3) were related to all types of CB. Clients mentioned interactions between people and other (problem) behaviors as causing aggressive behavior, SIB, offending behavior and CB (not specified) (Brown & Beail, 2009; Duperouzel & Fish, 2010; Fish & Culshaw, 2005; Harker-Longton & Fish, 2002; Haydon-Laurelut et al., 2017; Isherwood et al., 2007; Stevens, 2006).

The last interpersonal factor (*subtype* 1.4) refers the life history and related adverse experiences. More specifically, sexual abuse was related to SIB (Brown & Beail, 2009), physical (e.g., violence at home) and emotional abuse (e.g., no one cares or looks after the person) were related to SIB and offending behavior (Brown & Beail, 2009; Isherwood et al., 2007). Victimization and bullying according to clients was related to offending behavior and CB (not specified) (Isherwood et al., 2007; Stevens, 2006) and multiple traumas were related to SIB (Brown & Beail, 2009). Last, unresolved events in the past were mentioned by clients to be also related to SIB (Brown & Beail, 2009).

Environmental factors leading directly or indirectly to challenging behavior

According to clients with ID, environmental factors - which are factors related to the physical environment of a person or related to society and its structure (Isherwood et al., 2007) - were related to aggressive behavior, offending behavior and SIB. First, factors related to the ward (*subtype* 2.1) were indicated to lead directly or indirectly to aggression or SIB. As such, the atmosphere on the ward and the locked environment were described by clients as causing aggression (Fish & Culshaw, 2005).

> *"Client: But people get pissed off with being here. That's why a lot of people kick off.*
> *Eloise: Through frustration?*
> *Client: That's why a lot of people kick off, they might not like it." (Fish & Culshaw, 2005, p. 99).*

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With regard to SIB, instability in the house and the specific ward may also contribute to clients' SIB (Brown & Beail, 2009; Harker-Longton & Fish, 2002).

Secondly, factors related to being or feeling socially excluded (*subtype* 2.2) were described by clients as leading to SIB and offending behavior (Duperouzel & Fish, 2010; Isherwood et al., 2007). Being and feeling locked up or being kept under conditions of security was cited as a reason for showing SIB (Duperouzel & Fish, 2010). In the study of Isherwood and colleagues (2007) clients mentioned being and feeling isolated from society in general as a key theme in explaining offending behavior. Aside from being isolated, clients did not feel included in society and sometimes they hoped that by displaying offending behavior this would help them to fit in (Isherwood et al., 2007). The sense of isolation and victimization was linked to the experience of strong emotions and resentment towards others and, in turn, was seen as being linked to offending.

Situational factors (*subtype* 2.3) were identified as relevant to contribute to aggressive behavior and SIB (Didden et al., 2008; Fish & Culshaw, 2005). Treatment and care planning as well as section renewals were also identified by clients as a reason for showing SIB (Duperouzel & Fish, 2010).

Intrapersonal factors leading to challenging behavior. At last, intrapersonal factors, which were described as personal characteristics belonging to the person (Haydon-Laurelut et al., 2017) or factors coming from within (Isherwood et al., 2007) were named as causing SIB, offending behavior or CB (not specified) (Brown & Beail, 2009; Didden et al., 2008; Duperouzel & Fish, 2010; Harker-Longton & Fish, 2002; Haydon-Laurelut et al., 2017; Isherwood et al., 2007). Some of the interpersonal factors were very specific, like skin-picking being seen as a stable feature of the Prader-Willi Syndrome (Didden et al., 2008).

There were six subtypes of interpersonal factors mentioned by clients. The syndrome or diagnosis (*subtype* 3.1) like an autistic spectrum disorder is said to be related to aggressive behavior (Haydon-Laurelut et al., 2017). Clients also reported medical or physical symptoms (*subtype* 3.2) as causing SIB, more specifically skin-picking behavior. Itchiness, eczema, and liking to have very short nails were mentioned as medical or physical reasons for skin-picking. Clients also reported that after an injection or after swimming, the itch got worse, which eventually led to skin-picking (Didden et al., 2008). Psychological reasons (*subtype* 3.3) which are described as mental health and alcohol or drug (ab)use, contribute to SIB and indirectly to offending behavior. In the study of Isherwood and colleagues (2007) clients mention such an indirect contribution:

> *"I was taking drugs at the time and everything got blocked (participant 4, 485; reason for offending)" (Isherwood et al., 2007, p. 230).*

In addition, the disinhibiting effects of both alcohol and drugs were described by clients in relation to offending behavior (Isherwood et al., 2007). Clients also mention mental health

(in general), vulnerability and self-neglect as contributing to offending behavior (Isherwood et al., 2007) Clients, in the study of Isherwood and colleagues (2007) describe both to mood at the time of the offence and feeling powerless in responding to distressing psychotic symptoms to be contributing to offending behavior. In offending, more specifically fire setting, seeing the flames and smoke have become a fascination or obsession (Isherwood et al., 2007). Furthermore, having a low opinion of yourself, nerves and brooding was said to be associated with SIB (Didden et al., 2008; Duperouzel & Fish, 2010).

Emotions (*subtype* 3.4) or more specifically not being able to cope with these emotions (*subtype* 3.5) may cause CB. Emotions and coping with emotions are mostly associated with the other main- and subtypes of attributions. Interpersonal, environmental and other intrapersonal factors may trigger emotions in the person, in which the client is not able to cope with these emotions in other ways then showing CB. As becomes clear from the next citation of a client explaining why he showed SIB:

> *"I felt really bad, everything was getting on top of me, I couldn't see a way out of it, and I did it, I didn't feel any pain. It gets all my feelings out and you come back and you are happy. I was getting what I realize now was a massive adrenalin rush, a massive amount of adrenalin rush" (Duperouzel & Fish, 2010, p. 609).*

Clients seem to be capable of articulating what is happening to them, what triggers their emotions, which eventually lead to showing CB (behavioral cycle). Interactions and other environmental triggers sometimes overwhelm the clients with emotions, feelings and cognitions they are not able to cope with. This lack of coping strategies may lead to SIB and aggressive behavior (Brown & Beail, 2009; Duperouzel & Fish, 2010). SIB served the purpose of 'getting your feelings out' (Duperouzel & Fish, 2010). Clients reported that SIB was seen as an aspect of their lives that had helped them to cope in the past and may ultimately be needed again as a coping strategy (Duperouzel & Fish, 2010). Clients reported to resort to SIB if they could not address the problems themselves (Duperouzel & Fish, 2010). The thought of suicide (Brown & Beail, 2009) was also described as reasons to injure oneself and ultimately for all the participants SIB was described as a form of self-help (Duperouzel & Fish, 2010). Emotions may overwhelm the person which may lead to aggressive behavior and SIB, and as such helping the person to relief from extreme emotional states (Duperouzel & Fish, 2010; Haydon-Laurelut et al., 2017). Clients also mentioned that they injured themselves to prevent them to become aggressive towards other persons, as a reaction towards emotions (Brown & Beail, 2009).

Clients mentioned various emotions and feelings as causing CB. Frustration was related to aggressive behavior (Brown & Beail, 2009; Haydon-Laurelut et al., 2017) and SIB (Brown & Beail, 2009; Harker-Longton & Fish, 2002), anger was related to aggression and offending behavior (Haydon-Laurelut et al., 2017; Isherwood et al., 2007) and SIB (Brown & Beail, 2009), sadness was related to aggression (Haydon-Laurelut et al., 2017) and SIB (Harker-

Longton & Fish, 2002), feeling upset and out of control was related to SIB (Brown & Beail, 2009; Harker-Longton & Fish, 2002) or offeding behavior (Isherwood et al., 2007). Feeling hopeless (Brown & Beail, 2009; Duperouzel & Fish, 2010), feeling bored (Didden et al., 2008), feeling guilt and shame (Brown & Beail, 2009; Duperouzel & Fish, 2010), nerves (Didden et al., 2008) and worrying about getting better (Harker-Longton & Fish, 2002), were all mentioned as a reason for SIB according to clients with ID. Not feeling safe or protected were indicated as a reason for offending behavior (Isherwood et al., 2007) and SIB (Harker-Longton & Fish, 2002) and bereavement was related to offending behavior (Isherwood et al., 2007) according to clients with ID.

Clients also described other intrapersonal factors (*subtype* 3.6) related to SIB. For example, clients sometimes did not know why they showed SIB (Didden et al., 2008). In the study of Didden and colleagues all clients mentioned that they started skin-picking very early in their lives but most did not know when and why they began skin-picking. Self-punishment was also described as a reason for SIB (Harker-Longton & Fish, 2002) and the positive emotional effects after displaying SIB were mentioned by participants as reasons for engaging in SIB, although they were short-lived (Brown & Beail, 2009). SIB (e.g., skin-picking) is considered as a habitual or automatic behavior (Didden et al., 2008; Duperouzel & Fish, 2010; Harker-Longton & Fish, 2002). In addition, the sense of being out of control was associated with physiological adaption to their SIB.

Discussion

The results of this systematic review including ten qualitative studies provides insight in clients' attributions of their own or other clients' CB. The results show that three main types of factors with different subtypes, i.e., (1) interpersonal factors (support staff, clients and general), (2) environmental factors (ward, social exclusion and situational factors), and (3) intrapersonal factors (syndrome or diagnosis, medical or physical reasons, psychological reasons, emotions and feelings, coping and other) were reported to cause CB. This wide range of types of attributions can be used as a framework for interpreting the triggers and maintaining factors of CB and for the development of appropriate support systems for people with ID showing CB. The findings are also an argument of developing treatment and support plans in collaboration with people with ID, in which their experiences are taken into account.

For every type of CB clients described interpersonal factors as factors causing CB. More specifically, clients with ID mention interactions with support staff, their attitude and (the lack of) reactions or interventions of support staff to trigger SIB or aggression. They also report that other clients, either passively or actively, may contribute to their SIB or aggression. This finding is consistent with previous studies indicating that the environment and especially behavior and attitudes of support staff, may indeed play an important role in both triggering and maintaining CB (van den Bogaard, Nijman, Palmstierna, & Embregts, 2018b; Griffith,

Hutchinson, & Hastings, 2013; Hastings et al., 2013; Whittington & Wykes, 1996). In a non-systematic review of Hastings and colleagues (2013) a framework is presented in which the role of the environment is stipulated, and according to this framework support staff can be a trigger and maintaining factor for CB. The results of a study of van den Bogaard, Nijman, Palmstierna, & Embregts (in review) show that support staff mostly mention client characteristics and client behavior to be the cause of CB shown by the client. They only assign a small number of causes to their own behavior. Support staff thus literally know that their influence is significant, though it seems that this is not consciously acknowledged. Next, being around other clients may also have an impact on clients' CB. This is in line with the views of clients in earlier studies (e.g., McCorkell, 2011). In the study of McCorkell (2011) clients with ID, who had a community-based order, mention that they experienced more space and privacy in community settings compared to hospitalized setting. Our study shows that next to support staff, also clients are able to give an indication about antecedents and consequences of CB, and thus are an import source to consult in designing support and treatment of CB.

According to clients with ID, environmental factors may lead directly or indirectly to CB. Factors related to the ward, feeling socially excluded and situational factors such as treatment plans contribute to their CB. These factors are also seen in other studies (e.g., Griffith et al., 2013). In the thematic synthesis of Griffith and colleagues the negative atmosphere and lack of autonomy were mentioned as causes of CB. This also becomes clear in a study of McCorkell (2011), in which clients who are in rehabilitation indicate the great differences between their opportunities (e.g., leisure activities; occupation) when living in community again compared to living hospitalized.

Finally, the results of our review point at the fact that clients attribute their CB to various intrapersonal factors, and also that some of the mentioned intrapersonal factors are not generic (i.e., specific disorder or medical condition (like itchiness). These intrapersonal factors often seem to be preceded by interpersonal and environmental factors, like interactions with support staff causing stress and emotions. Next, clients are not able to cope well with these emotions, and seem to choose CB as a coping strategy. Clients were thus able to formulate both the direct and indirect link with their CB. Intrapersonal factors potentially causing CB are acknowledged in other studies focusing on the causes of CB from the perspective of the environment (Hastings et al., 2013). In the non-systematic review of Hastings and colleagues (2013) biological and psycho-social vulnerabilities are mentioned causing CB by studies assessing support staff, but the indirect relation is not explicitly acknowledged. Our review clearly point at the fact clients are capable to give indications of interrelated sources influencing each other, eventually causing CB. People with ID use a comparable spectrum of factors as causes for CB in accordance with support staff (Hastings et al., 2013). It would be interesting for future research to analyse incidents of CB in more detail, as is known from other settings (e.g., mental health settings), that clients and support staff do not always mention the same causes for CB (Duxbury & Whittington, 2005) and support staff are not always able to mention the triggers for CB (Bowers et al., 2011).

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The strength of this review is that it explicitly focused on the attributions of CB. Opposed to previous reviews extracting attributions of CB within the frame of focusing on experiences of people with ID and CB related to received service support and interventions in general (e.g., Griffith & Hutchinson, 2013). Although only ten studies met our inclusion criteria, our thematic synthesis provides a rich and complete description of the whole spectrum of types of attributions of CB from the perspective of clients. The resulting overview may be a starting point for research to investigate the various factors more in depth and develop interventions to reduce CB. This overview can also be helpful for practice to critically evaluate behavior and attitudes of support staff in order to possibly reduce CB of persons with an ID.

Next, studies were not excluded based on the setting. People with mild ID or borderline intellectual functioning (MBID) are at higher risk of developing psychopathology and do often attempt to hide their disability (Snell et al., 2009). Therefore their ID and co-occurring problems often go unrecognized or are misdiagnosed. A failure to recognize their MBID and co-occurring problems (Nieuwenhuis, Noorthoorn, Nijman, Naarding, & Mulder, 2017; Wieland, Haan, & Zitman, 2014) causes them to receive care in different settings like general or forensic psychiatric care, specialized addiction services or prisons (e.g., Nouwens, Smulders, Embregts, & van Nieuwenhuizen, 2017; Søndenaa, Rasmussen, Palmstierna, & Nøttestad, 2008). The included studies thus provide attributions of people with ID residing in a wide range of different settings.

Finally, this review focused on assessing the attributions about actual CB and excluded studies focusing on assessing beliefs about fictitious situations of CB (e.g., Dagnan & Weston, 2006), as well as questionnaire studies in which the causal link between prior events and subsequent CB is not explicitly acknowledged by the participants (e.g., Murphy et al., 1996). This is potentially even more interesting as it provides a unique insight in the causes from the person demonstrating the particular behavior and may elicit different patterns of attributions compared to studies focusing on fictitious behavior (Allen, 1999; Dagnan & Weston, 2006).

Limitations

A relatively strict definition of attributions is used in this review, in which only quotes of clients or interpretations of researchers about quotes of clients were incorporated as attributions, and in this way excluding for example questionnaire studies. As a result, studies included are all qualitative in nature. Synthesizing the results of the qualitative studies can give the opportunity for enhancing the naturalistic generalizability (Sandelowski, Docherty, & Emden, 1997), with respecting its essential context. However, the small number of studies can also be seen as a limitation, as it is questionable how transferable and generalizable this information is to other settings and populations, because of the high context-dependency of qualitative studies (Bearman & Dawson, 2013).

Although a broad definition of CB was used in the search strategy, the included studies only focused on four different types of CB (i.e., aggressive behavior, self-injurious behavior, offending behavior and CB not specified). In future research it would be recommendable to assess the attributions of clients on more types of internalizing and externalizing CB's.

Clinical implications

Insight in clients' own beliefs concerning the causes of their CB can be used as input for directing behavior, coaching support staff about how to best support their clients and for designing and developing appropriate and effective interventions for people with ID showing CB as well as for people living with other clients engaging in CB. Incorporating the views of clients, not only in research, but also in policy, practice and decision making, gives us a valuable insight in different perspectives. Incorporating clients' view in research on attributions and CB is desirable as it may improve our understanding of the triggers of CB and it may help us to prevent clients with ID and CB from showing behavior in the future, which can be challenging for themselves and their environment.

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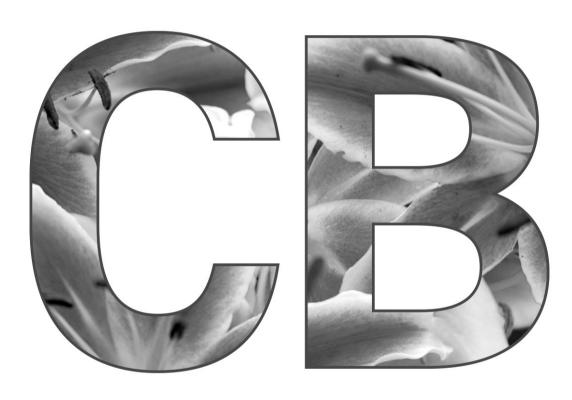
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5

Chapter 6

Attributions of aggressive behavior in people with mild intellectual disability to borderline intellectual functioning in a secure forensic psychiatric setting

Abstract

Background
Aggressive behavior is often displayed by people with intellectual disabilities (ID) in forensic health care settings. Research on the causes (i.e., attributions) of aggressive behavior are mostly studied from the perspective of support staff. As aggressive behavior is mostly a product of interaction between the person showing it and its environment, it is also valuable to include the perspective of people with ID as well.

Method
Four group interviews, consisting of a total of 20 people with mild ID or borderline intellectual functioning and forensic and/or psychiatric problems, were held to explore incidents of aggressive behavior. The attributions were analysed using the Leeds Attributional Coding System.

Results
Participants almost equally distributed the causes of aggressive behavior to themselves and their environment. Aggressive behavior was scored as unstable, internal, and personal in case the client or the environment was mentioned in the cause. Additionally, aggressive behavior was scored global and uncontrollable if the client was the agent, and specific and controllable if the environment was the agent.

Conclusion
This analysis of attributions regarding aggressive behavior given by clients resulted in information on causes of aggressive behavior from the perspective of clients. Incorporating their views will possibly increase involvement and commitment in support and treatment.

Aggressive behavior is a well-recognized issue in forensic mental health settings (Alexander et al., 2010; Bowers et al., 2011). Prevalence rates of aggressive behavior within these settings are especially high for people with mild intellectual disability (MID) or borderline intellectual functioning (BIF) compared to people without ID (Chester et al., 2018; O'Shea et al., 2015). For example, in their study in a secure mental health hospital in the UK, O'Shea et al. (2015) reported rates of aggressive behavior of people with mild MID of 83.5% compared to 61.3% for people without ID. People with MID and BIF account for a great number of aggressive incidents within forensic mental health settings, even though they do not form the largest forensic population (Baldry et al., 2013; Dickens et al., 2013).

Aggressive behavior can have negative consequences for both the aggressors themselves (e.g., physical injuries, decreased quality of care, increased restrictions, and higher medication use; Arnetz & Arnetz, 2001; Bowers et al., 2011; Deb et al., 2015; Tsiouris, 2010; van den Bogaard et al., 2018a) as well as the environment supporting them (e.g., negative emotions, stress and burnout, physical injuries, and high costs of care; Bowers et al., 2011; Erdos & Hughes, 2001; Griffith & Hastings, 2014; Singh et al., 2008; Mills & Rose, 2011). As these consequences are detrimental, a significant amount of research has already been conducted in various settings, including the secure forensic setting, to gain more insight into the prevention and management of aggressive behavior. So far, most of this research on aggressive behavior focussed on the perspective of the environment, by concentrating on the views of support staff, families, and other proxies (e.g., Bowers et al., 2011; Deveau & McGill, 2014; Hassiotis et al., 2018; Jacobs et al., 2016). Consequently, the views of people with MID and BIF themselves related to aggressive behavior are understudied. Incorporating the views of people with MID or BIF in care and support is, however, important for three main reasons. First, according to clients and support staff, being involved and engaged in services and therapies as a client is a precursor for progress in these areas (Morrissey et al., 2017). Second, support staff and people in psychiatric care have different opinions regarding the causes of aggressive behavior and therefore both views should be studied (Duxbury & Whittington, 2005) to develop optimal interventions. For example, Duxbury and Whittington (2005) found that, clients attributed aggressive behavior primarily to environmental conditions and poor communication, whereas nurses attributed aggressive behavior mainly to the clients' mental illnesses and in-client environment. Third, based on their review, Bowers et al. (2011) showed that the antecedent 'no clear cause' was one of the themes with the highest proportion precipitating aggressive incidents (i.e., 32%). Hence, asking clients about these causes might be helpful. Although the three studies do not specifically report on people with MID or BIF in a secure forensic setting, they do underline the importance of incorporating the clients' perspective regarding causes of aggressive behavior.

In order to identify the available studies focussing on the causes (i.e., attributions) of challenging behavior according to people with ID themselves, van den Bogaard et al. (2019) conducted a systematic review. Two of the included studies ($N = 10$) focussed on the experiences of people with ID (level of ID was not specified) regarding aggressive behavior.

