Expressions of stress of people with severe intellectual disabilities and sensitive caregiving to regulate stress: A qualitative study
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ABSTRACT

Background: People with severe to profound intellectual disabilities have particular needs for others to help them regulate stress. Such support may be hampered by difficulties in detecting and interpreting expressions of stress. This study aimed to describe and identify stress-related behaviours and sensitive, stress-regulating responses to these behaviours.

Method: Video recordings of psychotherapeutic interactions between four clients with severe intellectual disabilities and behavioural problems and two attachment therapists were analysed using a stepwise spiral of analysis approach. Stress-related behaviours were identified with a behaviour rating scale for arousal and valence.

Results: Distinct stress-related behaviours were subdivided into stress-specific, non-stress-specific, and client-specific behaviours. Additionally, examples of responsive behaviours to clients’ expressions of varying arousal and valence were found.

Conclusions: A wide variety of expressions indicative of different levels of arousal were found, with few expressions specific for stress. The descriptions of responsive behaviours might support parents and caregivers in external stress regulation.

KEYWORDS
Severe and profound intellectual disabilities; stress-regulating relationship; expressions of stress; parents and professional caregivers; sensitive and responsive behaviour

People with severe to profound intellectual disabilities depend on others to understand their needs in daily life, because of a combination of severe to profound intellectual, motor and/or sensory disabilities and/or health problems (Nakken & Vlaskamp, 2007). Accordingly, they need effective buffers, such as sensitive and responsive caregivers, to regulate their stress and prevent development of behavioural problems (Janssen et al., 2002), such as self-injury, stereotypies, and aggression (Poppes et al., 2010). The high prevalence of behavioural problems in people with severe and profound intellectual disabilities (e.g., 82% of the participants in the study of Poppes et al., 2010) has been linked to limited resilience against life’s challenges due to limited coping skills and limited access to resources such as the support from attachment figures (Janssen et al., 2002).

Bowlby (1969/1982) theorised that perceived conditions of danger or stress in the presence of attachment figures are likely to activate attachment behaviour of the child. Behaviours such as crying, reaching out, and crawling towards the attachment figure serve the function to attain or maintain proximity to attachment figures (Cassidy, 2008). The way in which attachment figures respond to such behaviours determines whether physiological arousal and emotions are modulated (Willemen et al., 2009). Sensitive responses facilitate the most effective and adaptive ways for regulating stress and coping. However, if signals of distress are missed or ignored, arousal may escalate and engender problem behaviour. Thus, sensitive and responsive parents and other attachment figures are important in supporting children’s stress regulation skills.

Even though people with severe to profound intellectual and multiple disabilities, henceforth referred to as severe intellectual disabilities, have difficulties using the attachment figure as an external stress regulator due to limited cognitive skills (Janssen et al., 2002), they do show attachment behaviour, such as proximity- and contact-seeking and contact-maintaining (Vandesande et al., 2019). Rather than using locomotor skills, they may vocalise, gaze, and smile. These behaviours might be subtle and difficult to discern, especially in children with motor or visual impairments (Vandesande et al., 2019), which are prevalent in this population (Nakken & Vlaskamp, 2007).
The uniqueness and subtlety of these attachment behaviours means that attachment behaviours are often idiosyncratic and ambiguous (Vandesande et al., 2019), presenting a challenge for others to respond sensitively (Janssen et al., 2002).

Despite the fact that it is challenging to discern and identify behaviours related to stress and attachment in people with severe intellectual disabilities, parents seem to evolve an intuitive understanding of the signals of their child’s communication, wellbeing, and pain (Kruithof et al., 2020). Parents are thought to develop this unique, experiential knowledge over time while caring for their child. However, the fragility of this knowledge is also described (Kruithof et al., 2020), as most adults with severe intellectual disabilities in the Netherlands live in care facility homes (Vugteveen et al., 2014) where different caregivers are involved and caregiver turnover is high (Buntinx, 2008). Parents’ knowledge is partly transferable to professionals, but it takes considerable time and emotional involvement to learn how to readily interpret the communication and wellbeing of these clients (Kruithof et al., 2020). Professionals are involved with multiple clients and are limited in their time, making it difficult for them to develop this intuitive understanding that parents do have.