That is, Clarkson et al. (2009) asked participants about their perceptions and experiences regarding direct support staff. In their study, the only reported attribution of aggressive behavior by people with ID was dishonesty of support staff. In addition, Fish and Culshaw (2005) explored the explanations of people with ID regarding aggressive incidents and the consequences of physical interventions, revealing the atmosphere on the ward, the locked environment, and support staff (e.g., support staff did not listen to the client) as causes of aggressive behavior.

In sum, although the prevalence of aggressive behavior in people with MID or BIF in forensic settings is high and they do account for a great part of the aggressive incidents, the attributions of people with MID or BIF displaying aggressive behavior themselves in these settings are not yet explored. Therefore, in this study, we explored the attributions regarding aggressive behavior of people with MID or BIF within a secure forensic psychiatric setting. More insight into their attributions possibly helps them to become more motivated for support and treatment (Morrissey et al., 2017). Besides, as people with MID or BIF are able to tell how they felt before the aggressive behavior, it might help support staff to become more sensitive towards these emotional states and to intervene more proactively (Bowers et al., 2011).

Method

Participants and setting

In total, 20 individuals with MID (IQ 50-70) or BIF (IQ 70-85) participated in this study. All participants resided on average for 21 weeks (range 3-49 weeks) in a secure forensic psychiatric hospital in the Southern part of the Netherlands. Within this setting, they received treatment for their forensic and psychiatric problems (e.g., substance related disorder or psychosis). The participants (19 men) had a mean age of 35.2 years (SD = 8.9; range 20-53 years). The level of intellectual functioning was determined based on data from psychometric sound IQ tests as described in the participants' files. The mean IQ on file was 64 (SD = 7.9; range: 50-83, for 2 participants no specific IQ scores were available, but the psychologist of both clients reported IQ-scores between 50 and 85 based on their clinical expertise); 16 were diagnosed with MID, 4 participants with BIF. In addition to their forensic problems, 95% of the participants were diagnosed with one or more co-occurring psychiatric diagnoses using the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V, American Psychiatric Association, 2013), of which substance-related disorders (n = 18), schizophrenia spectrum and other psychotic disorders (n = 4), and personality disorders (n = 4) were the most common diagnoses.

Procedure

After ethical approval from the Ethics Review Board of Tilburg University (EC 2014.21) and the participating healthcare organization, the researchers informed all support staff

of the forensic psychiatric hospital about the aim and content of the study during a team meeting. The purpose of informing them was to alleviate any potential concerns regarding the invasiveness of the research for the clients, to involve them in starting this research and to support clients in case they would have any questions regarding the study. Next, in two information sessions, the researchers informed all potential participants (i.e., all persons with MID or BIF residing at the secure forensic psychiatric hospital) about the goal, content, and procedure of the study, using visual aid. That is, the researcher explained that, after the information session, clients would be invited to participate in a group interview by one of their support staff members. It was explained that, during the group interview, they would be asked to provide descriptions of what happened before, during, and after incidents of aggressive behaviors on the ward (in general) in which they were involved or which they had witnessed. Moreover, during the information sessions, it was explained, both verbally and written on the information sheet and informed consent form, that participants would not be named in reports. Two support staff members were present at each information session as they knew the clients well and answered their questions and clarified their indistinctness.

After written consent to participate, participants were informed about the time and location of the group interview. In total, four group interviews were executed, one on each ward of the secure forensic psychiatric hospital. In order to make the clients feel comfortable, a psychologist with experience in ID research and an experienced staff member familiar with the target population and clients executed the group interview. The researcher gave an extensive briefing and checked the interviews to confirm open questioning, without influencing the participants. Using familiar staff to execute the group interview is considered to help the participants to feel comfortable and helps to elicit most information (Norman & Parker, 1990). Besides, the advantage of a group interview over an individual interview is that group interviews are less confrontational, not directly related to one's own incident, and it might feel safer to talk in a group (e.g., Kitzinger, 1994). In addition, a video camera instead of a voice recorder was used after consultation with the participants themselves; a voice recorder reminded them of negative events in the past (e.g., conviction at a police station) and the position of the camera was focused on the interviewers instead of the clients. Confidentiality and anonymity of the information was emphasized; it was explained that the group interviews would be transformed into text, without disclosing the participant's identities.

The group interviews took place in a familiar room in forensic psychiatric hospital. To make the clients feel as comfortable as possible and to avoid clients to see this conversation as a regular talk with the psychologist, the group interview took place in the recreational room of the forensic psychiatric hospital. Tea/ coffee and pie were served, and participants received a small financial reward (€ 10) for their participation. On average, the group interview had a duration of 33 minutes (range 27 – 43 minutes). Two group interviews consisted of five participants, one consisted of four and one of six participants.

Instrument

To get a full description of incidents of aggressive behavior among people with MID and BIF with additional forensic and psychiatric problems in a secure forensic setting, we used a semi-structured interview schedule based on van den Bogaard et al. (2018c) who focussed on the attributions of support staff working with people with MID or BIF. Using open-ended questions to elicit non-biased responses of the participants, they were asked to give a description of what happens when a person (the client themselves or other clients on the ward) became aggressive. In case the answer was unclear or incomplete, the interviewers asked clarifying questions related to 1) the antecedent (i.e., the triggers of aggressive behavior, such as closeness or denial of request), 2) the aggressive behavior (i.e., the specific topography of the behavior, such as verbal or physical aggression), 3) the target of the behavior (i.e., the person or materials to whom the behavior was aimed at, such as other clients or support staff), 4) the consequences of the behavior (i.e., consequences of the behavior for the victim, such as feeling threatened), 5) the measures that were taken to stop the aggressive behavior (i.e., what was done to stop the behavior, by the person him/herself or the environment, such as going to own room or holding), and 6) feelings of the aggressor or victim related to the behavior (i.e., what did the persons involved felt before, during or after the incident?). Adaptations to the interview schedule of van den Bogaard et al. (2018c) were made to ensure that the questions were comprehensible for people with MID or BIF (e.g., simple and clear language and visualization of the information).

The Leeds Attributional Coding System (LACS; Stratton et al., 1988) was used to analyse the data of the group interviews. The LACS is a method developed to explore attributions made by one person, based on individual or group interviews (Munton et al., 1999). The research method is designed to explore transcripts in six steps. That is, each group interview was recorded and transcribed verbatim, to indicate the source of the attribution (step 1). Next, the transcripts of the group interviews were independently screened by two researchers (1st author and an experienced ID researcher) to identify which text contains attributions of aggressive behavior (step 2). Attributions are "expressions of the way a person thinks about the relationship between a cause and an outcome" (Munton et al., 1999, p.6). The extractions were compared and differences were discussed until consensus was reached. Following this, the first author separated the cause (e.g., I (client) did not like what support staff said to me (= cause)) and outcome (e.g., that is why I (client) called her (support staff) names (= outcome)) in the attributions (step 3) and identified the speaker (i.e., the person providing the attribution), agent (i.e., the person or situation mentioned in the cause of the attribution), and target (i.e., the person or situation mentioned in the outcome of the attribution) (step 4). Subsequently, the attributions were coded by the first author on five causal dimensions (see Appendix 1; step 5). To calculate the Percentage of Agreement Index (Suen & Ary, 1989), a second ID researcher coded 25% of the group interviews; the percentage of agreement was 91.4%. Last, the codes were analysed to conduct descriptive and comparative analyses (step 6).

Analysis

The analyses were carried out in two steps. First, a qualitative content analysis was conducted to explore the content of the attributions of participants. The content analysis was executed by the first author by deductively coding the attributions based on the code list derived from the review of van den Bogaard, Lugtenberg et al., (2018). The complete coding was checked by a second ID researcher, and disagreements were discussed until consensus was reached. Second, in addition to the content analysis, descriptive statistics were used for identification of the agent and exploration of the scores on the five attributional dimensions of LACS.

Results

In the result section, the content of the attributions will be described first, followed by an overview of the scores of the attributions on the five attributional dimensions of the LACS per type of agent (Stratton et al., 1988).

Content of the attributions

In total, in the four group interviews, participants provided 127 attributions about aggressive behavior, differentiating between attributions on the interpersonal, environmental, and intrapersonal level.

Regarding to interpersonal attributions, participants mentioned triggers related to support staff, other clients and other persons not specified as causing them to display aggressive behavior. Although participants did not specify other persons in these attributions, based on the description of the incidents, it seemed that these persons were closely related to the participants, such as other clients or support staff. Participants mentioned the reactions of support staff and other clients, but also the lack of reactions by support staff as triggers for aggressive behavior. Besides, participants mentioned various negative feelings as a consequence of the behavior of other people (e.g., support staff or other clients) which causes them to show aggressive behavior, such as being hurt, belittled and feeling abandoned. As one client tells why he became aggressive: *'If you live in the same area and people belittle you, behind your back'.* Other feelings that were mentioned by the participants causing aggressive behavior were annoyance, irritations and feeling one have to defend oneself towards other people. As one clients tells why he became aggressive: *'Because they (other clients) irritate me'.*

Environmental factors contributing to aggressive behavior were related to the physical context, feeling socially excluded and situational factors. That is, participants mentioned being at the ward and not with family, the atmosphere on the ward, and the dirt other clients leave behind as situational factors causing aggressive behavior. According to one client the reason for him to become aggressive was a sequence of different factors: *"It a sequence of the situation at home and dealing with the fact that you are here and not with your family. Although you can have some contact, they are not around at this moment".*

Last, regarding the intrapersonal attributions causing aggressive behavior, participants mentioned nine different types of reasons: 1) psychiatric disorder (e.g., having ADHD), 2) medical reason (e.g., epilepsy), 3) mental health (e.g., brooding), 4) emotions and feelings (e.g., anger), 5) coping with these emotions and feelings (e.g., not being able to talk about feelings), 6) life history (e.g., things that happened in the past), 7) status (e.g., wanting to get things done), 8) positive reward (e.g., feeling calm afterwards), and 9) other (e.g., becoming aggressive by talking about incidents of aggressive behavior).

Attributional dimensions per type of agent

The scores on the attributional dimensions per type of agent are displayed in Table 1. If clients were the agent, the attributions are primarily scored as unstable, global, internal, personal, and uncontrollable, suggesting that the causes of aggressive behavior are not likely to influence future outcomes (unstable; e.g., *"Well yes, if I (client) am not able to explain it with words, by talking, that's when I really break out"*). It also suggests that the causes of aggressive behavior are likely to influence several different outcomes as well (global). For example the following cause mentioned by a client, is likely to have many other outcomes in his life, besides becoming aggressive: *"There are clients who have a borderline personality disorder"*. He also might have difficulties is maintaining social contact with friends. The causes further originate from within the person (internal; e.g., *"one person has ADHD, everybody reacts differently"*), and tell something unique about the person (personal; e.g., "*I can get things done, the way I want to*").

In contrast, if other people (i.e., support staff, other clients, or others (not specified)) were the agent, the scores on the five attributional dimensions were, in addition to unstable, internal, and personal, mostly specific and controllable. This suggests that, when other people were the agent, causes of aggressive behaviors were not likely to influence many other outcomes, except for becoming aggressive (specific; e.g., *"Others (not specified) want to have power over you")* and that the agent was able to influence the outcome (e.g., controllable; *"Support staff do not react"*).

Discussion

Aggressive behavior displayed by people with MID or BIF is a common phenomenon in forensic mental health settings, though studying causes of this behavior from the perspective of people with MID or BIF themselves is rare, though important as it can provide a rich inside in their explanations of their behavior and, as a result, help to develop more effective interventions. Therefore, this study explored the attributions regarding aggressive behavior of people with MID and BIF and additional forensic and psychiatric problems residing in a secure forensic psychiatric hospital. In order to do so, four group interviews were held with 20 clients and transcribed verbatim to extract attributions regarding aggressive

Table 1. Scores on Five Attributional Dimensions per Type of Agent

	Agent									
	Client		Support staff		Other clients		Situations		Other people	
LACS dimensions	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
	61		21		11		8		26	
Stable	13	(21.3)	6	(28.6)	0	(0.0)	3	(37.5)	6	(23.1)
Unstable	48	(78.7)	15	(71.4)	11	(100.0)	5	(62.5)	20	(76.9)
Global	42	(68.9)	8	(38.1)	0	(0.0)	5	(62.5)	16	(61.5)
Specific	18	(29.5)	13	(61.9)	11	(100.0)	3	(37.5)	9	(34.6)
Not coded	1	(1.6)	0	(0.0)	0	(0.0)	0	(0.0)	1	(3.8)
Internal	56	(91.8)	21	(100.0)	11	(100.0)	0	(0.0)	22	(8.5)
External	5	(8.2)	0	(0.0)	0	(0.0)	0	(0.0)	2	(7.7)
Not coded	0	(0.0)	0	(0.0)	0	(0.0)	8	(100.0)	2	(7.7)
Personal	52	(85.2)	21	(100.0)	11	(100.0)	0	(0.0)	20	(76.9)
Universal	9	(14.8)	0	(0.0)	0	(0.0)	0	(0.0)	3	(11.5)
Not coded	0	(0.0)	0	(0.0)	0	(0.0)	8	(100.0)	3	(11.5)
Controllable	17	(27.9)	18	(85.7)	11	(100.0)	0	(0.0)	21	(80.8)
Uncontrollable	44	(72.1)	3	(14.3)	0	(0.0)	0	(0.0)	2	(7.7)
Not coded	0	(0.0)	0	(0.0)	0	(0.0)	8	(100.0)	3	(11.5)

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behavior. Next, the content of the attributions provided by the participants were analysed. Subsequent, we examined which persons and what situations were mentioned in the cause of the attribution (agent) and we explored the scores on the five attributional dimensions (stable/unstable, global/specific, internal/external, personal/universal, and controllable/ uncontrollable) according to the LACS (Stratton et al., 1988) to indicate the characteristics of the attributions.

Based on the content analysis, it can be concluded that participants attributed aggressive behavior to a broad range of interpersonal, environmental, and intrapersonal factors. As such, participants emphasized their own role as well as the role of their environment (support staff, other clients, and other persons (not specified)) in causing aggressive behavior. More specifically, in about half of the cases, participants mentioned characteristics and behaviors of themselves causing CB, such as having a personality disorder or feeling distressed. In the other half of the attributions, participants indicated characteristics of situations, and behaviors of other clients and support staff as causing aggressive behavior. They indicated various feelings that were evoked in them by behaviors of other people (e.g., getting frustrated because

support staff treat the client like a child), which eventually led to aggressive behavior. These findings are comparable to recent findings exploring the motives of patient without an ID in a forensic psychiatric care setting regarding aggressive behavior (Lewis & Ireland, 2019). In this study patients also mentioned the three types of causes (interpersonal, intrapersonal and environmental factors). Besides, the results provide support staff more insight into the emotional state of a client prior to an incident, and, as such, provides a greater psychological understanding of the client. Asking people with MID and BIF and forensic and psychiatric problems about their perspectives on the causes of aggressive behavior -and probably also for other forms of challenging behavior- might also help support staff to become aware of their contribution in triggering and maintaining aggression, and to observe not only behavioral, but also emotional cues (Bowers et al., 2011).

Moreover, getting insights in the emotions and feelings experienced by clients precipitating aggressive behavior might also be helpful for the clients themselves. As people with ID have fewer psychological resources to cope with stressful events (van den Hout et al., 2000), it would be very helpful to get more insights into their own emotional experience before and during a negative event (e.g., CB). Several interventions, such as Cognitive Behavior Therapy (CBT) or self-management training, can be used effectively to develop cognitive skills and self-control techniques in people with ID to manage their mental health and emotional problems (Beail, 2003; Taylor & Novaco, 2005; Willner, 2005). Training individuals to manage their own emotions and feelings makes them less dependent on their environment (Taylor & Novaco, 2005) and possibly more motivated for change (Morrissey et al., 2007). Although these studies not focus specifically on aggressive behavior in people with MID of BIF, it would be valuable to test if these training courses are helpful for aggressive behavior in people with MID or BIF with forensic and psychiatric problems.

Next, the attributions were analyzed by scoring them on five attributional dimensions. In the case participants themselves were the agent, they attributed most causes of aggressive behavior as unstable, internal, personal, global, and uncontrollable. If other people (e.g., support staff or other clients) were the agent, participants did attribute aggressive behavior as unstable, internal, personal, but they also attributed the behavior as specific and controllable. This suggests that participants attribute causes of aggressive behavior to aspects which are more under the control of their environment and which do not influence a lot of other outcomes. Getting to know more about the attributional dimensions of aggressive behavior of clients might be helpful to connect with their experiences and hence to attune treatment to their wishes and needs (Morrissey et al., 2017). For example, if someone attributes aggressive behavior mostly as external to himself, that person might not take responsibility for his behavior, and hence, this might imply a lack of progress in treatment due to not taking responsibility for his behavior. Or, if a person attributes aggressive behavior as stable (i.e., not likely to change in near future), this can result in a passive attitude as the person does not experience possibilities to change the situation. So, knowing the way a person attributes his behavior gives the person himself more insight into his own behavior and the relation with

the environment, but also provides the environment information about the reason this person might act in a certain manner. Both can be helpful in preventing aggressive behavior. It would therefore be recommendable to examine both the attributions of clients and staff members to direct treatment and support. Finally, due to the small number of attributions it was impossible to analyse attributional styles (i.e., patterns on the five attributional dimensions) of people with MID or BIF with forensic and psychiatric problems. Focussing on attributional styles and patterns in future research can give insights in adaptive and maladaptive ways of thinking and relating behavior, cognitions and interrelated emotions (Dix, 1991).

Although this study relies on the use of qualitative data based on real incidents and gives rich information of the experiences of people with MID or BIF and forensic and psychiatric problems regarding aggressive behavior, the results of this study should be interpreted in the light of several limitations. That is, data collection took place in one secure forensic psychiatric hospital in the Netherlands and relies on retrospective information retrieved from the participants. In future research, it would be recommendable to extract more data derived from real incidents in different settings and related to different behaviors (e.g., self-injurious behavior) and different types of behaviors (e.g., verbal versus physical aggression) as well as linking this information to individual characteristics, behavioral and treatment outcomes. Moreover, it would be recommendable for future research to interview both people with MID and BIF and support staff about the same incident. This will give more insight into each other's perspective and may provide opportunities to develop treatment interventions that connect both the needs of people with MID and BIF and forensic and psychiatric problems with possibilities of support staff in preventing or reducing aggressive behavior.

In sum, this study showed that people with MID and BIF and forensic and psychiatric problems are capable of describing causes of incidents of aggressive behavior in detail, making it possible to extract attributions. The diversity in the answers of participants in the current study regarding the contribution of the clients themselves, support staff, other clients and situations in triggering aggressive behavior suggest that people with MID and BIF are sensitive to the internal and environmental contributing factors of aggressive behavior. Although the incorporation of the views of people with MID and BIF in forensic mental health care is still developing, this study shows the potential of incorporating the views of this population and also to embed this information in a broader context of support and treatment. Understanding behavior as a product of interaction between the person showing the behavior and its environment (Banks et al., 2007) starts with recognizing that the views of both professionals and clients are valuable and, thus, in order to manage this behavior, people with MID and BIF in forensic mental health care need to be asked about their opinion as well.
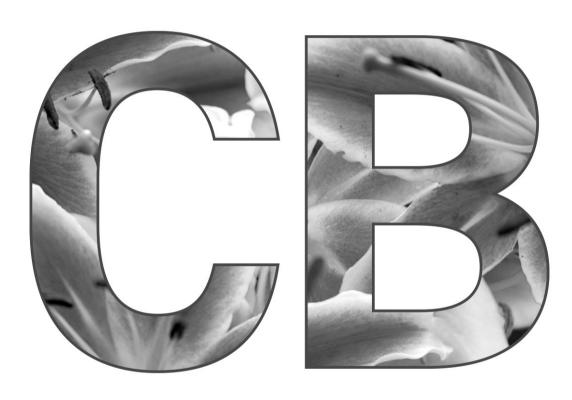
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Appendix 1. Definition of causal dimensions used in the Leeds Attributional Coding System

Causal dimension	Definition of causal dimension
Stable/unstable	Stable causes are causes that are likely to continue to influence outcomes in the future
Global/ Specific	Global causes are those cause that are likely to have a significant impact on several different outcomes
Internal/ external	Internal causes are those believed to originate from within the person being coded
Personal/universal	Personal causes contain information concerning something unique or idiosyncratic about the person being coded
Controllable/ uncontrollable	Controllable causes are causes in which the person thinks he could have influenced the outcome

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Chapter 7

Attributional styles of support staff working with people with intellectual disabilities exhibiting challenging behaviour

Abstract

Background
Attributions are cognitive variables that influence a person's behavior. Although much research has been conducted on attributions of support staff regarding challenging behavior (CB) of people with intellectual disability (ID), research studying patterns on attributional dimensions (i.e., attributional styles) are scarce.

Method
Using semi-structured interviews, 19 support staff were asked to describe incidents of aggressive, self-injurious, and harmful sexual behavior. Data on attributions were analysed using the Leeds Attributional Coding System.

Results
Four attributional styles significantly differed between aggressive, self-injurious, and harmful sexual behavior. Besides, support staff mostly mentioned characteristics and behavior of clients with ID to cause these three types of CB.

Conclusions
The results indicate that it is important to train support staff to recognize and understand the influence of their attributions and behavior on the existence and maintenance of CB.

People with intellectual disabilities (ID) are at higher risk of developing psychopathology compared to people without ID (Matson & Shoemaker, 2011), and they relatively often engage in disruptive and challenging behaviors (CB), such as aggressive behavior, self-injurious behavior (SIB) and harmful sexual behavior (HSB) (Luiselli, 2012). CB can be seen as 'the product of interaction between the individual and its environment' (Banks et al., 2007). Therefore, the environment of people with ID, and their support staff in particular, may be a key factor in the prevention and management of CB (Hastings, 2010; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018a).

Indeed, several earlier studies addressed the explicit role support staff may have in triggering and reacting to CB. For example, support staff mention that their interactions with people with ID can be triggers for CB, and they judge their interventions to be necessary to stop or control CB (e.g., Nijman & à Campo, 2002; Tenneij & Koot, 2007; van den Bogaard, Nijman, Palmstierna, & Embregts, 2018a). In addition, behavior of support staff that potentially may influence the existence and persistence of CB has also been described by people with ID themselves (e.g., Brown & Beail, 2009; Fish & Culshaw, 2005; Griffith, Hutchinson, & Hastings, 2013; Jones & Stenfert Kroese, 2006; van den Bogaard, Lugtenberg, Nijs, & Embregts, 2018). For instance, in their recent review, van den Bogaard, Lugtenberg and colleagues (2018) found that people with ID mentioned staffs' attitudes, reactions, but in some cases also a lack of reactions, as triggers for different types of CB (e.g., aggressive, self-injurious, and offending behavior). Furthermore, previous studies suggested that environmental triggers may vary per type of CB (Griffith et al., 2013; Nijman & à Campo, 2002). Nijman and à Campo (2002) for example found that SIB is more prevalent in the evening compared to aggressive behavior (50% vs 32%), and more often takes place in the patients' room (66% vs 9%). Their study also demonstrated that at least 54% of the triggers of aggressive behavior are related to actions of the environment and their support staff (i.e, denial of a request of the client or reaction to fellow-client behavior), whereas this percentage appears to be lower for SIB (23%). Interestingly, actions of the environment, and actions of support staff in particular, such as restrictive interventions aimed at preventing dangerous situations, paradoxically can also trigger a repeated occurrence of CB (Griffith et al., 2013; Nijman, à Campo, Ravelli, & Merckelbach, 1999). Furthermore, support staff more often use restrictive measurements (e.g., holding with force, seclusion, and / or medication) to stop aggressive behavior compared to SIB or harmful sexual behavior (Foster, Bowers, & Nijman, 2007; van den Bogaard et al., 2018a; 2018b).

The behavior of support staff is related to their attributions on CB of clients with ID (Snow, Langdon, & Reynolds, 2007; Wanless & Jahoda, 2002). In the last decades, several studies focused on attributions of support staff regarding CB (e.g., Cudré-Mauroux, 2010; Noone, Jones, & Hastings, 2006; Rose, Gallivan, Wright, & Blake, 2014). Studies comparing the attributions of various types of CB showed differences between these attributions (e.g., Dilworth, Philips, & Rose, 2011; Hastings, Reed, & Watts, 1997; MacKinlay & Langdon, 2009; Stanley & Standen, 2000). For instance, MacKinlay and Langdon (2009) compared

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the attributions of sexual offending behavior with the attributions of challenging behavior (operationalized as aggressive behavior) using the Attributional Style Questionnaire (ASQ; Peterson et al., 1982). According to support staff, sexual offending behavior was, for the support staff group, more often attributed by factors that originate in the environment (called external), that continued influencing the behavior over time (stable), and that were less controllable by the client compared to aggressive behavior. In addition, Stanley and Standen (2000) concluded that carers attributed SIB as more likely to continue to influence the behavior over time (stable) and less controlled compared to aggressive behavior and destructiveness. Finally, Williams, Dagnan, Rodgers, and McDowell (2012) indicated that attributions can change as a result of training. Support staff who are provided with information about CB, are more likely to produce behaviors that will not initiate CB.

Although much research has been conducted on attributions of support staff regarding CB of people with ID, to our knowledge, none of these studies have focussed on the patterns of the attributional dimensions (i.e., attributional styles) of support staff regarding CB. An attributional style can be described as a cognitive personality characteristic which reflects the way people habitually explain what happens in their life (Houston, 2016). If people, within attributional models, attribute positive events to stable, global, and internal causes, and negative events to unstable, specific and external causes, these attributional styles are considered "healthy". The opposite emerges if negative events are attributed to stable, internal and global causes, which is considered "depressogenic" (Abramson, Metalsky, & Allow, 1989), because these attributions assume that the individual having them has little influence or options to prevent such negative events. Indeed, associations between certain attributional styles and distress in adult relationships have been found in earlier research (e.g., Silvester, Bentovim, Stratton, & Hanks, 1995). In addition, studying the attributional styles of support staff is vital as these styles may influence the affective and behavioural reactions within relationships (Dix, 1991), as well as the quality of the relationships (Fincham, Beach, & Baucom, 1987). Finally, research on training attributions of support staff (e.g., Grey, McClean, & Barnes-Holmes, 2002) indicated that attributions can change as a consequence of prolonged training in providing behaviour support.

As identifying attributions based on real incidents, instead of vignettes, is likely to result in a more representative and complete picture of the attributions of support staff (Snow et al., 2007), the Leeds Attributional Coding System (LACS; Stratton, Munton, Hanks, Heard, & Davidson, 1988) was used in the current study to identify the attributions of support staff (see 'analysis' for more information about this coding system) based on real incidents they had with people with ID. Moreover, using LACS, we were able to explore and compare the attribution styles of three frequently reported different types of CB (i.e., aggressive behaviour, SIB and HSB).

Method

Participants and setting

Nineteen staff members (five males) working with people with mild intellectual disability (IQ between 50-70) to borderline intellectual functioning (IQ between 70-85), hereafter designated as people with mild to borderline intellectual disability (MBID), were recruited from a healthcare service for people with ID in the South-East of the Netherlands. The only inclusion criterion for participation in this study was: having witnessed aggressive behaviour, SIB and/or HSB in people with MBID. Support staff had a mean age of 33.2 years (SD = 10.2, range: 22.7-57.4 years) and had worked with people with ID and CB for at least 9.6 years (SD = 8.0, range: 2.5 – 36.0 years). Three (15.8%) staff members had junior or pre-vocational education, 10 staff members (52.6%) had secondary vocational education and six (31.6%) support staff members had higher or post-graduate professional education. All support staff had followed a training regarding the prevention and management of aggressive behaviour, but not regarding SIB or HSB.

Procedure

Following approval from the Ethics Committee of Tilburg University (EC-2014.21) and the participating healthcare organization, the researchers provided the management team, consisting of four managers each serving several locations, with information about the study, who thereupon selected 19 support staff to participate based on their working experience with people with MBID and CB. Following this, the first author provided full information about the research to the managers, which informed the support staff about the research. All staff members, who were approached by the manager, agreed to participate. After written informed consent was provided, support staff were asked to describe what they considered to be CB, which types of CB were shown by the people with ID they support, and what the frequency and severity was of incidents concerning CB. Thereupon, support staff were asked to describe the incident of aggressive behavior, SIB, and/or HSB they remembered most. The average duration of the interviews was 50 minutes (range: 34-65 min). After the interview, the possibility for aftercare (e.g., a follow-up interview with the manager) was offered, but none of staff members made use of this.

Instrument

A semi-structured interview was used to obtain a description of an incident of aggressive behavior, SIB, and/or HSB, and corresponding attributions. The interview was based on the information of the Staff Observation Aggression Scale-Revised (Nijman et al., 1999; van den Bogaard et al., 2018a) for aggressive behavior, the Self-Harm Scale (van den Bogaard et al., 2018b) for SIB, and the Harmful Sexual Behavior Scale (van den Bogaard, Nijman, & Embregts, 2018) for HSB. The structure of the interview was in line with earlier research on attributions in which semi-structured interviews were used to generate attributions

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(Lundström, Åström, & Graneheim, 2007; Noone et al., 2006; Todd & Watts, 2005). Two researchers asked support staff if they had witnessed aggressive behavior, SIB, and/or HSB with respect to persons with ID. In case the answer was affirmative (n = 19 for aggressive behavior, n = 17 for HSB, and n = 13 for SIB), support staff were asked to describe the incident that they remembered most. They were encouraged to talk freely and afterwards the researchers asked clarifying questions about the CB. Clarifying questions were related to a) the antecedent (e.g., What immediately preceded to the CB and seemed to have triggered the CB); b) the nature of the behavior (e.g., What did the CB consisted of?), c) against whom the CB was directed (e.g., Was the CB directed to other clients, support staff, or the person with ID himself?); d) the consequence(s) (e.g., What were the emotional and physical consequences of the CB for you and the client?); e) the measures support staff used to stop the CB (e.g., What did you do to stop the CB?); f) temperospatial characteristics of the CB (e.g., Where and when did the CB happen?); and g) feelings concerning the CB (e.g., What did you feel and what do you think the client felt during, and after, the CB)?

Each interview was recorded and transcribed verbatim. The first author extracted and coded the attributions using the Leeds Attributional Coding System (LACS; Stratton et al.,1988). LACS transforms qualitative data into quantitative data based on real incidents. Real incidents elicit different attributions in support staff (Lucas, Collins, & Langdon, 2009) and also increase the ecological validity of the results (Wanless & Jahoda, 2002). LACS consists of six stages (Stratton et al., 1988): 1) identifying the source of the attributions (i.e., the transcripts in which support staff described the incidents of CB); 2) extracting the attributions (e.g., identifying text which contains causes of CB); 3) separating the cause and outcome elements of the attributions (e.g., The client shouts and throws stuff (= outcome CB), because things did not went the way he wanted (= cause); 4) identifying the speaker (i.e., the person providing the attribution), agent (i.e., the person mentioned in the cause of the attribution), and target (i.e., the person mentioned in the outcome of the attribution); 5) coding the attributions on five causal dimensions (see Appendix 1 the definition of these dimensions); and 6) analysing the codes (e.g., importing the codes into a statistical program to conduct descriptive and comparative analyses).

In order to test the reliability of the extracting and coding phase, a second researcher rated 25% of the interviews. The Percentage Agreement Index was used to compare the similarities and differences between the two raters (Suen & Ary, 1989). In line with earlier studies using the LACS (e.g., Noone et al., 2006; Stratton et al., 1988), a percentage of agreement for the extraction of the attributions was calculated (i.e., 72%) in addition to a percentage of agreement on the coding (i.e., 85%).

In total, 629 attributions were mentioned by support staff. Nineteen staff members mentioned a total of 371 attributions regarding aggressive behavior, 17 staff members mentioned 145 attributions about HSB, and 13 staff members mentioned 113 attributions about SIB. More specific, 13 support staff mentioned attributions regarding all three types of CB, four staff members mentioned attributions on two types of behaviors (i.e., aggressive behavior and HSB), and two staff members only mentioned attributions on aggressive behavior.

Analysis

The analyses were carried out in two steps. First, descriptive statistics were used to identify the agents per type of CB and to explore the scores on the five attributional dimensions. Second, after calculating the most frequent attributional styles for each type of CB, Chi-square tests of independence were used to determine whether there is an association between the most frequent attributional styles and the three types of CB. If the Chi-square test showed a significant association ($p \leq .05$), additional posthoc tests using adjusted standardized residuals were used to compare the scores on the three types of CB. In order to reduce the likelihood of Type I errors, an alpha level of .008 was set for these posthoc analyses given the large number of comparisons. Only differences at or below this alpha level were considered significant.

Results

Agents per type of CB

As can be seen in Table 1, support staff mentioned various persons and situations to be the cause of CB (agents). Most frequently, they considered clients to be the agent (72.5%), followed by support staff (20.7%), and situations or other persons, such as family or a passer-by (6.8%). There was a significant association between the agent and the type of CB ($\chi^2 (4) = 22.151$, $p \leq .001$). Additional posthoc comparisons revealed that support staff were less likely to be mentioned to be the cause of SIB (adjusted standardized residuals = -3.169, $p = .002$), whereas they relatively often were mentioned as the cause of aggressive behavior (adjusted standardized residuals = 3.068, $p = .002$). Moreover, when situations or other persons, such as family or a passer-by, were the agent, they were relatively often to be mentioned to be the cause of SIB (adjusted standardized residuals = 3.406, $p = .001$).

Scores on five attributional dimensions

Stable / unstable. The causes support staff provide about aggressive behavior, SIB, and HSB are mostly scored as unstable (Table 2). It should be noted, however, that this was less often the case when clients were the agent instead of support staff. Hence, if support staff were the agent, the scores indicated that support staff were more likely to assume that the causes of CB can change over time (e.g., "*He (client) became aggressive, because he is hot-tempered*", (stable aggressive behavior, participant 4) vs. "…, *I told him he couldn't do that at that moment*" (unstable, aggressive behavior, participant 7)). An interesting difference between the three types of CB is that, when support staff were the agent, HSB was deemed to be more stable compared to aggressive behavior and SIB, suggesting that the causes of HSB are more likely to continue to influence outcomes in the future.

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Table 1. Overview of Type of Agents per Type of Challenging Behavior

	Aggressive behavior		Self-injurious behavior		Harmful sexual behavior		Total	
	N 371		N 113		N 145		N 629	
	n (%)		*n* (%)		*n* (%)		*n* (%)	
Agent								
Client	258	(69.5)	86	(76.1)	112	(77.2)	456	(72.5)
Support staff	92	(24.8)	11	(9.7)	27	(18.6)	130	(20.7)
Other	21	(5.7)	16	(14.2)	6	(4.1)	43	(6.8)

Global / specific. Regarding the global/specific dimension, differences were found between the ratings of the causes of aggressive behavior, SIB, and HSB with respect to the agent. That is, the indicated causes of aggressive behavior, SIB, and HSB were rated as global when the client was the agent (e.g., *"He is also schizophrenic"* (global, SIB, participant 13)), whereas the causes of aggressive behavior, SIB, and HSB were rated as specific when support staff were the agent (e.g. *"The client became aggressive, because we (support staff) offered him his medication"* (specific, aggression, participant 2)). Hence, it appears that support staff made attributions in which their own influence regarding the impact of the causes of CB was minor compared to the influence of clients.

Internal / external. Both in cases in which support staff or the client were the agent, the vast majority of the causes of all three types of CB were rated as internal (see Table 2). For example, regarding a cause of aggressive behavior in which support staff were the agent, a support staff member stated: *"If he (client) notices that I (support staff) am tense in that situation* (internal, aggressive behavior, participant 8)". An example of an internal cause of SIB with the client as agent is the following: *"And....he (client) has experienced a lot in the past, sexual abuse, is also physically abused and so on"* (internal, SIB, participant 16)." Hence, causes of CB are, regardless of whom the agent is (i.e., client or support staff), shown to be more originating from within the agent, than from the in the environment, external to the person.

Personal / universal. When support staff were the agent, they frequently reported causes of CB being universal in the case of aggressive behavior and SIB (e.g., *"Or the lights that he (clients) turns off, and at which he reacts if you (support staff member) puts it back on"* (universal, aggressive behavior, participant 10)). Contrary, with respect to HSB, most causes were rated as being personal (e.g., *"I (support staff) was, at that time, one of the youngest in the team, so, maybe, yes. I worked with men or older women, so maybe he saw that mostly, at that time"* (personal, HSB, participant 5)). If the client was the agent, the causes support staff gave are rated mostly as being personal for all three types of CB (e.g., *"He (client) is very much in his under-stimulation and then he kicks off"* (personal, aggressive behavior, participant17)).

Table 2. Number and Percentage of Attributions Made By Support Staff Regarding Three Types of Challenging Behavior for Staff or Clients as Agent

	Aggressive behavior		Self-injurious behavior		Harmful sexual behavior	
	Staff	Client	Staff	Client	Staff	Client
	N 92	N 258	N 11	N 86	N 27	N 112
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Stable	10 (10.9)	102 (39.5)	1 (9.1)	42 (50.0)	11 (40.7)	51 (45.5)
Global	16 (17.4)	212 (82.2)	2 (18.2)	81 (94.2)	6 (22.2)	80 (71.4)
Internal	91 (98.9)	246 (95.3)	11 (100)	83 (96.5)	27 (100)	107 (95.5)
Personal	35 (38.0)	244 (94.6)	3 (27.3)	86 (100)	19 (70.4)	108 (96.4)
Controllable	76 (82.6)	120 (46.5)	8 (72.2)	27 (31.4)	13 (48.1)	83 (74.1)

Hence, when the client was the agent, the results suggest that the causes of CB contain information concerning something unique or idiosyncratic about the client.

Controllable / uncontrollable. Support staff attributions of aggressive behavior and SIB, in which they were the agent, were scored in the majority of the cases as controllable. That is, these attributions indicate that staff can exert some control over the cause to be prevented in the future (e.g., *"That is, I think, if you (support staff) are not on time, you just let him (client) continue and continue"* (controllable, SIB, participant 19)). For HSB, the picture was less clear: in about half of the cases, support staff attributions indicate that they have control over the cause of CB, if they were the agent (e.g., *"But you see, if you (support staff) let it go, the behavior gets worse "* (controllable, HSB, participant 6)). On the other hand, if the client was the agent, support staff attributions of HSB are rated as controllable (e.g., *"That is what I (support staff) say, well, if he (client) turns it on, he does it to provoke"* (controllable, HSB, participant 5)). In aggressive behavior and SIB, support staff most often reported causes which are not controllable for the client (*e.g., "Socially and emotionally he functions at about 6 months of age"* (uncontrollable, aggressive behavior, participant 10)). Hence, the attributions mentioned by support staff indicate that they can exert more control over aggressive behavior and SIB compared to clients, and less control over HSB compared to clients.

Attributional styles per type of CB

Based on the distinct scores on the five attributional dimensions of the LACS (stable/unstable, global/specific, internal/external, personal/universal, and controllable/uncontrollable), attributional styles in this study were operationalized as a composition of the scores on these five dimensions. Only the attributional styles in which the client was the agent were taken into account, due to the smaller number of attributions ($N = 130$) in which support staff were the agent.

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The most frequent attributional styles are presented in Table 3. As can be seen, seven different attributional styles can be distinguished; other potential attributional styles occurred ≤ 2 times on each type of CB and were therefore not included in further analyses. Four out of these seven attributional styles revealed to have significant associations. That is, when the causes of CB were rated as being stable, global, internal, personal, and uncontrollable (attribution style 2), there was a significant association between the style and the type of CB (χ^2 (2) = 13.879, p = .000). Posthoc comparisons revealed that attribution style 2 was seen relatively often in SIB (adjusted standardized residuals = 2.899, p = .004), whereas it was relatively less often seen in HSB (adjusted standardized residuals = -3.047, p = .002). Furthermore, when the causes of CB were rated as being unstable and, in line with attribution style 2, global, internal, personal, and uncontrollable (attribution style 5), there also was a significant association between the style and the type of CB (χ^2 (2) = 9.692, p = .008). Additional posthoc comparisons revealed that attribution style 5 was seen relatively less often in HSB (adjusted standardized residuals = -2.818, p = .005). Hence, regardless of whether the cause of HSB was stable or unstable, the combination of global, internal, personal, and uncontrollable was less common in HSB.

In addition, when the causes of CB were rated as being stable, specific, internal, personal, and controllable (attribution style 3), there was again a significant association between the style and the type of CB (χ^2 (2) = 26.1869, p < .001). Follow-up posthoc comparisons revealed that attribution style 3 was seen relatively more often in HSB (adjusted standardized residuals = 5.104, p < .001), whereas it was seen relatively less often in aggressive behavior (adjusted standardized residuals = -3.040, p = .002). Finally, when the causes of CB were rated as being unstable and, in line with attribution style 3, specific, internal, personal, and controllable (attribution style 6), there was a significant association between the style and the type of CB (χ^2 (2) = 7.289, p = .026). Posthoc comparisons, however, did not indicate any differences.