In a study examining the effect of the Integrative Therapy for Attachment and Behaviour (ITAB; Sterkenburg et al., 2009), in which the professional therapist spent a lot of exclusive time with the client, the possibility of building a therapeutic attachment relationship between professionals and clients with severe intellectual disabilities was demonstrated. This therapy program focuses on behavioural problems, especially during stress, in clients with disrupted attachment histories. In the first phase of this therapy, the therapist attempts to build an attachment relationship with the client through intensive contact with sensitive and responsive interactions (Sterkenburg & Schuengel, 2020). Suggestive of the development of a therapeutic attachment relationship was the increase in proximity-seeking attachment behaviour during stress and significant lower sympathetic arousal during experienced stress towards the attachment therapist in comparison to the control therapist, whose treatment only consisted of positive attention (Schuengel et al., 2009). Through intensive contact and sensitive and responsive interactions, stress-regulating relationships between professional therapists and clients with severe intellectual disabilities might have developed.

Accurate and intuitive understanding of often ambiguous signals in communication might be difficult to achieve for professional caregivers without expert guidance. The basis for such guidance may be found in specific stress-related behaviours and helpful responses to those behaviours. Kruithof et al. (2020) described that parents communicated with professionals by objectifying their interpretations. The first step in creating a general objectification is to describe the stress-related behaviours of people with severe intellectual disabilities in a way that supports caregivers in recognising and interpreting signals of stress. Secondly, to regulate the observed stress, caregivers need to be responsive to stress-related behaviours. Examples of responsive behaviours of the attachment therapists of the ITAB-study may serve as a possible guide, as these attachment therapists regulated the clients’ stress with highly sensitive and responsive behaviour (Schuengel et al., 2009), confirmed with the maximum score on the NICHD sensitivity scale (NICHD, 1993; Sterkenburg & Schuengel, 2010).

To support caregivers in recognising and being sensitive to signals of stress of people with severe intellectual disabilities, the primary aim of this study was to identify expressions of stress from concrete behavioural descriptions during interactions with a potential professional attachment figure. The secondary aim of this study was to describe examples of stress-regulating, responsive behaviours of the therapists in interaction with clients with severe intellectual disabilities.

**Method**

**Study design and analysis**

In this qualitative study, the Spiral of Analysis (Boeije, 2010) was used to collect and extract concrete behaviours of clients and therapists from the ITAB-videos (Sterkenburg et al., 2008) and link these behaviours to clients’ stress. The Spiral of Analysis is a well-established method based on the principle of constant comparison in the Grounded Theory Approach (Glaser & Strauss, 1967).

The systematic approach of the Spiral of Analysis (Boeije, 2010) consists of three stages. First, in open coding, concrete behaviours of clients during interaction with the therapists were labelled with a code. Second, in axial coding, categories and subcategories were identified from the coded behaviours. Finally, in selective coding, all the codes were linked to the stress level of clients and therapists’ behaviours in response to clients’ stress were described. In this final step, the descriptions of behaviour were aggregated with the levels of arousal and valence of clients to make the new information operable for the understanding and supporting of stress regulation of people with severe intellectual disabilities.

**Participants**

From the ITAB-study (Sterkenburg et al., 2008), four of the six participants were included as these
representatives gave written informed consent for the use of the ITAB-videos in the current study. These participants were children (10, 16, 17, and 17 years old) of both sexes, living in a group facility home or in foster care and from Dutch as well as foreign descent. All participants had a severe intellectual disability (IQ ranged from 20 to 34, on file) and a history of limited opportunities to form stable attachments (due to repeated changes of primary caregivers and/or rearing in unusual settings). They were blind or had a visual impairment.

At the start of the ITAB-study, the participants showed persistent and severely challenging behaviour, assessed with the “Severe Challenging Behaviour Consensus Protocol – National Institute for Health Care Management” (in Dutch; Consensusprotocol Ernstig Probleemgedrag – Nationaal Ziekenhuisinstituut; Kramer, 2001). Clients with an aversion to physical contact and those diagnosed with an autism spectrum disorder were excluded from the ITAB-study.

The ITAB was performed by two registered clinical psychologists, both working as psychotherapists at the Department of Psychotherapy of Bartiméus: an organisation that provides education, care and services for people with visual and/or intellectual disabilities. Besides being clinical psychologists, therapist 1 was also graduated as developmental psychologist and therapist 2 as child and adolescent psychotherapist. Therapist 1 is the developer of ITAB and also the last author of this paper, and therapist 2 received the ITAB-training from therapist 1. Both therapists had extensive therapeutic experience in working with people with severe intellectual disabilities and attachment and behavioural problems (respectively 14 and 7 years).

Medical ethical approval was obtained from the Vrije Universiteit Medical Centre Medical-Ethics Review Board (project: “Testing an attachment-based behaviour modification treatment” – Protocol 02/130).

Materials

ITAB-videos

The ITAB consisted of three phases of which the first phase, the attachment-based therapy, is based on the ontogenesis of attachment relationships Bowlby (1969/1982). The sessions during this phase were focused on: (1) establishing contact in ways experienced as enjoyable by the client (sub-phase “bonding and making contact”), (2) establishing synchrony in interactions (sub-phase “symbiosis”), and (3) scaffolding exploration and play (sub-phase “stimulation and individuation”), fostering the development of a therapeutic attachment relationship (Sterkenburg & Schuengel, 2020). As the current study focused on stress-regulating relationships, only videos from this first phase were included. One of three therapy sessions per week, over four to five months, was video recorded during the ITAB-study. In total 79 sessions of the four participants in this phase were videotaped. Sessions had a standard duration of 45–50 min. For an overview of the videos per client and per sub-phase of this first ITAB-phase, see Table 1.

“Arousal & valence-scale”

An adjusted version of the scoring system “Behaviour Observations – Arousal & Valence” (Sterkenburg & Frederiks, 2017) was used to assess the clients’ stress during the ITAB-sessions. This coding system was developed by observing adults with visual and severe to profound intellectual disabilities and was previously used in research to assess the emotional behaviour of children with severe intellectual disabilities in a stress-regulating relationship (Vandesande et al., 2020). The intrarater reliability for both arousal and valence proved to be substantial (Vandesande et al., 2020). The coding system consists of two scales: arousal, the amount of emotion or tension a person experiences, and valence, the positive or negative value of the emotion or tension. Arousal was measured on a 6-point Likert scale from 1 (very low) to 6 (very high), of which in the current study only the scoring anchors were changed to “low alertness” (1), “under-stimulated” (2), “alert & active” (3), “slightly tense” (4), “tense” (5), and “overstung” (6). The original valence-scale is a 13-point Likert scale from −6 (very high negativity) to 0 (neutral) to 6 (very high positivity). For this study, the valence-scale was reduced to a 6-point Likert scale from “very high negativity” (−3) via “very low negativity” (−1) and “very low positivity” (1) to “very high positivity” (3).

| Table 1. Division of the videos per sub-phase and the total number of videos. |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Sub-phase                  | 1.1 Bonding and making contact ($n^*$) | 1.2 Symbiosis ($n^*$) | 1.3 Stimulation and individuation ($n^*$) | Total ($n^*$) |
| Client | Therapist | 1 | 2 | 3 | 4 | Total |
| 1 | 1 | 8 | 5 | 7 | 20 |
| 2 | 1 | 7 | 6 | 7 | 20 |
| 3 | 2 | 5 | 6 | 10 | 21 |
| 4 | 2 | 6 | 4 | 8 | 18 |
| Total | 26 | 21 | 32 | 79 |

$n^*$ = number of videos.
The Arousal & Valence-scale operationalises a state of stress as an arousal-score of 6 (overstrung) or a valence-score of −3 (very high negativity) or −2 (negativity). The words used in the descriptions of these scores that indicate stress are “overstrung,” “freaking out,” “no control over behaviour,” “stressed” and “slightly stressed”. Henceforth an arousal-score of 6 or a valence-score of −3 or −2 is referred to as a “stress-score.”