Discussion

In this study, the attributional styles of 19 support staff members on three different types of CB (i.e., aggressive behavior, SIB, and HSB) of people with MBID were explored and compared. In order to do so, we first analysed the agents per type of CB, next we analysed the attributions on the five causal dimensions of the LACS: stable/unstable, global/specific, internal/external, personal/ universal, and controllable/uncontrollable and, finally we analysed the attributional styles. The results indicated that, in general, support staff more often attributed causes of all three types of CB to the client, compared to themselves, other persons, and situations. Regarding SIB, this is in line with previous research, in which the causes of SIB were mostly attributed to aspects coming from within the person showing SIB (internal; Snow et al., 2007). However, with respect to aggressive behavior, support staff relatively more often also account themselves as agent compared to SIB and HSB. This

Table 3. Attributional Styles of Support Staff with Client as Agent per Type of Challenging Behavior

	Aggressive behavior		Self-injurious behavior		Harmful sexual behavior	
Attributional style	n	(%)	n	(%)	*n*	(%)
1.Stable, global, internal, personal, controllable	31	(12.0)	10	(11.6)	23	(20.5)
2.Stable, global, internal, personal, uncontrollable	61	(23.6)	30	(34.9)	14	(12.5)
3.Stable, specific, internal, personal, controllable	2	(0.8)	0	(0.0)	11	(9.8)
4.Unstable, global, internal, personal, controllable	52	(20.2)	15	(17.4)	28	(25.0)
5.Unstable, global, internal, personal, uncontrollable	55	(21.3)	24	(27.9)	12	(10.7)
6.Unstable, specific, internal, personal, controllable	25	(9.7)	2	(2.3)	15	(13.4)
7.Unstable, specific, internal, personal, uncontrollable	10	(3.9)	1	(1.2)	1	(0.9)

* All other styles (*n* = 89) are only mentioned zero, one or two times on each type of CB

is consistent with the results Nijman and à Campo (2002) found, namely that aggressive behavior is more often caused by interactions compared to SIB. Observations studies of support staff regarding CB (van den Bogaard et al., 2018a; 2018b) also support this finding by showing a more evident role of support staff in triggering aggressive behavior compared to SIB; for HSB this is less evident, as support staff often do not know what triggers HSB (van den Bogaard, Nijman, & Embregts, 2018).

We found that the attributions of all three types of CB are rather similar on the dimensions of global/specific and internal/external. The scores on the stable/unstable, personal/universal, and controllable/uncontrollable dimension differed however between aggressive behavior, SIB, and HSB. Support staff attributed causes of HSB as less controllable, universal, and stable for themselves and more controllable and specific for the client, compared to aggressive behavior and SIB. These differences between aggressive behavior and SIB on the one hand, and HSB on the other hand, are in some aspects comparable to the results found in a study of MacKinlay and Langdon (2009). That is, they found that attributions of sexual offending behavior were rated as less controllable by support staff compared to aggressive behavior. However, they also found that attributions of sexual offending behavior were more stable and less controllable by the client compared to aggressive behavior, which contradicts our findings. As MacKinlay and Langdon (2009) also found that attributions differed for more severe forms of sexual offending behavior, this might explain the difference between both studies, as in our study most attributions were not about severe forms of sexual offending behavior but rather about harmful sexual behavior such as making inappropriate sexual comments.

In addition, although similar for all three types of CB, an important finding of this study is related to the attributional dimension stable/unstable. That is, if support staff were the agent, they mostly attributed causes of CB to be unstable, and thus possible to change.

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However, if clients were the agent, support staff did not always see this possibility to change (i.e., they relatively more frequently rated the cause of CB to be stable). This is an important aspect in interactions between support staff and clients, as attributing CB to stable causes might trigger passivity in clients as well as staff. In this case, it is possible that support staff do not provide adequate feedback on the behavior of the client because they think clients are unable to change their behavior, and thus potentially reduce the effect they can have on the behavior of the client. Educating support staff that CB can be the product of interaction between the person showing CB and its environment might provide support staff important insights in interpreting, and managing, CB of their clients. Indeed, Williams and colleagues (2012) showed that it is possible to change support staff attributions after training.

The results further indicated that, with respect to the attributional styles - in this study operationalized as a composition of the scores on the five attributional dimensions - seven common styles can be distinguished. Interestingly, in 40% of the cases, these attributional styles consisted of the stable, global, and internal dimension. Experiencing challenging behavior might be a negative event for support staff. The phenomenon of attributing causes (i.e., stable, global, and internal) to negative events, is hypothesized to be "depressogenic" and assumes that support staff as well as clients have little influence to prevent such events (Abramson et al., 1989). Given that the impact of CB on support staff can be enormous, it is evident that support staff might have difficulties to understand and respond to CB (Whittington & Burns, 2005), that they experience negative emotions like fear and sadness (Bromley & Emerson, 1995; Zijlmans, Embregts, Bosman, & Willems, 2012), in addition to feeling threatened (van den Bogaard, Palmstierna, Nijman, & Embregts, 2018a), emotionally exhausted (Mills & Rose, 2011; Rose, Horne, Rose, & Hastings, 2004) and stressed (Mitchell & Hastings, 2001). In this study, we focussed on attributional styles of support staff without relating them to data on for example depression and emotional exhaustion, which would be recommendable for future research.

The findings of this study should be considered in the light of several limitations. Firstly, we only interviewed support staff on their attributions regarding CB. In stating that CB is an interaction between the client and its environment, it would be recommendable in future studies to also interview clients and to take into account their views regarding the causal dimensions of their CB. Next, we asked support staff to rate the incident of aggressive behavior, SIB, and HSB that they remembered most, regardless of when these incidents had taken place. The passing of time may have influenced the way support staff thought about (the causes and triggers of) the reported incidents. Future research should focus on incident-interviews with recent incidents of both the support staff and clients involved, to get more accurate and double-viewed information of the causal dimensions of CB. Furthermore we differentiated on three types of CB (i.e., aggressive behavior, SIB, and HSB), but, based on the data, it was not possible to differentiate between, for example, verbal and physical aggression. Both types of aggressive behavior have a different impact on support staff (van den Bogaard et al., 2018a), and they might generate different attributions. For this reason,

it is interesting to make a distinction between different types of aggressive behavior in future studies.

In sum, this study indicated that, in addition to differences in attributions of support staff regarding causal dimensions of three types of CB (i.e., aggressive behavior, SIB, and HSB), there are also differences in attribution styles regarding these types of CB. Interestingly, attributions are likely to shape the behavior of support staff and give rise to their ideas of possible causes and preventive options of the CB (e.g., Hill & Dagnan, 2002; Stanley & Standen, 2000). Therefore, training and coaching support staff in understanding their own attributions and related behavior, and more specific what their influence is on the existence and maintenance of CB, will help support staff to react more effectively on CB.

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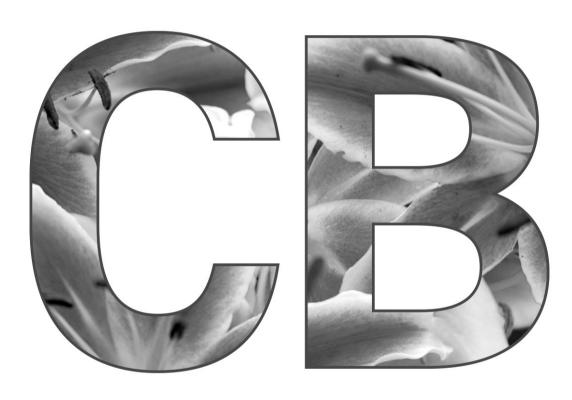
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Appendix 1. Definition of causal dimensions used in the Leeds Attributional Coding System

Causal dimension	Definition of causal dimension
Stable/unstable	Stable causes are causes that are likely to continue to influence outcomes in the future
Global/ Specific	Global causes are those cause that are likely to have a significant impact on several different outcomes
Internal/ external	Internal causes are those believed to originate from within the person being coded
Personal/universal	Personal causes contain information concerning something unique or idiosyncratic about the person being coded
Controllable/ uncontrollable	Controllable causes are causes in which the person thinks he could have influenced the outcome

Chapter 8

General Discussion

The main objective in this thesis was to get a better understanding of aggressive behavior, self-injurious behavior (SIB), and harmful sexual behavior (HSB) of people with mild intellectual disabilities or borderline intellectual functioning (MBID). People with MBID are characterized by some significant features. First, people with MBID have a higher risk to develop both psychiatric disorders and CB compared to the normal population (Baldry, Clarence, Dowse, & Trollor, 2013; Chester, Völlm, Tromans, Kapugama, & Alexander, 2018; Dickens, Picchioni, & Long, 2013; Gigi et al., 2014; Hassiotis et al., 2008; O'Shea et al., 2015). O'Shea and colleagues (2015) for instance, reported that people with a mild ID in a secure mental health hospital, had a rate of 83.5% regarding aggressive behavior, while this was 61.3% in people without ID. Moreover, Hassiotis and colleagues (2008) showed that people with borderline intelligence showed higher rates of psychiatric disorders (i.e., neurotic disorders, substance misuse and personality disorders) compared to the typical developing population. Besides that, ID are often invisible or not recognized (Kaal, Nijman, & Moonen, 2015; Wieland & Zitman, 2016), resulting in clients with ID residing in many different settings, such as general mental health settings, specialized addiction services or prisons (e.g., Hayes, Shackell, Mottram, & Lancaster, 2007; Kaal, Nijman, & Moonen, 2015; Langdon, Clare, & Murphy, 2011; Nouwens, Smulders, Embregts, & van Nieuwenhuizen, 2017; Søndenaa, Rasmussen, Palmstierna, & Nøttestad, 2008). For example, people with MBID are overrepresented in the criminal justice systems (Langdon, Clare, & Murphy, 2011) and due to some risk factors (e.g., lower socioeconomic status and co-occuring psychiatric disorders; Dickson et al., 2005) have higher rates (up to five times for men and 25 times for women) for offending (Hodgins, 1992). As these services are not always specialized in supporting people with MBID with specific needs, it can be questioned if they receive adequate care and support in those cases. Support staff, in general mental health care, are not always trained to recognize the MBID and also miss expertise to treat their co-occurring psychiatric problems (Chen et al., 2006; Stolker et al., 2001). As people with MBID are still understudied in research, more research is required to get to know more about this population, to attune care and support to their wishes and needs.

In this thesis, the characteristics of aggressive behavior (Chapter 2), self-injurious behavior (Chapter 3) and harmful sexual behaviors (Chapter 4) of people with MBID and co-occurring psychopathology were explored using structured clinical assessment instruments. To be more specific, incidents of aggressive behavior were measured using an adapted version of the Staff Observation Aggression Scale – Revised (SOAS-R; Nijman et al., 1999), which was termed the SOAS-R-ID (Nijman & Palmstierna, 2005). Support staff mapped incidents of SIB using the Self-Harm Scale (SHS; Nijman & Palmstierna, 2004; Nijman, Palmstierna, van den Bogaard, & Embregts, 2016) and HSB-incidents were reported by using the Harmful Sexual Behavior Scale (HSBS; van den Bogaard, Nijman, & Embregts, 2013). The second goal was to gain more insight in the attributions (causes) regarding CB from people with ID themselves, as well as support staff. In Chapter 5, a systematic literature review was executed on the attributions of people with ID regarding their own or other clients' behavior. Next,

people with ID were asked, in group interviews, about the antecedents, characteristics and consequences of incidents of aggressive behavior (Chapter 6). Finally, this thesis also explored the causal beliefs (attributions) of support staff related to aggressive behavior, SIB and HSB (Chapter 7). Support staff were individually asked about their experiences regarding incidents of aggressive behavior, SIB and HSB.

Main results

First, the characteristics of the three studies focusing on aggressive behavior, self-injurious behavior and harmful sexual behavior will be addressed (part I). Following this, the results on the three studies on the attributions of CB will be discussed (part II).

Characteristics of challenging behavior

Aggressive behavior. For aggressive behavior a total of 210 unique incidents were reported by support staff during a nine months observation period, using the SOAS-R-ID. The rates of aggressive behavior were comparable to other studies performed in similar settings and studies in general mental health care (Tenneij & Koot, 2008; Nijman et al., 2005), namely 8.9 incidents per client per annum. The majority of the reported incidents (53.3%) of aggressive behavior had no physical or psychological consequences according to the reporting support staff. In case support staff did report consequences, these were mostly (almost 80%) of a psychological nature (i.e., feeling threatened). In line with these findings, the reported aggressive behavior mostly consisted of verbal aggression (57%), followed by physical aggression (27%) and property aggression (10%).

Although 22 of the 33 participants (67%) displayed aggressive behavior at least once according to support staff, a minority of the people who displayed aggressive behavior ($n = 4$) caused over half of all the incidents of aggressive behavior, which is also in line with earlier research focusing on aggressive behavior in the Netherlands (e.g., Tenneij & Koot, 2008). This finding indicates that it may be efficient to invest time and resources in analyzing the circumstances and potential triggers of aggressive behavior of a small group of clients who engage in aggressive behavior repeatedly. The triggers of aggressive behavior were mostly of interactional nature (55%), aimed at support staff (77.1%) or other clients (19%). In 29% of the incidents, support staff did not know what caused the aggressive behavior. In order to stop the aggressive behavior, support staff mostly used verbal techniques. However, more intrusive techniques (e.g., holding) were also used in about a quarter of the cases. Aggressive behavior most often took place in area's with more people being around (e.g., entrance of the office of support staff, kitchen, or living room). People with MBID who showed aggressive behavior ($n = 22$) were compared with people with MBID who did not show aggressive behavior ($n = 11$). No differences were found on the variables measured (e.g., gender, age, adaptive abilities). These findings point out towards the crucial role of the environment in

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triggering and maintaining aggressive behavior and suggests the importance of focusing on both the person showing the CB and the environment in which it occurs, when intervening.

Self-injurious behavior. Support staff reported 104 incidents of SIB during the nine months of data-collection. The rate of SIB, 4.0 incidents per participating client annually, is higher compared to the prevalence rates in other studies in a comparable setting (Tenneij & Koot, 2008) and in other settings (e.g., mental health setting; Nijman & à Campo, 2002). Eight of the 33 clients (24%) displayed some form of SIB. SIB mostly consisted of cutting and head banging. Two of the eight participants caused over 85% of all the SIB incidents. So, again this seems to suggest focusing preventive measures on a small selection of clients may be efficient in reducing the number of episodes of CB on wards caring for clients with a combination of ID and psychiatric disorders. Triggers were related to both intrapersonal factors (34%; e.g., psychological state), as well as interpersonal factors (31%, e.g., interactions with environment) and in 31% of the cases unclear for support staff. According to support staff, most incidents (62%) had no or only 'minor' consequences. The other incidents (38%) resulted in severe injuries, in which medical assistance was necessary (e.g., cuts). To stop SIB, support staff mostly used restraining techniques, followed by verbal interventions. SIB most often took place in a private room of the client, without the presence of other people, which is in line with results from earlier studies in which SIB most often takes place in private places (Nijman & à Campo, 2002). Despite the mostly hidden nature in which people with ID display SIB, the impact of the SIB on the environment (e.g., being confronted with severe injuries or an unconscious person, due to strangling) and the sometimes severe measures support staff have to take to stop this behavior, asks for more attention towards the (psychological) support of support staff.

People with MBID who showed SIB were compared with people with MBID who did not show SIB. People with MBID who showed SIB were more often female, diagnosed with a borderline personality disorder (BPD) and had better communication skills compared to the control group. The association between a BPD and SIB is also found in earlier research in people with psychiatric problems (Nijman & à Campo, 2002; Zanarini et al., 2008). The association between SIB and gender was not found in other studies (Lowe et al., 2007; McClintock, Hall, & Oliver, 2003). Last, the association between SIB and communication skills was not in line with earlier studies (Lowe et al., 2007; McClintock, Hall, & Oliver, 2003). Besides, analysis of the two clients who displayed most incidents of SIB showed that their SIB differed on type of SIB, time of the day the SIB took place, consequence of and measures to stop the SIB. These findings suggests the importance of a more individualized analysis of the SIB incidents, in order to intervene most effectively.

Harmful Sexual Behavior. For HSB, support staff reported 34 incidents, caused by 8 of the 33 participants (24%). Clients who displayed HSB mainly showed inappropriate (non-directed) communication, followed by (non-directed) exposure and inappropriate touching

of support staff and other clients. Three participants were responsible for almost 80 percent of the reported HSB incidents. In 62% of the incidents support staff did not know what triggered the HSB. If support staff knew what triggered the HSB, the reasons given were mostly interactional (21%), aimed at support staff and other clients. Support staff mostly (71%) did not report any consequences related to HSB incidents. In the remaining part of the incidents of HSB support staff reported negative psychological consequences related to HSB (i.e., feeling threatened or uncomfortable). Support staff mostly distracted the clients and used verbal techniques to stop the behavior. This is also seen in other studies (e.g., Rushbrooke, Murray, & Townsend, 2014) focussing in HSB.

These findings seem to signify a somewhat different picture of HSB compared to aggressive behavior and SIB. For example, the triggers are mostly unclear and other consequences and measures to stop the behavior are reported. It may be valuable to educate support staff towards the understanding of HSB and the processes that accompany HSB both in people showing it as well as in themselves (e.g., co-occurring emotions and reactions towards the behavior).

To summarize, for all three types of CB that were studied, it was found that a limited selection of clients were involved in a majority of the documented incidents. This suggests that prevention should be aimed at analyzing the triggers and reasons for engaging in incident behavior in this high risk group with the aim to formulate interventions. The current study shows promising results to use the three registration forms that were adapted or designed for this population. These forms can be useful for analyzing the circumstances and triggers that are associated with CB in clients with MBID, and to formulate and test the effects of preventive measures that aim at reducing CB.

Besides, for all three types of CB a significant amount of triggers is unknown to support staff. This suggests that on the one hand it would be recommendable to train staff in the principles of the functionality of behavior, including CB. On the other hand, it would be advisable to also incorporate the views of the persons with MBID who show CB to complete the picture of their CB. Asking people with MBID about the triggers and consequences can be complementary to the views of support staff, to get as much information about the CB as possible, in order to intervene in the most effective way.

Attributions of people with MBID and support staff

So far, studies related to attributions regarding CB mainly focused on the perspectives of proxies (e.g., support staff). In this thesis, two studies have focussed on the attributions of people with ID. A systematic review (Chapter 5) about the attributions of people with MBID about their own and other clients' behavior and a qualitative interview study (Chapter 6) focussing on the attributions of people with MBID about aggressive behavior in a forensic psychiatric setting. One further study has focussed on the attributions and attributional styles of support staff regarding aggressive behavior, SIB and HSB (Chapter 7).

In the systematic review, 12.882 articles were selected of which 10 studies were included. These 10 studies had reported about the attributions of people with ID and co-occurring

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forensic and psychiatric problems related to their own or other clients' actual CB. The studies focussed on four types of behavior, SIB, aggressive behavior, offending behavior and CB not specified. People with ID attributed causes of CB to interpersonal factors (i.e., factors related to interactions with other persons, like support staff or other clients or the society and its structure (Isherwood, Burns, Naylor, & Read, 2007), environmental factors (i.e., factors related to the physical environment), and intrapersonal factors (i.e., personal characteristics of a person, Haydon-Laurelut et al., 2017 or factors coming from within, Isherwood et al., 2007). While only a small amount of studies report about the attributions of CB of people with ID, these views show similarities with the views of support staff. This suggests that the views of people with ID regarding the causes of CB should be taking into account more often, as a valuable source of knowledge.

In the qualitative interview study (Chapter 6) we asked people with MBID and co-occurring forensic and psychiatric problems residing in a forensic psychiatric hospital to describe incidents of aggressive behavior (e.g., what triggered aggressive behavior, what kind of aggressive behavior was displayed, and what happened after the aggressive behavior). Based on the transcriptions of interviews, attributions on interpersonal, environmental, and intrapersonal themes could be distinguished, with a great diversity of attributions on each theme. Clients without an ID in a forensic psychiatric care setting reported the same motives regarding aggressive behavior (Lewis & Ireland, 2019). Again, these findings suggest that people with MBID in forensic mental health settings can be an important source of knowledge related to the causes of their aggressive behavior. Therefore, also in forensic mental health settings, people with ID should be asked about their views more often.

 Related to the agent (i.e., the person or situation in the cause of the attributions), clients mentioned an almost equal distribution between their environment and themselves causing aggressive behavior. The scores on the five dimensions of the Leeds Attributional Coding System (LACS, Stratton et al., 1988) differed related to the person mentioned as agent, on the stability and controllability dimensions. In case the client was mentioned in the cause of the aggressive behavior, they attributed it as global (i.e., having a significant impact on several outcomes) and under less control of the person showing the behavior, compared to attributions in which other people were mentioned in the cause.

Finally, in Chapter 7 we interviewed support staff with respect to three different types of CB, aggressive behavior, SIB and HSB, with the same interview schedule as used in the study in which people with ID were asked about their attributions (Chapter 6). As not only attributions of CB, but also the attributional styles (i.e., patterns on the attributional dimensions) give more information about the way a person thinks related to the CB, both were explored regarding the three different types of CB. Support staff mostly (more than 70%) indicated intrapersonal factors of people with ID to be causing CB, followed by interactions with, behavior or characteristics of support staff (20%) and other persons and situations (almost 7%). In line with earlier studies (e.g., Nijman & à Campo, 2002; Snow et al., 2007), the distributions of agents per type of CB differed. Support staff were less likely to

be mentioned as agent in SIB, but more likely to be mentioned as agent in aggressive behavior and HSB. Besides, in this study, seven attributional styles could be distinguished, which in 40% contained the stable, global, and internal dimensions. Scores on these dimensions can give an indication of the impact of CB on support staff, as these attributional styles are indicative for staff not feeling they can exert control over the CB. Evidence from earlier studies reported the difficulties staff might experience in understanding and responding to CB (Whittington & Burns, 2005), which coincide with negative emotions like fear and sadness (Bromley & Emerson, 1995; Zijlmans, Embregts, Bosman, & Willems, 2012), feeling threatened (van den Bogaard, Palmstierna, Nijman, & Embregts, 2018), emotionally exhausted (Mills & Rose, 2011; Rose, Horne, Rose, & Hastings, 2004) and stressed (Mitchell & Hastings, 2001).