Procedures

Table 2 gives an overview of the systematic procedure of the Spiral of Analysis (Boeije, 2010) in this study. The table shows which actions were performed per step, how many videos were coded during each step and by which coders.

The coding process was coordinated by researcher 1, who is also parent of a child with a severe intellectual and multiple disability. To perform the coding, two focus groups were composed of motivated students in the field of social care. The students received instructions prior to coding and coded in joint sessions as well as individual. In order to achieve agreement, the codes were discussed in the focus groups.

Open coding

During open coding, ITAB-videos were analysed by describing the behaviour of the clients and their level of arousal (1–6) and level of valence (1–6). Every observed behaviour of the client was given a code and an arousal and valence score according to the adjusted Arousal & Valence-scale (Sterkenburg & Frederiks, 2017). The codes of these concrete descriptions of behaviour consisted of the letter C (client) and a number for the specific behaviour. For example, C29 was the code for “clapping hands.” Additionally, the coders answered the questions “What behaviour does the client show when experiencing stress?” and “What behaviour does the therapist show in response to the client?”

Open coding was performed as a two-step-process in which first codes were generated and subsequent these codes were checked and saturated by using “new” data. As in this study videos of four clients were available, the videos of three randomly chosen clients were used to generate the codes and the videos of the fourth client were used to validate the generated codes. In order to be as complete as possible in generating codes, sufficient videos and videos from all three sub-phases had to be analysed, as different sub-phases could provide unique information. Therefore, the authors estimated that it would be sufficient to select nine videos per client with three randomly selected videos from each of the three sub-phases of attachment therapy. Due to technical problems, three of the videos of client 1 had to be replaced with two videos of client 2. This resulted in a total of 26 coded videos. The generated codes were divided into three categories: “Position” (with four subcategories), “body parts” (with seven subcategories) and “sounds.” These codes were used to analyse the randomly selected videos (without distinguishing between sub-phases) of the fourth client.
Table 4. Non-stress-specific behaviour clients.

| Category   | Behaviour                        | Times coded (n) | Clients (n) |
|------------|----------------------------------|----------------|-------------|
| (1) Actions| Takes toy/object                  | 9              | 2           |
|            | Throw object away                 | 7              | 3           |
| (2) Sounds | Laughing                         | 21             | 3           |
|            | Talking                           | 28             | 3           |
|            | Crying/Whining noises             | 9              | 3           |
|            | Grumble/moan                      | 15             | 3           |
| (3) Position| Walk/move place                   | 8              | 2           |
|            | Standing                          | 18             | 4           |
|            | Sitting                           | 47             | 4           |
|            | Sitting on therapist's lap         | 9              | 2           |
| (4) Whole body| Moving whole body along         | 10             | 4           |
|            | with therapist                    |                |             |
|            | Detach body from therapist        | 18             | 4           |
| (5) Upper body| Rocking upper body              | 21             | 3           |
| (8) Hands  | Pushes therapist/object           | 23             | 4           |
|            | Rubs eyes                         | 7              | 2           |
|            | Beats                             | 16             | 4           |
|            | Stroking/feeling/fiddling         | 9              | 3           |
|            | Put hands over/near ears          | 2              | 2           |
| (9) Feet   | Bouncing on feet                  | 5              | 2           |
| (10) Head  | Bending head forward              | 20             | 3           |
|            | Lifts head                        | 12             | 3           |

*a = times the behaviour is coded in moments of stress. *b = clients with whom behaviour occurred.