To summarize, people with MBID mention the same themes causing the aggressive behavior as people without ID and support staff, however there seems to be a different in the person they think is causing the aggressive behavior. People with MBID almost equally distribute the causes of aggressive behavior towards their environment and themselves, while support staff more often attribute causes of all three types of behavior towards the person with MBID. As the review in this thesis shows, only a small amount of research focusses on the perspective of people with ID regarding the causes of CB. These results call for a greater involvement of people with MBID in both research and clinical practice and the need to address these sometimes opposing views. The perspective of people with MBID, as well as that of support staff should therefore be taken into account, which will help to get more insight in these sometimes complex interactions.

Methodological reflections

Research in clinical practice. Research in clinical practice differs significantly from research in controlled settings. First, conducting research in a clinical setting can give insights in real life situations and behaviors, but it can also have an impact on the participants available (convenience sampling), the process of the research, the methodologies used, and the generalizability of the results. In this thesis we were dependent on the willingness of the potential participants who were at the treatment facility at the moment of our research. Reasons for not taking part in our research differed: some people with MBID did not take part because the research could interfere with their personal well-being, while other people with MBID did not take part because they were suspicious about giving information, because it was also being recorded. By doing research in clinical practice it should be taken into account that incorporating people with MBID who have complex needs requires careful planning in cooperation with the ones who support them, in which the goal of the research, the research steps and practical issues related to the execution of the research (e.g., time investment, incentives, location) are explained in an accessible way (Haydon-Laurelut et al., 2007). This can enhance their participation and consequently add to the already existing knowledge base of CB of support staff. There are already some developments in research

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in which the added value of asking people with ID about their views is acknowledged. For example, support staff and clients did not always agree on the causes of specific incidents of CB (Duxbury & Whittington, 2005). Besides, support staff are not always able to mention the cause of CB (Bowers et al., 2011) which makes it valuable to take into account both perspectives. It is also valuable to incorporate the perspective of clients, as this increases the involvement and engagement of people with ID in services and treatment which may impact their motivation related to this (Morrisey et al., 2017). Related to research, it would be interesting to incorporate the views of people with MBID as informants, or co-researchers (Nind & Vinha, 2014), as this not only helps to attune research questions to their wishes and needs, but also to develop research methods that are applicable to this population.

Besides, conducting research in clinical practice is affected by the events on a ward and in teams. As such, support staff indicated high workload, which sometimes resulted in forgetting or not having enough time to report incidents. In addition, observational instruments require support staff to be around when incidents happen. Related to the specific types of CB (e.g., SIB) and interaction between clients, support staff was not able to see all the incidents, resulting in underreporting of incidents. On the one hand, this is a challenge of doing research in clinical practice as some types of behavior are difficult to observe because of their low frequency or hidden nature. Other instruments, like video recording or conducting interviews, could then be used to get information on these types of behaviors. On the other hand, doing research in clinical practice, gives a better insight in the natural context in which behavior occurs. It not only provides scientific information, but also practical information to the CB of a specific client, which can help to immediately use the information to intervene and to get direct feedback on the applicability of the instruments (Bickman & Rog, 2008).

Next, executing research in a clinical setting also has a stimulating effect. Asking teams to report incidents highlights the importance of documenting (and analyzing) incidents and may facilitate teams to discuss behavior of clients, but also to reflect on the role support staff may play in maintaining and reinforcing CB. As is known from earlier research, support staff are not always aware of their contribution related to triggering and maintaining CB (Hastings et al., 2013). Completing an incident form every time a client displays CB can potentially impact one's own behavior, as the reporting forces one to overthink the behavior of the client, but also one's own behavior.

In the studies related to extracting attributions, we asked support staff and people with MBID to report and talk about real incidents. Real incidents can be a rich source of information regarding the perspective of support staff and people with MBID, they do evoke other reactions and feelings (Lucas, Collins, & Langdon, 2009) and positively impact the ecological validity of the results (Wanless & Jahoda, 2002). However, asking people about their experiences regarding a specific incident of CB also relies on their observational skills and their memory capacity.

Implications

The results of the six studies in this thesis have some implications. First we will describe some implications for future research, followed by implication related to policy and practice of people with MBID and CB.

Scientific implications

In the various studies we used adapted or newly designed instruments to get more insight in the CB of people with MBID within the natural context in which it occurred. This was important, as there seemed to be hardly any instruments available specifically for this target population and some forms of CB (e.g., SIB and HSB), also taking into account the context in which this behavior was displayed. The three used instruments may be helpful for future studies to gain insight in the characteristics of these forms of CB of people with MBID, but also in the environment in which the behavior occurs. It has given insight in the behavior of support staff, preceding the CB, but also in the way they respond to the CB of the client. However, it should be acknowledged that in this thesis data related to the psychometric properties were only gathered for the SOAS-R-ID (interrater reliability and validity), and not for the other two assessment instruments (SHS and HSBS). Future research is necessary to further investigate the psychometric properties of the SOAS-R-ID, and to explore the reliability and validity of the SHS and HSBS. Firstly, this can be done by comparing the outcomes of these three observation instruments with other instruments documenting CB. For example, data regarding aggressive behavior on both the SOAS-R-ID and Modified Overt Aggression Scale (MOAS, Kay et al., 1988) could be compared, as the MOAS is already often used to rate aggressive behavior in people with ID (e.g., Oliver, Crawford, Rao, Reece, & Tyrer, 2007). Secondly, by expanding this study across different settings in which people with MBID and CB reside (e.g., (forensic) mental health care or prisons) to generate a larger data set but also to explore in what way a different context influences CB. Such a larger data set also may make it possible to refine the scoring system based on the severity estimates of support staff, in a comparable way as was done in the study of Nijman and colleagues (1999) regarding the SOAS-R. Besides that, constructing a larger dataset makes it possible to compare potential variables that influence the existence and maintenance of CB of specific subgroups of clients. Generating more data on repetitive incidents from the same clients may also help to react and intervene in a more personalized way, which can help to reduce CB in the end.

Related to the studies focusing on attributions, there are also some implications. First, the studies focusing on the attributions of both people with MBID and support staff were both carried out in one treatment facility. Future research should expand to other facilities in which the studies are executed, as this can give insights in the influence of different environment on the attributions of people with MBID and support staff. Besides, it would be interesting to ask people with MBID, but also support staff, about a more diverse range of

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challenging behavior. People with ID were only asked about aggressive behavior, but as the observational studies showed, different types of CB are characterized by different antecedents and consequences. Support staff were asked about three different types of CB, but for future research it may also be recommendable to distinguish attributions of more fine-grained subtypes of aggression (e.g., verbal, property and physical aggression), as these different subtypes could possibly generate different attributions. Last, it would be interesting to generate larger datasets, as it would be interesting to examine if there is a connection between the type of CB, the attributions, attributional styles, and person giving the attribution. By doing this, more information related to specific subgroups and behaviors can be extracted, which helps to attune support and treatment more to the specific causes per type of behavior mentioned by people with ID and their support staff members.

Implications for policy and practice

Fairly recently (2016) the Dutch act '*Quality, complaints and disputes in care' [Wet kwaliteit, klachten en geschillen zorg (Wkkgz)]* came into effect, which influenced and will influence care and support for people with MBID and CB. Based on this act every employee in health care is required to report (in the file of the client) the nature, the circumstances and the time of incidents that has led, could have led, or still could lead to significant consequences for the client. Health care organizations are obliged to have an internal procedure to register and analyze these incidents and following this, to improve their health care process (Vilans & Zorg Zaken Groep, 2017). In this thesis, we developed or adapted three observational assessment instruments that can be used by care organizations to report incidents of CB. These instruments are helpful in implementing guidelines, such as described in the NICE guidelines (2015): '*Challenging behavior and learning disabilities: prevention and interventions for people with learning disabilities whose behavior challenges*'. This multicomponent guideline, which has much similarities with the Positive Behavioral Support framework, highlights the importance of increasing our understanding of the CB of an individual based on the assessment of the behavior in its context. This is necessary in order to intervene adequately, and prevent and reduce the CB within a context focused on improving the quality of life, inclusion, participation, and the defence and support of valued social roles of the people with ID who display CB (Gore et al., 2013). The structured clinical assessment instruments in this thesis might help clinical practise to implement these guidelines. The SOAS-R-ID (Nijman & Palmstierna, 2005), SHS (Nijman & Palmstierna, 2004; Nijman, Palmstierna, van den Bogaard, & Embregts, 2016), and HSBS (van den Bogaard, Nijman, & Embregts, 2013), are easy to use, help to identify the clients who display the different types of CB, and may be helpful in getting a better understanding of the three types of CB within their context in which they occur.

Based on the results of the three studies, using the instruments, it is shown that the majority of those CBs are displayed by a minority of people with MBID. We therefore recommend care organization to explicitly focus on those people who repeatedly display aggressive, self-

injurious and harmful sexual behavior. Exploring the triggers and consequences of a clients' CB in the context in which it occurs is important in order to develop an individualized care plan (Toogood, Boyd, Bell, & Salisbury, 2011) and to formulate preventive measures. The three observational instruments can be used as a first step in the functional assessment of CB, as they give a rather global picture of the CB of a person within its context (e.g., which persons show CB, what kind of CB are shown, what is the impact of the CB regarding support staff). This analysis can be the start for further exploring the CB of specific clients and influencing factors (e.g., the persons' abilities, co-occurring disorders) and to initiate intervention to change and manage the CB. As is known from previous research, that behavioral interventions are often used and effective in the reduction of CB. Again, the observational instruments could help to monitor and evaluate treatment interventions. Especially formal behavioral interventions result in positive outcomes for people with ID and MBID, as still many interventions are informal and do not results in great outcomes (e.g., Feldman, Atkinson, Foti-Gervais, & Condillac, 2004). Research and clinical practice, on this aspect, should work closely together, to develop interventions that suit the needs of the clients and persons giving the interventions, but also have a thorough evidence base.

In the Netherlands, several developments related to assessment and treatment interventions for people with ID and CB exist (e.g., Embregts & Zijlmans, 2016; Hoitzing, van Lankveld, Kok, & Curfs, 2010; van de Weerd & van Wouwe, 2015). Tournier, Hendriks, Hastings, Jahoda and Embregts (in preparation) for example are executing a research to gain insight into the key elements of a treatment intervention called Triple-C. In their research, Tournier and colleagues developed a logic model to describe the intervention and its underlying assumptions. The logic model provides insight into the key elements of the approach and relations with existing theory. It is considered as a first step to define the underlying logic of a practice-based intervention and a first step to inform research to test the potential effectiveness of Triple-C. In the future it would be recommendable to incorporate structured clinical assessment instruments in different treatment interventions, specifically designed for people with mild to borderline ID and CB.

Connecting scientific, clinical and expert-by-experience knowledge. The acknowledgement of the gap between scientific knowledge and knowledge from clinical practice (Drahota et al., 2016) is the first step towards integrating these types of knowledge towards evidence-based practice (EBP; Sakkett et al., 1996; Roulstone, 2011), that optimises the quality of care and support for people with ID (Schalock et al., 2008; Reinders & Schalock, 2014). In EBP, scientic knowledge, knowledge from clinical experts and knowledge of service-users is combined (Embregts, 2018). From previous research (e.g., Kersten, Taminiau, Schuurman, Weggeman, & Embregts, 2018) the key role of professionals in knowledge sharing and applications is already acknowledged. There is also increased awareness of the value of experts by experience, in stimulating them to express their feelings, thoughts and wishes and incorporating their views in policy, practice and research (Thornicroft & Tansella, 2005). For

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example, in January 2020 the '*Care and Coercion act*' will come into effect, with the aim to reduce involuntary care for people with ID and people with psychogeriatric problems. This act does not differentiate between the different forms of involuntary care and states that the perspective of the client is leading. If a person with ID or their representatives do not agree, or if the person with ID shows resistances related to the given care or supports, it is defined as involuntary. Another example is the initiative of the Dutch Government, called: the National Program Disabled People. This program aims to develop, share and applicate knowledge to improve the quality of care for people with ID, multiple disabilities and acquired brain injury and improve their participation and right of say in society. As a requirement to get funding for this program, people with and without ID have to collaborate in research together (Embregts, Taminiau, Heerkens, Schippers, & van Hove, 2018). The last example is the job application of two experts-by-experience Tilburg University (Collaborative Center Living with an Intellectual Disability, department Tranzo). This initiative is based on the fact that by doing practice-based research, every source of knowledge (experience based, professional and scientific knowledge) is of equal value (Embregts, 2018). Incorporating these three sources of knowledge will provide answers, which will attune more to what is needed in clinical practice and education related to the care for people with ID. Participation of people with ID also leads to more enriched research process and its outcomes (e.g., Frankena, Naaldenberg, Cardol, Linehan, & Van Schrojenstein Lantman-De Valk, 2015; Puyalto, Pallisera, Fullana, & Vilà, 2016; Woelders, Abma, Visser, & Schipper, 2015) and positive feelings in people with ID (e.g., able to help other (Flood, Bennett, & Melsome, 2012), being valued (Bell & Mortimer, 2013; Nind & Vinha, 2014), feeling confident and increase self-esteem (Flood et al., 2012; Iriarte, O'Brien, & Chadwick, 2014). Despite these positive developments to enhance participation and inclusion of people with ID, people with ID who display CB often experience greater barriers related to their participation and inclusion (Banks et al., 2007). Only recently, the views opinions of people with MBID and CB, especially those residing in forensic health care settings, are incorporated in research and clinical practice. Based on the results of the studies in this thesis, we recommend that people with MBID and CB should always, after every incident they display, be asked what they think caused the CB. Only if this incident interview is too confrontational, has a significant impact on the psychological well-being of the client, or is in any other way contra indicative for the well-being of the client or their environment, it can be decided to transpose the interview.

Besides, it is important to ask people with MBID about their CB in an open, non-judgmental way, as this will generate the most representative view. This is important as the views of support staff and people with MBID can differ, but also because asking people with MBID can have a positive relation with their motivation to change their behavior. This will not only provide information related to the triggers, which can be used to prevent CB in future, but it will also involve people with MBID in their own treatment process. Stimulating people with ID expressing their feelings, thoughts, and wishing (Thornicroft & Tansella 2005) within an autonomy-supportive environment (i.e., an environment in which support

staff minimises control while supporting clients' initiatives and accepting their perspective; Williams et al., 2006), might help clients to become more motivated to change their CB. That is, in a study of Frielink et al. (2018) among people with MBID, it is shown that perceived autonomy support was positively associated with high quality forms of motivation (i.e., autonomous motivation), the three basic psychological needs (autonomy, relatedness and competence) and well-being. For example, an environment who makes a person with ID feel more autonomous, stimulates him or her to be involved and engaged in their own treatment (Morrissey et al., 2017), which can lead to enhanced treatment outcomes. Support staff, but also other formal and informal network members, should therefore encourage people with MBID and CB to give their views regarding the causes of CB, which can help them to stop showing the behavior and focus on the more positive behaviors.

As CB is often seen as the product of interaction between the person showing it and their environment, both perspectives, of support staff and clients, should be taken into account (Bos, Kool-Goudzwaard, Gamel, Koekkoek, & van Meijel, 2012; Grol & Kool, 2019; Van Hecke, Vanderplasschen, Van Damme, & Vandevelde, 2019). Getting to know each other perspective has some advantages: first, staff can become more aware of their contribution in relation to triggering and maintaining CB. Getting to know the other perspective can help to not only discover the behavioral cues by observation, but also the emotional cues by asking the perspective of the other person (Bowers et al., 2011). Secondly, for clients it would also be helpful to express their views and to become involved and engaged in services and therapies, which will possibly result in increased motivation, which can be a precursor for progress in these areas (Morrissey et al., 2017). Moreover, talking about the experiences and emotions related to the CB of a person with ID might be helpful for them to gain more insight in their own emotions and feelings and to manage these emotions and feelings, which makes them less dependent on their environment (Taylor & Novaco, 2005), as persons with ID lack of psychological resources to cope with stressful events (van den Hout et al., 2000).

Training. Staff are often the key agents in the lives of people with MBID, as they support and take care of the client (Eagar et al., 2007), and also play a key role in delivering behavioral interventions (Allen, 1999) to prevent and manage CB. Therefore support staff should be equipped with the right knowledge, skills and attitudes to deal with behavior that challenges (NICE Guidelines; The National Collaborating Centre for Mental Health in the UK, 2015). The results of the observational, as well as the attributional studies can become a part of a training program. It can make support staff aware about the way they conceive CB and their forthcoming reactions. In earlier developed training programs for support staff of people with ID who show CB (e.g., Willems, Embregts, Hendriks, & Bosman, 2016; Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2011) it is shown that training support staff helps them to attune their reactions more to the behavior of the client. Giving support staff insight in their own emotional reactions can impact their behavior toward clients with ID and CB in a positive way (Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2015). Supervising and

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coaching should focus on support staff becoming aware of the subjective impact of CB on themselves (e.g., their negative emotions), and help them, through self-reflection and self-insight, to react related in a CB reducing way (e.g., less controlling behavior) (Willems et al., 2016).

Besides, it is important to bear in mind that for a training to be effective, there a several components that need to be taken into account (Oorsouw, Embregts, Bosman, & Jahoda, 2009). In their meta-analysis, van Oorsouw and colleagues describe that it is important to combine in-service training with coaching-on-the-job; to use multiple techniques in in-service formats, and to incorporate verbal feedback, praise and correction in coaching-on-the-job formats. Finally, to increase the effectiveness of training program, the developers should carefully prepare the training (e.g., goals, format, and techniques used).

As people with ID indicated and as becomes clear from research, people with ID should be trained in adopting better strategies to manage their behavior that is challenging (NICE, 2015). There is only a small group of people with ID and CB who receive proactive interventions for their behavior (Ruef, 2002), while this could help them to reduce their behavior by themselves (Clare, 1993). As becomes clear in the study regarding the attributions of people with ID, they are capable of formulating the process that leads to CB and this information may also be used in interventions.

Last, it would also be recommendable to not only train both groups separately, but integrate people with ID and support staff into a training program, as both can learn from each other (NICE, 2015).

Synchronizing instruments. It would also be recommendable to synchronize the content of these observational instruments in already existing reporting systems in health care organizations. Although every health care organization has a system to report incidents (personal communication), not all of these systems are based on instruments that are studied before and thus the psychometric qualities of these instruments is unclear. If health care organizations all use the same instruments, it would generate a rich source of information, not only to analyze incidents of individual clients, but also to analyze processes in teams and organizations. This information, on a larger scale (i.e., inter-organizational), could then be used to get a clearer picture of CB in the care for people with MBID and CB. A first step, on a national level, towards synchronizing outcomes, and using data on a larger scale, are the developments related to the Minimal Data Set for people with ID (MDS, Kunseler, Schuengel, Embregts, & Mergler, 2015) and developments in generating 'big data'. One of the main goals of these developments is to generate a nation-wide large scale database, in which information can be analyzed on a broader scale.

General conclusion

The aim of the present thesis was to contribute to a better understanding of three different forms of CB (i.e., aggressive behavior, SIB and HSB) in people with mild to borderline ID. The results of the present thesis give information on CB from two perspectives; support staff and people with MBID. Based on the observational data it can be concluded that the three types of behavior are displayed by a minority of people with MBID. The results also show that the clinical pictures of the CB of these persons differ. It is therefore advisable, in research and clinical practice, to focus on this group of people.

Based on the interview data it can be concluded that the three types of CB are associated with different attributions in support staff. Besides, the study regarding the attributions of people with ID indicate that they are capable in giving their view related to their own and other clients' aggressive behavior. Related to the results of the studies focusing on attributions, we advise to ask people with MBID more often to give their opinion and view and to assemble their views with the views of those who support them, to attune care and support to their wishes and needs.

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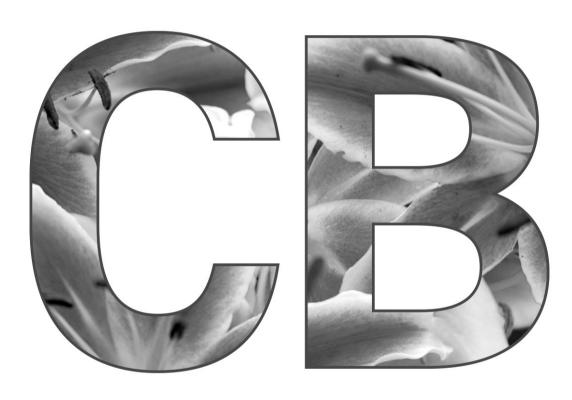
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Summary

People with intellectual disabilities (ID) are at greater risk of displaying challenging behavior (CB) compared to people without ID. Frequently reported types of CB are aggressive behavior, self-injurious behavior and harmful sexual behavior. Prevalence rates of CB vary between 10 and 60%, due to the type of behavior studied, the setting of the studies, and the method of data collection used. CB has negative physical, psychological, and social consequences for the person showing it and their environment.

Although CB is displayed in every range of ID, relatively little attention has been paid to people with mild ID (IQ 50-70) or people with borderline intellectual functioning (IQ 70-85), hereafter designated as people with mild to borderline intellectual disabilities (MBID). This group often attempts to hide their disabilities and therefore, their ID often goes unrecognized. This failure to recognize their ID causes them to receive care which is not adapted to their needs.

The main goal of the thesis is to gain insight in the CB (aggressive behavior, self-injurious behavior or harmful sexual behavior) of people with MBID and the coherent antecedents and consequences. Besides, this thesis focusses on the development of clinical useful observational instruments to register CB, which helps to shape future interventions. In this thesis we focused on two perspectives: the functional/behavioral perspective and the cognitive perspective. In the functional/behavioral perspective, CB is seen as a product of interaction between the person and their environment. In this perspective, CB is seen as a social construct that serves a function. Based on the cognitive perspective, CB is explained by the mental processes and representations of a person.

To increase our knowledge about CB based on the functional/behavioral perspective, we used structural clinical observations (Part I) to map aggressive behavior (**Chapter 2**), self-injurious behavior (**Chapter 3**) and harmful sexual behavior (**Chapter 4**). Based on the cognitive perspective (Part II), the attributions of people with an ID (**Chapter 5 and 6**) and their support staff (**Chapter 7**) are examined to gain more insight in the triggers and consequences of CB. The results of Part I and II are described in more detail below.

Part I

In the first part of this thesis, support staff was asked to report CB every time they had witnessed an incident. To report the incidents, we used three different observational instruments. Aggressive behavior was examined using an adapted version of the Staff Observation Aggression Scale-Revised (SOAS-R), designed for people with ID (**Chapter 2**). Self-injurious behavior was examined using an adapted version of the Self-Harm Scale (SHS), designed for people with ID (**Chapter 3**). Finally, harmful sexual behavior was examined using a newly designed measure, the Harmful Sexual Behavior Scale (HSBS) (**Chapter 4**). Data were collected during a nine months period at three closed ward of one treatment facility. This treatment facility was specialized in the care for people with MBID and co-occurring psychopathology.

Aggressive behavior

During the nine months observation period, support staff reported 210 unique aggressive incidents. In total, 22 out of 33 clients (67%) showed some form of aggressive behavior, with a frequency of 8.9 incidents per client per annum. A minority of the people who displayed aggressive behavior, caused the majority of the incidents. Aggressive behavior was most prevalent on Thursdays and between 9 and 11 a.m. and 7 and 9 p.m. Triggers of the aggressive behavior were mostly of an interactional nature, between clients and support staff or between clients. In almost one third of the incidents (29%), support staff could not indicate what triggered the aggressive behavior. Aggressive behavior mostly consisted of verbal aggressive behavior, aimed at support staff. In the majority of the aggressive incidents (53%), no consequences were reported. If consequences were reported, these were mostly psychological (e.g., feeling threatened). Support staff most of the times used verbal techniques to stop the behavior, like telling the client to stop. There were no significant differences between aggressive and non-aggressive clients on variables like gender, age, of adaptive abilities.

Self-injurious behavior

Support staff reported 104 unique incidents of self-injurious behavior, during the nine months of observation, which equals 4 incidents per client per year. Eight out of the 33 clients (24%) showed some form of self-injurious behavior, of which two clients displayed more than 85% of the incidents. The self-injurious behavior mainly existed of cutting and head banging. Triggers mentioned by support staff were related to intrapersonal factors (34%; e.g., psychological wellbeing) and interpersonal factors (31%; e.g., interactions with their environment). In 31% of the cases, support staff could not indicate what triggered the self-injurious behavior. Support staff mostly reported no or minimal consequences (62%), in the other cases (38%) the consequences were severe with medical assistance needed. Support staff often used physical restraint to stop the self-injurious behavior (56%), such as holding the arms of a client. They also tried to stop the self-injurious behavior using verbal interventions (36%). The majority of the self-injurious behaviors took place in the room of the client (93%), without other people being around. There were three significant differences between clients who did and did not display self-injurious behavior. Clients who displayed self-injurious behavior were more often female, were more often diagnosed with a borderline personality disorder and had better communicative abilities compared to the groups of clients who did not display self-injurious behavior.

Harmful sexual behavior

During the nine months of data collection, support staff reported 34 incidents of harmful sexual behavior, caused by 8 out of 33 clients (24%). The harmful sexual behavior mainly consisted of inappropriate (non-directed) communication, exposure and inappropriate touching of support staff and other clients. Three participants were responsible for almost 80% of the incidents. It was often not clear for support staff what triggered the harmful

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sexual behavior (62%). If the trigger was clear for support staff, these were mainly interactions (21%). Although in the majority of the incidents no consequences were reported following the harmful sexual behavior (71%), in some cases psychological consequences were reported (e.g., feeling threatened or uncomfortable). Clients were mostly distracted or support staff used verbal techniques to stop the behavior.

Challenging behavior

The characteristics of the three types of CB differ, but there are also some similarities. For aggressive, self-injurious, and harmful sexual behavior, the majority of the incidents was caused by a minority of clients. This shows that prevention should be aimed at analyzing these individual cases, aimed at formulating interventions. The three adapted or newly developed observations instruments can be useful in analyzing the circumstances and triggers that are associated with CB in clients with MBID, and to register the effects of preventive measures aimed to reduce or prevent the CB.

The results also show that support staff were not always able to indicate the triggers of the CB. Possibly, support staff are not aware of the functionality of behavior and the role they play in triggering and maintaining CB. Training support staff in the functionality of behavior could help them to react in more adaptive ways. On the other hand, these results call for the involvement of clients in analyzing the circumstances, triggers and consequences in which CB occurs. By taking both perspectives into account, it is possible to intervene in the most effective way.

Part II

In the second part of this thesis, the attributions of people with MBID about CB are examined using a systematic review (**Chapter 5**) and a qualitative interview study (**Chapter 6**). In addition, the attributions and attributional styles of support staff were examined using the Leeds Attributional Coding System (LACS) (**Chapter 7**).

Attributions of people with MBID

In a systematic review (**Chapter 5**), 12.882 studies were selected based on the used search strategy, of which 10 studies were included. These 10 studies described the attributions of people with MBID about their own or other people's CB and were focused on four types of CB, namely: aggressive behavior, self-injurious behavior, offending behavior, and behavior not specified. People with MBID attributed CB to interpersonal causes (e.g., factors related to interactions with other persons), environmental factors (e.g., factors related to the physical environment), and intrapersonal factors (e.g., factors coming from within a person).

In the qualitative interview study (**Chapter 6**), group interviews about aggressive behaviour were conducted with people with MBID residing in a forensic psychiatric hospital. They

were asked to describe what triggered the aggressive behavior, what the aggressive behavior looked like, and what the consequences were of the aggressive behavior. In this study we only examined attributions regarding aggressive behavior, as this is frequently occurring in forensic psychiatry. The interviews were transcribed and coded using the LACS. Attributions were scored on five dimensions: stable/unstable, global/ specific, internal/external, personal/ universal and controllable/uncontrollable. Participants mentioned a great diversity of interpersonal, environmental, and intrapersonal factors causing the aggressive behavior. In addition, the results showed that clients mention an almost equal distribution of themselves and their environment causing the aggressive behavior. The attributions given differed related to the person mentioned in the cause, on the dimensions stability and controllability. If clients were mentioned as causing the aggressive behavior, this was attributed more often as global (i.e., having a significant impact on several outcomes) and less under control of the person showing the behavior, compared to other people mentioned as causing aggressive behavior.

Attributions of support staff

In **Chapter 7,** support staff were interviewed regarding aggressive, self-injurious, and harmful sexual behavior. In this study, the same interview schedule was used as in the study regarding the attribution of clients (Chapter 6). The attributions and attributional styles were examined related to the three types of CB. Attributional styles are patterns on the five attributional dimensions (stable/unstable, global/ specific, internal/external, personal/ universal and controllable/uncontrollable) and give information about the way a person thinks towards CB. Support staff attributed all three forms of CB to intrapersonal factor of the client (>70%), characteristics of support staff themselves (20%) and other persons or situations (7%). Support staff less often mentioned themselves in the cause of self-injurious behavior, and more often related to aggressive and harmful sexual behavior. In addition, seven attributional styles could be distinguished. Forty percent of the seven attributional styles contained the stable, global, and internal dimension. Scores on these dimensions are indicative for the impact of the CB on support staff, suggesting that support staff do not feel they can exert control over the existence of the CB.

The results show that support staff and clients attribute causes of aggressive behavior mostly to the same causes (interpersonal, environmental, and intrapersonal). Clients attribute these causes almost equally to themselves and their environment. Support staff, on the other hand, more often mentioned factors insight the client to be the cause of the CB. These results seem to be indicative for the different views of support staff and clients regarding the antecedents of CB. Both perspectives should therefore be taken into account, which will help to get more insight in these sometimes complex interactions.

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Discussion

To conclude, in **Chapter 8** the results of this thesis are summarized, integrated and discussed. Next, the methods used will be reflected on and the meaning and implications of these results for research and practice are addressed.

Methodological reflections

Executing research in clinical practice significantly differs from executing research in a controlled setting. On the one hand, this provides insight in real life situations and behavior. On the other hand, it makes the researcher more dependent on the situation and persons in this situation.

By doing research with such a complex population, it is important to align with their environment. Together with, for example support staff, the researcher can choose the best way to approach the potential participant and what aspects are important to know in advance, before starting to conduct the research. To facilitate this process, the researcher should take time to explain the goal and process of the research to the respondents and to arrange all practical issues. Besides focusing on the client, the important role support staff play should also be acknowledged. They often experience high workload and are not capable in seeing everything that happens on a ward. Taking all this into account, will help to increase the participation of people with ID in research, which in turn helps to gain more insight in these complex behaviors within the clinical setting and increase the knowledge-base regarding CB.

Implications

Scientific implications. In the studies focusing on structured clinical assessment of CB (Chapter 2, 3, and 4), we used adapted or newly designed instruments for people with MBID and CB. These instruments help to gain more insight regarding CB, and take the context in which the behavior occurs into account. Although only psychometric properties (interrater reliability and construct validity) of the SOAS-R-ID were calculated, future research is necessary to explore the validity and reliability of the SHS and HSBS.

Studies focusing on attributions (Chapter 5, 6, and 7) gain more insights about CB based on two perspectives, employing a method that can be used in both populations. In future research it would be interesting to expand the setting in which this research is conducted, to be able to investigate the influence of the setting. Although support staff is asked to describe three types of CB, it would also be interesting to further explore the attributions of people with MBID regarding different types of CB.

Implications for policy and practice. The observational instruments of Chapter 2, 3, and 4 can be used to meet the requirement of the fairly recently (2016) introduced act 'Quality, complaints and disputes in care' [wet Kwaliteit, klachten en geschillen zorg (WKKGZ)]. This act describes that an employee in health care is required to report the nature, circumstances, and time of an incident, that has led, could have led or still could lead to significant

consequences for the client. Besides, health care organizations are obliged to have an internal procedure to report and analyze incidents. The observational instruments can also be used to help implementing guidelines regarding CB and to estimate the effects of these guidelines.

The results show that the majority of the incidents regarding CB are caused by a minority of people with MBID. Organizations should focus their attention on this relative small group of clients. To explore the triggers and consequences of CB within the context in which it occurs, is important to develop individual care plans and take preventive measures. The three observational instruments described in this thesis might be used as a first step in the functional assessment of CB, as it gives a rather global overview of the clients, their behavior and context in which the behavior occurs. In addition, those instruments can be used to evaluate interventions aimed at reducing CB.

The research in this thesis also shows the importance of connecting different types of knowledge, in this thesis professional and experiential knowledge. There is an increased awareness of the added value of experiential knowledge. For example, in the 'Care and Coercion Act', effective in 2020, is formulated that the views of the client is leading. Several funding bodies, including ZonMw, require researchers to incorporate experiential knowledge. Participation of people with ID is an enrichment of the research process and research results, and can also add value for the people with ID themselves. Only recently, people with MBID and CB are involved in doing research and more attention has been paid to their perspective. In future, the participation of people with MBID in research should be expanded, especially in research focusing on CB.
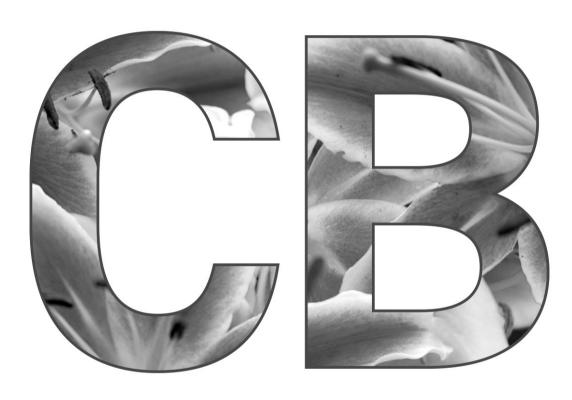
Incorporating the views of people with ID in research requires a specific approach. It is important to involve them in an open and non-judgmental way, as only then a representative view can be generated. This will not only provide more information about CB, it can also be helpful for them to become more involved in their own treatment process. Stimulating people with ID to formulate their feelings, thoughts and wishes, based on an autonomy-supportive environment, makes them more motivated to change and positively impacts their well-being.

Asking both people with MBID and support staff about their views has more advantages. Support staff can become more aware of their triggering and maintaining role regarding CB. In addition, asking the other person about his/her perspective, can help to get a better understanding of the other person. Talking with people with MBID also helps to gain more insight into the emotional cues, next to the behavioral cues of CB. For people with MBID this also might help to gain more insight in their own experiences and emotions and to learn how to deal with it. Training can be helpful in creating this awareness.

The last recommendation for practice is to synchronize the observational instruments used across health care organizations. Based on this synchronization, larger datasets can be generated, which makes it possible to analyze CB on a much larger scale.

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Conclusion

The aim of this thesis is to gain more insight in the three types of CB (aggressive behavior, self-injurious behavior, and harmful sexual behavior of people with MBID. The results give an overview of CB from a functiFonal/behavioral and cognitive perspective. A small group of clients, based on the observational data, are responsible for the majority of the incidents of CB. The results also indicate that the clinical picture of the CB of these persons differ. Research and clinical practice should therefore focus on this specific group. Based on the results of the interview study regarding attributions of CB, it can be concluded that the attributions per type of CB differ. The results of the interview study with clients showed that they were able to express their views. Future research should take both perspectives into account, to attune care and support based on these perspectives.

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Easy read Summary

Why are we conducting this research?

People with mild intellectual disabilities more often display challenging behavior compared to people without intellectual disabilities. In this research we focus on three types of challenging behavior:

- Aggressive behavior   → for example hurting somebody else on the body
- Self-injurious behavior   → hurting oneself
- Harmful sexual behavior → for example touching somebody who does not want this

In this research we want to get to know why people with mild intellectual disabilities show these kind of behaviors.

What have you been examining?

This research consists of three parts

1. We asked support staff to complete a list if they saw one of the three types of challenging behavior. On the list the support staff member could indicate what he thought was the reason of the challenging behavior and the way he responded to the challenging behavior.
2. We have looked if somebody else already conducted this research regarding the reasons why people with intellectual disabilities display challenging behavior, according to themselves.
3. We interviewed support staff and people with intellectual disabilities. We asked them why they thought people with mild intellectual disabilities display challenging behavior.

What are the most important results of this research?

1. People with mild intellectual disabilities and support staff both give a lot of different reasons as a cause for challenging behavior. For example:
   - Something happens between two persons: for example a staff member is not clear towards a client
   - Something happens in a person: for example somebody has problems to deal with stress
   - Something happens in a situation: for example somebody is in a situation he/she does not like
2. There is not much research that also asks what people with an MBID themselves think that are the causes of challenging behavior.
3. Support staff do not always know why a client shows challenging behavior.

What is in it for clinical practice?

By conducting this research we do know more about the reasons why people show challenging behavior. We have focused on aggressive behaviour, self-injurious behaviour and harmful sexual behavior. For every type of challenging behavior different reasons are mentioned why it happens, like a reaction of a support staff member or characteristics of a person. The results can be used to better support people with intellectual disabilities, who display challenging behavior.

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Samenvatting

Mensen met een verstandelijke beperking vertonen over het algemeen vaker grensoverschrijdend gedrag dan mensen zonder verstandelijke beperking. Veelvoorkomende vormen van grensoverschrijdend gedrag zijn agressief gedrag, zelf beschadigend gedrag en seksueel ongepast gedrag. Prevalentiecijfers van deze vormen van grensoverschrijdend gedrag lopen erg uiteen (van 10 tot 60%), afhankelijk van het type gedrag, de setting en methode van onderzoek. Grensoverschrijdend gedrag van mensen met een verstandelijke beperking heeft een enorme impact op henzelf en hun omgeving, op fysiek, psychologisch en sociaal gebied.

Grensoverschrijdend gedrag komt voor bij alle niveaus van verstandelijke beperkingen, maar er is tot op heden relatief weinig aandacht geweest voor mensen met een lichte verstandelijke beperking (LVB; IQ 50-70) of zwakbegaafd niveau van functioneren (ZB; IQ 70-85). Deze groep probeert hun beperkingen over het algemeen zoveel mogelijk te verbergen, waardoor deze vaak niet herkend wordt. Dit zorgt ervoor dat ze niet altijd op plekken terecht komen waar hun ondersteuningsbehoeften wordt gezien, waardoor ze niet de zorg krijgen die ze eigenlijk nodig hebben.

Het doel van dit proefschrift is het verkrijgen van inzicht in grensoverschrijdend gedrag (agressief gedrag, zelfbeschadigend en seksueel ongepast gedrag) bij mensen met een LVB of ZB en de daarmee samenhangende antecedenten en consequenten. Daarnaast richt dit proefschrift zich op het ontwikkelen van voor de praktijk bruikbare observatielijsten om grensoverschrijdend gedrag te registeren, hetgeen handvatten biedt voor toekomstige interventies. In dit proefschrift staan twee perspectieven centraal, te weten het functioneel/ gedragsmatige perspectief en het cognitieve perspectief. Vanuit het functioneel/gedragsmatig perspectief wordt gedrag gezien als het product van de interactie tussen de persoon en diens omgeving, waarbij gedrag een sociaal construct is dat een functie dient. Vanuit het cognitief perspectief wordt gedrag daarentegen verklaard door mentale processen en representaties.

Om meer zicht te krijgen op grensoverschrijdend gedrag vanuit het functioneel/ gedragsmatige perspectief is in dit proefschrift gebruik gemaakt van structurele klinische observaties (Deel I). In drie opeenvolgende hoofdstukken worden de kenmerken van agressief gedrag (**Hoofdstuk 2**), zelfbeschadigend gedrag (**Hoofdstuk 3**) en seksueel ongepast gedrag (**Hoofdstuk 4**) beschreven aan de hand van gestructureerde klinische observaties. Vanuit het cognitief perspectief (Deel II) is er in dit proefschrift aandacht besteed aan de attributies (causale overtuigingen) van mensen met een verstandelijke beperking (**Hoofdstuk 5 en 6**) en hun begeleiders (**Hoofdstuk 7**), teneinde meer zicht te krijgen op de aanleiding en gevolgen van grensoverschrijdend gedrag. De resultaten van beide delen worden hieronder nader beschreven.

Deel I

In het eerste deel van het proefschrift zijn begeleiders gevraagd om grensoverschrijdend gedrag te rapporteren op het moment dat zij dit hadden waargenomen. Hierbij werd gebruik

gemaakt van drie verschillende observatielijsten. Agressief gedrag werd in kaart gebracht door middel van een aangepaste versie van de Staff Observation Aggression Scale-Revised (SOAS-R) voor gebruik bij mensen met een verstandelijke beperking (**Hoofdstuk 2**). Zelfbeschadigend gedrag werd in kaart gebracht door gebruik te maken van een aangepaste versie van de Self-Harm Scale (SHS) voor gebruik bij mensen met een verstandelijke beperking (**Hoofdstuk 3**). Ten slotte werd seksueel ongepast gedrag in kaart gebracht door gebruik te maken van een nieuw ontwikkelde observatielijst, de Harmful Sexual Behavior Scale (HSBS) (**Hoofdstuk 4**). De gegevens werden gedurende negen maanden verzameld op drie groepen binnen een gesloten afdeling. Deze afdeling was gespecialiseerd in de zorg voor mensen met een LVB of ZB en bijkomende psychopathologie.