...until the point of saturation was reached, which means no more additional codes were found. This occurred after 10 videos were coded and at this point 108 codes were generated to describe behaviour of the clients.

Axial coding

The main goal of axial coding was to arrange the codes resulting from the open coding in categories and subcategories. In this step the ITAB-videos were each divided in two fragments of 20 min. Each coder of focus group B coded 40 randomly chosen video-fragments. At least two coders coded each fragment independently in order to discuss disagreements. In total 61 videos were coded (per client respectively 17, 15, 16, 13 videos), of which some coders coded the first 20 min and other coders coded the last 20 min.

The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min. The coders of focus group B discussed with researcher 1 how the videos were coded and how the coders coded the last 20 min.

Axial coding

In the final step of the coding process, selective coding, the codes of behaviour were linked to the arousal- and valence-scores in order to identify expressions of stress. The coding files containing a stress-score (an arousal-score of 6 or a valence-score of −3 or −2) were selected. This resulted in a selection of coding files of 28 videos, with the distribution of 10, 7, 3 and 8 among the clients.

To investigate links between the clients’ behaviour and stress, a table was created of the coded codes in combination with the given stress-score. This table included 80 codes of behaviour. Only codes that were marked as “behaviour when experiencing stress” at least once were included. To find out whether behaviour only occurred in moments of stress or also in moments with no stress, the collected codes were divided in stress-specific and non-stress-specific behaviour, by checking the occurrence of the collected codes when a stress-score was not scored.

Selective coding

To link responsive behaviour of the therapists to clients’ arousal, a table was created containing not only the stress scores, but all levels of increased arousal (4, 5 and 6), because the researchers assume that stress regulation occurs not only at moments of stress, but also at moments of increased arousal to prevent stress. In the columns per arousal level the answers to the question “What behaviour does the therapist show in response to the client?” described in open coding were listed. The same above-mentioned 28 coding files were used as in these files stress was scored and therefore these files should also contain the increased arousal before and after the stress. The created table included 64 responsive behaviours, with some identical behaviours in the different levels of arousal. A distinction of positive and negative valence was made by colouring the behav-

Table 5. Client-specific behaviour clients.

| Client | Category | Behaviour                     | Times coded (n) |
|--------|----------|-------------------------------|-----------------|
| 1      | 8. Hands | Fluttering hands              | 1               |
| 10. Head | 3. Shaking head          | 3               |
| 4      | 2. Sounds | Pant/breathing heavily      | 10              |
| 4      | Whole body | Dancing            | 3               |
| 4      | Whole body | Jumps up and down  | 4               |
| 6      | Lower body | Kicking (object) | 2               |
| 8      | Hands    | Touch/remove plasters    | 10              |

*a = times the behaviour is coded in moments of stress.
Results

**Behaviour of the clients linked to stress**

The links found between the behaviour and the stress of the clients resulted in a distinction between stress-specific behaviour (Table 3), non-stress-specific behaviour (Table 4), and client-specific behaviour (Table 5). To illustrate, the code “talking” often occurred in combination with a stress-score, but also at other levels of arousal and valence (non-stress-specific). However, the code “yelling” only occurred in combination with a stress-score, suggesting that yelling was a specific expression of stress. Some codes coincided with stress only for a specific client.

Table 3 shows the four stress-specific behaviours found in the analysis of the coding files. These codes only occurred in combination with a stress-score. Two of the behaviours are client-specific as well, as they only occurred at a specific client in moments of stress.

Table 4 gives an overview of the 22 non-stress-specific behaviours found in this study. These codes occurred in combination with a stress-score, but also at other levels of arousal and valence.