Agressief gedrag

Gedurende negen maanden hebben begeleiders in totaal 210 unieke agressie-incidenten gerapporteerd. Tweeëntwintig van de 33 cliënten (67%) lieten agressief gedrag zien, met een gemiddelde frequentie van 8,9 incidenten per cliënt per jaar. Het grootste deel van de incidenten werd veroorzaakt door een kleine groep cliënten. Agressief gedrag kwam het meeste voor op donderdag en op twee specifieke momenten van de dag: tussen 9 en 11 u in de ochtend en 19 en 21 u in de avond. De aanleiding voor het vertonen van agressief gedrag was meestal een interactie, danwel tussen de cliënt en begeleider danwel tussen cliënten onderling. In bijna een derde van de incidenten (29%) konden begeleiders niet benoemen wat de aanleiding van het gedrag was. Het agressieve gedrag bestond veelal uit verbale agressie en was met name gericht op begeleiders. Bij een meerderheid van de agressieve incidenten (53%) werden geen gevolgen gerapporteerd. Als er wel gevolgen waren, waren die meestal van psychologische aard (bijvoorbeeld bedreigd voelen). Veelal werden verbale technieken gebruikt om het agressieve gedrag te stoppen, zoals de cliënt aanspreken op het gedrag. Er waren geen significante verschillen tussen de groep cliënten die agressief gedrag liet zien en de groep die geen agressief gedrag liet zien, op demografische variabelen zoals geslacht, leeftijd, IQ en diagnose.

Zelfbeschadigend gedrag

Begeleiders rapporteerden 104 unieke incidenten gericht op zelfbeschadigend gedrag in de negen maanden durende observatieperiode. Dit komt overeen met gemiddeld 4 incidenten per cliënt per jaar. Acht van de 33 cliënten (24%) lieten een vorm van zelfbeschadigend gedrag zien, waarbij twee van hen bij meer dan 85% van de incidenten betrokken waren. Het zelfbeschadigend gedrag bestond voornamelijk uit snijden en hoofdbonken. Intrapersoonlijke factoren (34%; bijvoorbeeld psychologisch welbevinden) en interpersoonlijke factoren (31%; bijvoorbeeld interacties met de omgeving) werden genoemd als aanleiding voor zelfbeschadigend gedrag. In 31% konden begeleiders niet benoemen wat de aanleiding was van een incident. De meeste incidenten (62%) hadden geen of minimale gevolgen voor het slachtoffer; in de andere 38% waren de gevolgen ernstig, waarbij medisch ingrijpen

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noodzakelijk was. Om het zelfbeschadigend gedrag te stoppen, maakten begeleiders met name gebruik van technieken om de cliënt fysiek in bedwang te houden (56%), zoals het vasthouden van de armen. Met enige regelmaat (36%) probeerden begeleiders het gedrag ook te stoppen door middel van verbale interventies. Het zelfbeschadigend gedrag vond meestal plaats op de kamer van de cliënt, zonder dat er andere personen bij aanwezig waren. Er zijn drie significante demografische? verschillen tussen cliënten die zelfbeschadigend gedrag lieten zien en cliënten die dit gedrag niet lieten zien. Cliënten die zelfbeschadigend gedrag lieten zien waren vaker vrouw, hadden vaker de diagnose borderline persoonlijkheidsstoornis en ze hadden betere communicatieve vaardigheden dan de groep die deze gedragingen niet lieten zien.

Seksueel ongepast gedrag

In de 9 maanden durende observatieperiode rapporteerden begeleiders 34 incidenten van seksueel ongepast gedrag, veroorzaakt door 8 van de 33 deelnemers (24%). Het seksueel ongepast gedrag bestond voornamelijk uit seksueel ongepaste communicatie, exposure en ongepast aanraken van personen uit de omgeving. Drie deelnemers waren verantwoordelijk voor bijna 80% van de incidenten. Vaak was het voor begeleiders niet duidelijk wat de oorzaak was van het gedrag (62%). Indien de oorzaak wel duidelijk was, werden met name de interacties tussen de cliënt en begeleiders of tussen cliënten onderling aangeduid als aanleiding (21%). Alhoewel er in de meeste gevallen geen gevolgen gerapporteerd werden door begeleiders als gevolg van het seksueel ongepast gedrag (71%), werden in sommige gevallen psychologische gevolgen gerapporteerd (bijvoorbeeld gevoelens van ongemak of dreiging). Om het gedrag te stoppen werd de cliënt afgeleid (bijvoorbeeld uit de situatie gehaald) of werden er verbale interventies ingezet (bijvoorbeeld praten over ander onderwerp).

Grensoverschrijdend gedrag

Zoals hierboven beschreven verschillen de kenmerken per vorm van grensoverschrijdend gedrag, maar er zijn ook een aantal overeenkomsten. Bij alle drie de vormen van grensoverschrijdend gedrag was er een kleine groep van cliënten die betrokken was bij het grootste deel van de gerapporteerde incidenten. Deze resultaten laten zien dat preventie zich zou moeten richten op het analyseren van deze individuele cases, teneinde interventies te gaan inzetten. De drie aangepaste/ontwikkelde observatielijsten zouden hierbij gebruikt kunnen worden, enerzijds om de kenmerken van het grensoverschrijdende gedrag in kaart te brengen en anderzijds om te registeren of ingezette interventies ook effectief zijn om grensoverschrijdend gedrag te verminderen of zelfs te voorkomen.

Uit de resultaten komt ook naar voren dat het voor begeleiders, bij alle drie de vormen van grensoverschrijdend gedrag, in een derde tot bijna twee derde van de incidenten niet bekend is wat de aanleiding is geweest voor het vertonen van het grensoverschrijdend gedrag. Het kan zijn dat begeleiders zich niet bewust zijn van het feit dat gedrag een functie heeft en dat zij een rol spelen in het uitlokken en in stand houden van gedrag. Het trainen van begeleiders in deze principes zou hierbij helpend kunnen zijn. Anderzijds zou het op basis van deze resultaten aan te raden zijn om ook het perspectief van de persoon die het gedrag laat zien, in

dit geval de cliënt, mee te nemen in het analyseren van de aanleiding van grensoverschrijdend gedrag. Door zowel het perspectief van de begeleider als van de cliënt mee te nemen kan een zo compleet mogelijk beeld van het gedrag worden verkregen en kan er op een zo optimaal mogelijk manier worden geïntervenieerd.

Deel II

In het tweede deel van dit proefschrift zijn de attributies van mensen met een LVB of ZB en grensoverschrijdend gedrag in kaart gebracht door middel van een systematisch review (**Hoofdstuk 5**) en een kwalitatieve interviewstudie (**Hoofdstuk 6**). Daarnaast zijn de attributies en attributiestijlen van begeleiders van mensen met een verstandelijke beperking en grensoverschrijdend gedrag onderzocht door middel van de Leeds Attributional Coding System (**Hoofdstuk 7**).

Attributies van mensen met een LVB of ZB

Op basis van de gebruikte zoekstrategie werden er in de systematische review (**Hoofdstuk 5**) 12,882 artikelen geselecteerd, waarvan er uiteindelijk 10 studies werden geïncludeerd in de review. De 10 studies beschreven de attributies van mensen met een LVB of ZB over hun eigen of andermans grensoverschrijdend gedrag. De studies richten zich op vier vormen van grensoverschrijdend gedrag, te weten: agressief gedrag, zelfbeschadigend gedrag, crimineel gedrag en niet nader gespecificeerd gedrag. Mensen met een LVB of ZB attribueerden grensoverschrijdend gedrag aan interpersoonlijke factoren (d.w.z. factoren gerelateerd aan interacties tussen personen), omgevingsfactoren (d.w.z. factoren gerelateerd aan de fysieke omgeving), en intrapersoonlijke factoren (d.w.z. factoren gerelateerd aan eigenschappen in de persoon zelf).

In de kwalitatieve interviewstudie (**Hoofdstuk 6**) werden mensen met een LVB of ZB binnen een forensisch psychiatrische setting in groepsgesprekken gevraagd om te beschrijven wat volgens hen de oorzaak was van agressief gedrag op de afdeling. Aangezien agressief gedrag een veelvoorkomende vorm van grensoverschrijdend gedrag is binnen de forensische psychiatrie, is voor deze studie enkel voor deze vorm van grensoverschrijding gekozen. Aan de deelnemers werd gevraagd om te beschrijven wat er vooraf ging aan het incident, hoe het gedrag eruit zag, hoe er op het gedrag werd gereageerd en wat de gevolgen waren van het gedrag. De interviews werden getranscribeerd en geanalyseerd door middel van de Leeds Attributional Coding System (LACS). De LACS is een systeem waarmee attributies gescoord kunnen worden op vijf verschillende dimensies: stabiel/onstabiel, globaal/specifiek, intern/ extern, persoonlijk/universeel en controleerbaar/oncontroleerbaar. De deelnemers noemden verschillende interpersoonlijke, omgevings- en intrapersoonlijke oorzaken. Daarnaast laten de resultaten zien dat cliënten ongeveer net zoveel oorzaken noemden vanuit zichzelf als vanuit de omgeving. De attributies die de cliënten gaven, verschilden op de dimensies

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stabiliteit en controleerbaarheid, afhankelijk van de persoon die in de oorzaak genoemd werd (bv., cliënt of begeleider). Als de cliënt werd genoemd in de oorzaak van het agressieve gedrag werd dit, in vergelijking met andere personen die in de oorzaak werden genoemd, meer geattribueerd als globaal (d.w.z., de uitkomst heeft ook impact op andere uitkomsten) en minder controleerbaar door de persoon die het gedrag laat zien.

Attributies van begeleiders

In **Hoofdstuk 7** werden begeleiders geïnterviewd over agressief gedrag, zelfbeschadigend gedrag en seksueel ongepast gedrag. Hierbij werd hetzelfde interviewschema gebruikt als bij de studie waar cliënten werden geïnterviewd (Hoofdstuk 6). In deze studie werden zowel de attributies als ook de attributiestijlen van begeleiders onderzocht. Attributiestijlen zijn patronen op de vijf dimensies (stabiel/onstabiel, globaal/specifiek, intern/extern, persoonlijk/ universeel en controleerbaar/oncontroleerbaar). Deze stijlen geven meer informatie over hoe een persoon denkt in relatie tot het grensoverschrijdend gedrag. Begeleiders attribueren de meeste oorzaken (> 70%) van alle drie de vormen van grensoverschrijding aan intrapersoonlijke factoren van de cliënt, gevolgd door eigenschappen van begeleiding zelf (20%) en andere personen en situaties (7%). Begeleiders noemden zichzelf minder vaak in de oorzaak gerelateerd aan zelfbeschadigend gedrag en vaker gerelateerd aan agressief en seksueel ongepast gedrag. Door middel van de analyses konden 7 attributiestijlen onderscheiden worden. Deze attributiestijlen bevatten in 40% van de gevallen de stabiele, globale en interne dimensie. Scores op deze dimensies zijn een indicatie van de impact van grensoverschrijdend gedrag op begeleiders en suggereren dat begeleiding niet het gevoel heeft dat ze controle kunnen uitoefenen op het ontstaan van het grensoverschrijdend gedrag.

Uit het voorgaande komt naar voren dat cliënten en begeleiders veelal dezelfde soorten attributies noemen voor het ontstaan van agressief gedrag (interpersoonlijke, intrapersoonlijke en omgevingsfactoren). Cliënten geven bij de attributies aan dat zij en de omgeving ongeveer even vaak de oorzaak zijn voor agressief gedrag. Begeleiders geven veelal cliëntfactoren als oorzaak van het ontstaan van de drie vormen van grensoverschrijdend gedrag. Aangezien het perspectief van de begeleider en cliënt ten aanzien van de aanleiding van grensoverschrijdend gedrag lijkt te verschillen, wordt ook in deze studies duidelijk dat het uitvragen van meerdere perspectieven noodzakelijk is om een compleet beeld te krijgen van grensoverschrijdend gedrag.

Discussie

Tot slot, in **Hoofdstuk 8** werden de resultaten uit dit proefschrift samengevat, geïntegreerd en besproken. Vervolgens is gereflecteerd op de gebruikte methoden en werden de betekenis en implicaties van de uitkomsten voor onderzoek en praktijk besproken.

Methodologische reflectie

Onderzoek doen in de klinische praktijk verschilt sterk van onderzoek doen in een gecontroleerde setting. Enerzijds geeft het inzicht in situaties en gedragingen zoals deze zich ook daadwerkelijk voordoen. Anderzijds zorgt onderzoek in de klinische praktijk ervoor dat de onderzoeker meer afhankelijk is van de situatie en personen die zich in die situatie bevinden.

Bij deze complexe doelgroep is het van belang om goed af te stemmen met de omgeving. Op welke manier kan de persoon het beste benaderd worden en waar moet op gelet worden? Het onderzoek moet daarbij goed uitgelegd worden aan de doelgroep. Het doel van het onderzoek, de stappen binnen het onderzoek, maar ook praktische zaken dienen duidelijk en goed overgebracht te worden aan alle respondenten. Daarnaast dient er aandacht te zijn voor de situatie waarin begeleiders zich bevinden, met een hoge werkdruk en niet altijd in de mogelijkheid om aanwezig te zijn bij alle incidenten. Door dit in ogenschouw te nemen, kan deelname van mensen met LVB en ZB en grensoverschrijdend gedrag aan wetenschappelijk onderzoek bevorderd worden en kunnen we meer zicht krijgen op complexe gedragingen in klinische settings. Dit zal een positieve invloed hebben op de al bestaande kennis over grensoverschrijdend gedrag.

Implicaties

Wetenschappelijke implicaties. In de studies gericht op gestructureerde klinische observatie (Hoofdstuk 2, 3 en 4) zijn observatielijsten aangepast of ontwikkeld, specifiek voor gebruik bij mensen met LVB of ZB en grensoverschrijdend gedrag, waarin grensoverschrijdend gedrag, samen met antecedenten en consequenten in kaart wordt gebracht. Hoewel alleen bij de SOAS-R-ID psychometrische data zijn verzameld (interbeoordelaarsbetrouwbaarheid en construct validiteit), lijken de observatielijsten bruikbaar voor de praktijk. In de toekomst is het wenselijk om de psychometrische eigenschappen van deze observatielijsten verder te onderzoeken.

De studies gericht op attributies (Hoofdstuk 5, 6 en 7) geven meer inzicht in grensoverschrijdend gedrag vanuit twee perspectieven, met een methode die inzetbaar is voor zowel mensen met als zonder verstandelijke beperking. Voor vervolgonderzoek zou het interessant zijn om deze studie uit te voeren bij meerdere instellingen, om zo de invloed van de setting te kunnen onderzoeken. Hoewel er bij begeleiders meerdere vormen van grensoverschrijdend gedrag zijn onderzocht, zou het ook interessant zijn om cliënten uit te vragen over meer vormen van gedrag.

Implicaties voor beleid en de praktijk. De observatielijsten ontwikkeld in Hoofdstuk 2, 3 en 4 zouden gebruikt kunnen worden om tegemoet te komen aan de eisen van de in 2016 ingevoerde wet Kwaliteit, klachten en geschillen zorg (WKKGZ). Deze wet beschrijft dat medewerkers verplicht zijn om de aanleiding, omstandigheden en tijd van een incident, die gevolgen kan hebben of heeft voor de cliënt, te rapporteren. Daarnaast zijn zorgorganisaties verplicht om een interne procedure te hebben om deze incidenten te registreren en analyseren.

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De observatielijsten zijn bruikbaar om richtlijnen ten aanzien van grensoverschrijdend gedrag te implementeren en te beoordelen wat het effect van deze richtlijnen is.

De resultaten laten zien dat de meerderheid van de incidenten veroorzaakt wordt door een kleine groep cliënten. Het is daarom aan te raden om binnen organisaties aandacht te besteden aan deze relatief kleine groep cliënten. Het exploreren van de aanleiding en consequenties van grensoverschrijdend gedrag in de omgeving waarbinnen het plaatsvindt, is belangrijk om individuele zorgplannen te kunnen ontwikkelen en preventieve maatregelen te nemen. De drie observatielijsten kunnen gebruikt worden als een eerste stap in de functionele analyse, aangezien ze een globaal beeld geven van de cliënt, het gedrag en diens omgeving. Ze kunnen bovendien ingezet worden om interventies te evalueren

Dit onderzoek laat ook het belang zien van het verbinden van verschillende kennisbronnen, in dit geval professionele en ervaringskennis. Het belang van het inzetten van ervaringskennis wordt steeds meer gezien. In de Wet Zorg en Dwang, die in 2020 ingesteld wordt, is het perspectief van de cliënt leidend. Vanuit verschillende subsidieverstrekkers, waaronder ZonMw, wordt het inzetten van ervaringskennis als voorwaarde gesteld bij het verkrijgen van subsidie. Deelname van mensen met een verstandelijke beperking verrijkt het onderzoeksproces en de uitkomsten en heeft ook een meerwaarde voor mensen met een verstandelijke beperking zelf. Pas recentelijk worden ook mensen met een LVB of ZB en grensoverschrijdend gedrag betrokken binnen onderzoek en wordt er meer aandacht besteed aan hun perspectief. In de toekomst zou deelname van mensen met een LVB of ZB en grensoverschrijdend gedrag aan onderzoek zeker uitgebreid moeten worden, met name gerelateerd aan het onderzoek naar grensoverschrijdend gedrag.

Het betrekken van mensen met een verstandelijke beperking bij onderzoek vraagt om een specifieke aanpak. Door hen op een open en niet-oordelende manier te betrekken, wordt er pas zicht verkregen op hun perspectief. Deze manier van bevragen geeft niet alleen meer informatie gerelateerd aan grensoverschrijdend gedrag, maar het helpt hen ook om meer betrokken te raken bij hun behandelproces. Het stimuleren van mensen om hun gevoelens, gedachten en wensen te formuleren, vanuit een autonomie-ondersteunende omgeving, maakt hen gemotiveerd om te veranderen en heeft een positieve invloed op hun welbevinden.
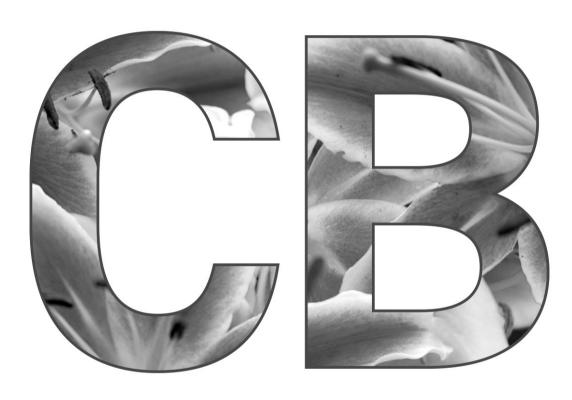
Het uitvragen van zowel het perspectief van de begeleider als de cliënt heeft nog meer voordelen. Begeleiders kunnen zich meer bewust worden van hun eigen rol in het uitlokken en instand houden van grensoverschrijdend gedrag. Daarnaast kan het uitvragen van twee perspectieven helpen om elkaar beter te begrijpen. Naast gedragsmatige signalen, wordt er namelijk ook inzicht verkregen in emotionele signalen. Door over het grensoverschrijdend gedrag te praten kan de cliënt ook meer zicht te krijgen op zijn of haar eigen ervaringen en emoties en daar ook beter mee om leren gaan. Training kan helpen om deze bewustwording van zowel begeleiders als cliënten in gang te zetten.

Als laatste is het belangrijk dat binnen instellingen zoveel mogelijk dezelfde observatielijsten worden gebruikt. Door deze synchronisatie kunnen grotere datasets gegenereerd worden, waardoor gegevens over grensoverschrijdend gedrag op grotere schaal geanalyseerd kunnen worden.

Conclusie

Het doel van dit proefschrift was om meer zicht te krijgen op drie vormen van grensoverschrijdend gedrag (agressief gedrag, zelfbeschadigend gedrag en seksueel ongepast gedrag) bij mensen met een LVB of ZB. De resultaten van dit proefschrift geven hiervan een beeld vanuit het functioneel/ gedragmatig en cognitief perspectief. Vanuit de observaties komt naar voren dat een kleine groep cliënten het grootste deel van het grensoverschrijdend gedrag veroorzaakt en dat het klinische beeld per persoon kan verschillen. Onderzoek en de klinische praktijk zouden zich daarom op deze groep moeten richten.

Op basis van de data afkomstig uit de interviews over attributies ten aanzien van grensoverschrijdend gedrag kan geconcludeerd worden dat attributies per type grensoverschrijdend gedrag van elkaar verschillen. In de studies komt ook naar voren dat mensen met een LVB of ZB in staat zijn om hun perspectief te belichten. Toekomstig onderzoek naar grensoverschrijdend gedrag zou beiden perspectieven moeten overwegen, zowel dat van de begeleiders, als ook dat van de persoon met een LVB of ZB.

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Makkelijk lezen samenvatting

Makkelijk lezen samenvatting

Waarom doen we dit onderzoek?

Mensen met een lichte verstandelijke beperking of zwakbegaafd niveau van functioneren laten vaker grensoverschrijdend gedrag zien dan mensen zonder verstandelijke beperking. In dit onderzoek kijken we naar drie vormen van grensoverschrijdend gedrag:

• Agressief gedrag → iemand anders pijn doen
• Zelf verwondend gedrags → jezelf pijn doen
• Seksueel ongepast gedrag → bijvoorbeeld iemand anders aanraken die dat niet wil

In dit onderzoek willen we te weten komen hoe het komt dat mensen met een lichte verstandelijke beperking grensoverschrijdend gedrag laten zien.

Wat hebben jullie onderzocht?

Dit onderzoek bestaat uit drie onderdelen.

1. We hebben begeleiders gevraagd om een lijst in te vullen als ze grensoverschrijdend gedrag hebben gezien. Op de lijst kon een begeleider opschrijven wat hij dacht dat de reden van het gedrag was en hoe hij hierop heeft gereageerd.
2. We hebben gekeken of er al eerder onderzoek is gedaan bij mensen met een verstandelijke beperking naar de redenen waarom iemand grensoverschrijdend gedrag laat zien.
3. We zijn in gesprek gegaan met begeleiders en mensen met een lichte verstandelijke beperking. We hebben hen gevraagd waarom mensen grensoverschrijdend gedrag laten zien.

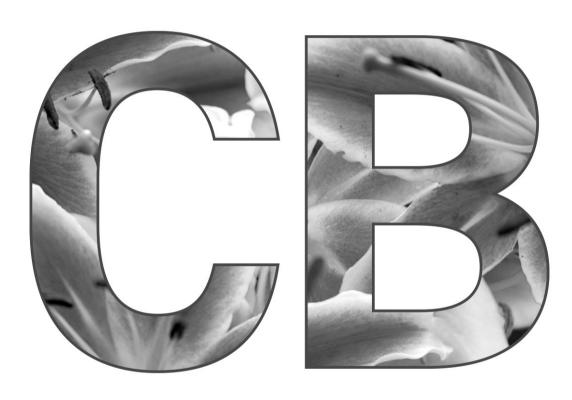### Wat zijn de belangrijkste resultaten van het onderzoek?

1. Er zijn verschillende redenen waarom iemand grensoverschrijdend gedrag laat zien. Bijvoorbeeld:
   - Er gebeurt iets tussen twee personen: bijvoorbeeld een begeleider is niet duidelijk
   - Er gebeurt iets in een persoon zelf: bijvoorbeeld iemand vindt het moeilijk om met stress om te gaan
   - Er gebeurt iets in een situatie: bijvoorbeeld iemand zit in een situatie die hij niet prettig vindt
2. In onderzoek is er aan mensen met een verstandelijke beperking zelf nog niet vaak gevraagd waarom grensoverschrijdend gedrag ontstaat.
3. Begeleiders weten niet altijd waarom iemand grensoverschrijdend gedrag laat zien.

Wat heeft de praktijk aan deze resultaten?

Door dit onderzoek zijn we meer te weten gekomen over de redenen van grensoverschrijdend gedrag. We hebben ons gericht op agressief gedrag, zelf beschadigend gedrag en seksueel ongepast gedrag. Bij elk type grensoverschrijdend gedrag worden andere redenen gegeven waarom het gebeurt, zoals reacties tussen personen of eigenschappen van een persoon zelf.

De resultaten kunnen gebruikt worden om mensen met een verstandelijke beperking, die grensoverschrijdend gedrag laten zien, beter te ondersteunen.

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Dankwoord

Het doen van wetenschappelijk onderzoek heb ik ervaren als een lange wandeling in de bergen. Het is een tocht geweest met pieken en dalen, soms alleen, maar heel vaak samen. De weg die ik de afgelopen jaren heb bewandeld, heeft me gevormd, als onderzoeker en als mens. Op die weg ben ik veel lieve, leuke, interessante en wijze mensen tegenkomen die me hebben geholpen, hebben gecoacht en nieuwe inzichten hebben gegeven om dit proefschrift mogelijk te maken. Graag wil ik deze mensen bedanken.

Na een prachtige, maar bovenal leerzame wereldreis, begon ik in 2004 aan de studie Pedagogische Wetenschappen en Onderwijskunde aan de Radboud Universiteit te Nijmegen. In het derde studiejaar liep ik stage op de Winkelsteegh (onderdeel van Pluryn) en mocht ik verschillende trainingen geven aan mensen met een verstandelijke beperking. Ik kwam in contact met begeleiders en gedragsdeskundigen die iedere dag opnieuw klaarstonden voor deze mensen. Door deze ervaringen werd ik bevestigd in de keuze die ik wilde maken: werken in de zorg voor mensen met een verstandelijke beperking. In het laatste jaar van de opleiding liep ik stage bij de Driestroom. In dat jaar heb ik enorm veel geleerd van mijn collega's, in een team dat voor me klaar stond. Dank hiervoor. In het bijzonder wil Annebé, Moniek en Lotte bedanken, voor hun kennis en kunde, maar ook voor de gezelligheid. Daarnaast wil ik de begeleiders van de Driestroom bedanken en in het bijzonder Maartje, Mayda en Pauli. Bij jullie op de groepen voelde ik me zeer welkom, omdat jullie me de passie van het vak lieten zien. Ik bewonder hoe jullie elke dag voor deze doelgroep klaar staan.

In dat laatste studiejaar 'moest' er ook een scriptie geschreven worden. Ik koos een thema dat me interessant leek, agressie bij mensen met een verstandelijke beperking, en kwam in contact met Wietske van Oorsouw, die samen met Petri Embregts mijn scriptie begeleidde. Wietske, ik heb je leren kennen als een enorm gedreven en getalenteerde onderzoeker. Je was de persoon die mij uitdaagde om een mooie scriptie te schrijven, dank daarvoor. Later werden we collega's en dat zijn we gelukkig nog steeds.

Mijn passie voor het doen van onderzoek was geboren en werd versterkt door het project dat ik na mijn afstuderen mocht gaan doen. Ik werd uitgenodigd door Petri met de vraag of ik wilde ondersteunen bij een onderzoek naar seksueel grensoverschrijdend gedrag bij mensen met een verstandelijke beperking vanuit zorgorganisatie ASVZ. Bij ASVZ was er een lijst ontwikkeld om de risicofactoren ten aanzien van seksueel grensoverschrijdend gedrag in kaart te brengen en zij wilden de verzamelde onderzoeksresultaten nader bestuderen. Hier kwam ik onder andere in contact met Marianne Heestermans. Een 'inhoudsvrouw', die zich al jarenlang sterk maakt voor deze doelgroep. Maar bovenal heb ik Marianne leren kennen als een heel warm en geïnteresseerd persoon. Marianne, wat ben ik blij dat we na dit eerste contact nog zoveel samen hebben mogen werken. Wat ben ik trots op het boek, dat Petri, jij en ik ontwikkeld hebben. Dank hiervoor.

Tijdens mijn betrokkenheid bij dit onderzoek, werd het Lectoraat Zorg voor Mensen met een Verstandelijke Beperking opgericht. Petri was de lector en vroeg of ik als onderzoeksassistent wilde gaan werken bij dit Lectoraat van de Hogeschool van Arnhem en Nijmegen. Samen met enthousiaste docenten, een statisticus, secretaresse en even later ook nieuwe onderzoeksassistenten hadden we een leuk klein team en kon ik mijn eerste onderzoekservaringen opdoen. Met veel plezier kijk ik daar op terug, dank daarvoor Ellen, Ida, Maaike, Joke, Lex, Noud, Jody, Steffi en Petri.

Vervolgens ben ik als onderzoeksmedewerker gaan werken bij Dichterbij Specialistische Zorg (nu STEVIG, onderdeel van Dichterbij). Na 2 jaar te hebben gewerkt bij STEVIG, bood Petri de mogelijkheid om het onderzoek naar grensoverschrijdend gedrag verder te gaan uitwerken in een promotieonderzoek. Ik wil Dichterbij, en in het bijzonder de raad van bestuur, bedanken voor de mogelijkheid dit promotieonderzoek te realiseren in verbinding met de Academische Werkplaats Leven met een verstandelijke beperking.

Het promotieonderzoek heb ik samen uit mogen voeren met twee geweldige promotores. Prof. dr. Petri Embregts en prof. dr. Henk Nijman. Petri, we kennen elkaar al heel wat jaren. Eerst als een van de docenten bij het vak Behandelingsmethodiek, vervolgens als begeleider van mijn scriptie, daarna als lector, promotor en nu in de begeleiding van mijn postdoc onderzoek. Gedurende onze samenwerking heb ik je leren kennen als een fantastisch mens en een geweldige leermeester. Ik ken niemand die zich met zoveel passie, kennis en gedrevenheid inzet voor deze bijzondere doelgroep. Jij liet mij kennismaken met onderzoek, op een wijze die inspireert en uitdaagt. Jij liet en laat mij leren, naar mezelf kijken en het beste uit mezelf halen, met betrokkenheid en een grote dosis humor. Dank voor alles en ik hoop dat we nog heel lang samen mogen werken. Henk, in 2012 stuurde ik je een mail met een vraag om met ons mee te denken. Vrijwel direct kreeg ik uitgebreide inhoudelijke reactie, en dat is typerend voor hoe je bent: behulpzaam en met veel expertise. Ik ben blij dat je mijn tweede promotor wilde worden. Je hebt me geleerd dat je met humor, enthousiasme en kennis van zaken mensen kan inspireren om samen de zorg te verbeteren. Dank voor je bijdrage aan mijn promotieonderzoek.

Door de start van mijn promotieonderzoek, werd de stap naar Tranzo (Tilburg University) gemaakt en daar werk ik nu nog, dus dat zegt wat. Henk en Dike, bedankt voor het warme ontvangst bij Tranzo en voor het creëren van een bijzonder fijne werkomgeving. Bij Tranzo heb ik veel mensen leren kennen met dezelfde passie voor de zorg en voor onderzoek. Bedankt iedereen voor de inhoudelijke uitwisseling, voor de gezelligheid en voor de ruimte die ik kreeg om mij als onderzoeker te ontwikkelen.

Mijn oprechte dank wil ik ook uitspreken aan de leden van de promotiecommissie: prof. dr. van de Mheen, prof. dr. Vandevelde, prof. dr. Moonen, dr. Kool, dr. Kaal en dr. Wieland. Ik

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ben u allen zeer erkentelijk voor het kritisch lezen en beoordelen van mijn proefschrift en uw bijdrage aan de verdediging.

Onderzoek doen is voor mij samenwerken met de praktijk, met cliënten en hun ouders, maar ook met begeleiders, psychologen en managers. Ik wil Dichterbij en OPSY bedanken voor de mogelijkheid om mijn data te verzamelen. Dank ook aan alle cliënten, ouders, begeleiders, psychologen en managers die mee hebben gedaan aan mijn onderzoek. Het is fijn dat jullie mee wilden denken in de vormgeving van het onderzoek, dat jullie je ervaringen wilden delen en dat jullie mij toelieten op de plekken waar jullie zorg en ondersteuning kregen of gaven. In het bijzonder wil ik Marleen, Martijn, Marieke en Annemarie bedanken. Jullie inhoudelijke expertise en jullie passie voor de doelgroep hebben mij geraakt en mij laten inzien dat we samen veel kunnen betekenen voor deze mensen.

Onderzoek doen is voor mij ook samenwerken in teamverband met andere onderzoekers, in mijn geval het team van de Academische Werkplaats Leven met een verstandelijke beperking (Tranzo, Tilburg University). Ik wil alle collega's bedanken voor deze fijne samenwerking. Het is mooi om te zien dat iedereen voor elkaar klaar staat om te helpen, dat we ervaringen kunnen uitwisselen en leren van elkaar. In het bijzonder wil ik Noud, Luciënne en Elsbeth bedanken. Noud, wij gaan al even terug samen. Bij het lectoraat als startende onderzoekers, vervolgens allebei begonnen aan een promotieonderzoek bij de Academische werkplaats, en daarna beiden gestart met een postdoc onderzoek. We hebben vaak een kamer gedeeld, en je bent echt mijn maatje geworden. In onderzoek geef je me theoretische inzichten, leer je mij om nog kritischer te kijken en zorg je voor statistische aanscherping. Jouw oog voor detail, jouw eindeloze inzet voor de ander en je betrokkenheid zijn voor mij een voorbeeld. Trots en blij ben ik dat je vandaag achter mij staat als paranimf. Luciënne, wij hebben elkaar ook leren kennen bij het lectoraat, als leden van de kenniskring. In de jaren die volgden, hebben we intensief samengewerkt en dat doen we gelukkig nog steeds. Bedankt voor jouw inzet bij het benaderen van organisaties, bij het zoeken naar respondenten en bij het maken van verbindingen tussen mensen. Bedankt ook voor je luisterend oor en voor het vertrouwen in mij. Elsbeth, ik wil je bedanken voor je oprechte aandacht en interesse, voor je kritische, maar altijd meedenkende houding. Wat fijn om je als collega te hebben.

Mijn proefschrift had ik nooit kunnen voltooien zonder mijn gezin, familie en vrienden. Renée, Jonas, Wilbert, Sander en Ton, al sinds de middelbare school delen we vele interesses en zien we hoe eenieder zich verder ontwikkeld. Ik vind het heerlijk om samen met jullie en Martijn, Janine, Rianne en Denise en alle kinderen lief en leed te delen.

Mijn handbalmaatjes van Vespo. Ik kan me geen gezelliger handbalteam voorstellen. Een uur lang alles vergeten en samen voor de winst strijden. Dank voor deze afleiding en gezelligheid.
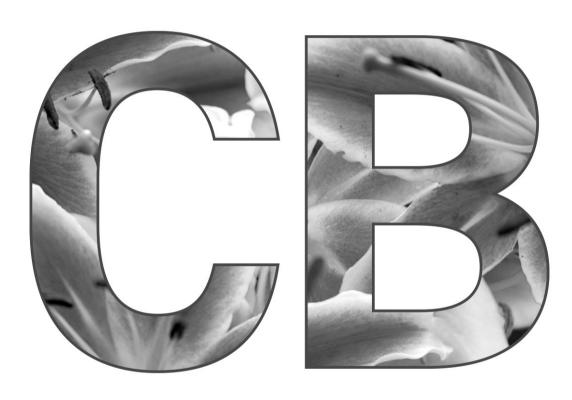
Mijn vier beste maatjes: Maartje, Josine, Renée en Petra. Maartje, dank voor alle dagen die we samen gezellig hebben gekletst, voor het uitwisselen van ervaringen over de zorg, maar met name voor je relativeringsvermogen. Er is niemand die zo mij zo snel in de relaxstand krijgt als jij. Josine, startend als sportmaatje, maar al snel veel meer dan dat. Jij bent er voor me, je luistert naar me en je herinnert me eraan dat we vooral moeten genieten van de mooie dingen in het leven. Renée, jij bent al heel lang mijn beste maatje, vanaf de derde klas van de middelbare school. Wat ben ik blij dat je weer lekker dichtbij woont, wat is het heerlijk om met je te kunnen kletsen, alles te kunnen delen en onze kinderen samen te zien spelen. Jij bent er altijd voor me. Dank. En Peet … Ik ken geen liever, meer oprecht mens dan jij. Jij gelooft altijd in mij, luistert naar me en staat voor me klaar. Samen handballen, samen fietsen, samen lunchen, samen borrelen, in onze drukke agenda's vinden we altijd wel een gaatje. Ik hoop dat we dit nog heel lang blijven doen en wat ben ik super vereerd dat jij vandaag mijn paranimf bent.
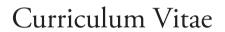
Lieve familie, Maria en Hans, Mandy, Maurice, Martijn, Mandy, Roel en Sandy en alle kinderen, wat fijn dat ik dit bijzonder moment met jullie mag delen.

Lieve pa en ma. Wie had gedacht dat er ooit een einde aan mijn promotieonderzoek zou komen. Maar het is nu toch echt zo. Dank voor alle kansen die jullie me hebben geboden. Jullie bleven er altijd op vertrouwen dat het zou lukken. Ik zie de trots in jullie ogen. Maar dit alles is alleen mogelijk omdat jullie er voor me zijn, voor ons gezin, voor jullie drie lieve kleinkinderen. Ik draag dit boek op aan de persoon waar ik zo veel van houd. Mijn lieve, grote zus Suzan. Onze kei. Zij was en blijft de drijvende kracht in mijn leven. Zij heeft mij doen inzien dat het leven zo mooi kan zijn, met zulke fantastische ouders die altijd voor haar hebben gezorgd. Altijd stonden jullie voor ons klaar. Dank hiervoor.

En last, but not least. Mijn gezin. Lieve William, bedankt voor al je steun en je geduld. Door jouw inzet heb ik de ruimte gevoeld om al deze jaren aan mijn proefschrift te werken. Je bent zo bijzonder, in je zijn. Je laat me nadenken, spiegelt mij en laat mij het beste uit mezelf halen. Dank daar voor.

Lieve Jelle, Fleur en Beau. Jullie knuffels, tekeningen, lieve blikken in jullie ogen en de onuitputtelijke liefde die ik van jullie krijg, hebben mij de kracht gegeven om dit te kunnen doen. Ik geniet van jullie en ben enorm trots op jullie. Dank jullie wel.
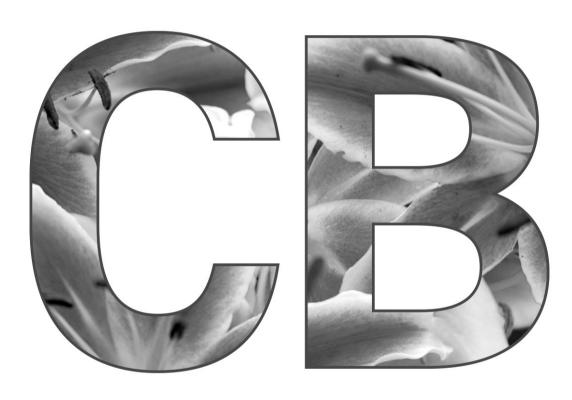
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Curriculum Vitae

Kim van den Bogaard was born on December 16, 1983 in Erp, the Netherlands. She graduated from pre university education at the Zwijsen College in Veghel in 2001. Afterwards, she studied Pedagogical and Educational Science at the Radboud University in Nijmegen (2004-2009), where she graduated cum laude with a master degree in Pedagogy (specialized in Learning and Development). During her study, she worked as a Discrete Trial Trainer with children with intellectual disabilities and/ or autistic spectrum disorder at Driestroom. After graduation, she combined working as a psychologist at Driestroom with working as a research assistant at the lectureship Support for People with an Intellectual Disability of the HAN University of Applied Sciences. In 2010, she started at Dichterbij STEVIG (previous Dichterbij Specialized Care), were she became a full-time researcher in care for people with intellectual disabilities. As of February 2012, she started at Dichterbij Innovation and Science as a science practioner to conduct her PhD-project at the Academic Collaborative Center Living with an intellectual disability (Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University) supervised by professor P. J. C. M. Embregts and professor H. L. I. Nijman. The results of this research are presented in this thesis. Currently, she is affiliated as a postdoctoral researcher at the Academic Collaborative Center Living with an intellectual disability.

Kim van den Bogaard werd op 16 december 1983 geboren te Erp. In 2001 behaalde zij haar vwo-diploma aan het Zwijsen college te Veghel. Vervolgens ging zij Pedagogische Wetenschappen en Onderwijskunde (PWO) studeren aan de Radboud Universiteit te Nijmegen (2004 - 2008), waar zij cum laude afstudeerde binnen de specialisatie Orthopedagogiek: Leren en Ontwikkeling. Tijdens haar studie heeft zij gewerkt als Discrete Trial Trainer binnen de Driestoom, op een groep voor kinderen met een verstandelijke beperking en/of autisme spectrum stoornis. Na haar afstuderen heeft zij haar baan als orthopedagoog binnen de Driestroom gecombineerd met onderzoek binnen het lectoraat Zorg voor Mensen met een Verstandelijke Beperking van de Hogeschool van Arnhem en Nijmegen. In 2010 is zij overgestapt naar STEVIG (onderdeel van Dichterbij, voormalig Dichterbij Specialistische Zorg) om zich daar volledig toe te leggen op onderzoek binnen de zorg voor mensen met een verstandelijke beperking. Per 1 februari 2012 is zij vanuit Dichterbij Behandelinnovatie en Wetenschap als science practioner gestart bij de Academische Werkplaats Leven met een verstandelijke beperking (Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University), waar zij onder begeleiding van prof. dr. P. J. C. M. Embregts en prof. dr. H. L. I. Nijman haar promotieonderzoek heeft uitgevoerd. De resultaten van dit onderzoek worden gepresenteerd in dit manuscript. Momenteel werkt zij als postdoc onderzoeker bij de Academische Werkplaats Leven met een verstandelijke beperking.

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