The codes presented in Table 4 are not specific to stress, but occurred with stress as well as with no stress. However, the variation in arousal and valence for the same code were visible in the initial descriptions of the behaviour during open coding. To illustrate, the code “laughing” was initially described in many different ways, like “laugh softly,” “laughing exuberantly,” “laugh very loud,” and “laughing chaotically.” Another illustration is the code “standing” with initial descriptions as “getting up and sitting down again frequently” and “stands up resolutely.” These kinds of additions of the intensity, volume and frequency of the behaviour occurred frequently and in many different descriptions. In the process of open and axial coding these kinds of differentiations were taking together to form one observable, unambiguously code; in the case of the illustrations respectively “laughing” and “standing.”

Table 5 presents seven client-specific behaviours regarding stress found in this study. Most behaviours also occurred in other clients, but not in combination with a stress-score.

Tables 3, 4, and 5 summarise 33 behaviours that occurred frequently at moments of stress, of which only four behaviours were specific to stress. The other 30 behaviours occurred both at moments of stress and at moments of no stress, whether these were client-specific or not. The non-stress-specific behaviours occurred more frequently and were more generalised across the four clients.

**Descriptions of therapist-behaviour in response to clients’ stress**

Table 6 presents the descriptions of behaviours of the therapists linked to the levels of arousal 4 (slightly tense), 5 (tense) and 6 (overstrung) with the distinction made between positive and negative valence. To illustrate, item 14 “distract attention” was seen at the level of arousal “tense” (5) at both positive and negative valence. “Take physical distance” was also seen at both positive and negative valence, but at the level of arousal “overstrung” (6). However, the behaviour “acknowledge
emotion” was seen at all high levels of arousal (4, 5, and 6) only with negative valence.

Discussion

In the identification process of expressions of stress, only a few behaviours could be identified as “stress-specific” behaviours while the majority of the stress-related behaviours found in this study were identified as “non-stress-specific” behaviours. Furthermore, the non-stress-specific behaviours were displayed more generally across sessions and across clients than the stress-specific behaviours. As a consequence of finding few stress-specific behaviours with limited generalisability, linking stress directly to specific client-behaviours may not be feasible. However, the non-stress-specific behaviours found in this study may still be used to identify stress, using information from other sources about the likely state of arousal and valence of emotions. The examples of stress-regulating, responsive behaviours described in this study could be linked to clients’ level of arousal and valence to indicate which levels of arousal and valence the behaviours can respond to.

Interpretation

Client-behaviour linked to stress

The limited possibilities for linking stress directly to specific behaviours is supported by the observation that most of the behaviours in moments of stress also occurred in moments of no stress (“non-stress-specific” and “client-specific” behaviours). In these cases, the differentiation in the stress level of the client appeared in the initial descriptions of the intensity, volume or frequency in the codes (e.g., “laugh softly,” “laughing exuberantly”). These descriptions of the intensity, volume, or frequency have been eliminated from the final behavioural descriptions (e.g., laughing), but in the end these nuances may be what is needed to recognise patterns of behaviour as expressions of stress. To illustrate, clients can rock their upper body gently, but also wildly. Not the behaviour itself (rocking upper body) gives information about the stress level but its intensity. In this study the Arousal & Valence-scale (Sterkenburg & Frederiks, 2017) was used to provide more information about the described behaviours. The finding of mostly non-stress-specific behaviours suggests that the behaviour itself cannot serve as an indication of the stress level and that valuing behaviour with an arousal- and valence score is necessary in order to label behaviours as potential expressions of stress.

Examples of responsive behaviours for external stress regulation

Some of the examples of responsive behaviours described in this study were responses to different or all levels of arousal and valence, for instance “describe emotions,” “acknowledge emotions,” “give compliments” and “look at client/make contact.” Some examples of responsive behaviours are more specific linked to a certain level of arousal or valence of the clients, which fits the principles of the “Circle of Security” (Marvin et al., 2002), an educational tool to explain attachment theory. The Circle of Security illustrates the ongoing process of external stress regulation, as a “safe haven,” that is alternated with stimulation of exploration, as a “secure base” (Ainsworth et al., 1978; Marvin et al., 2002). In the examples of therapists’ responsive behaviours, the stimulation of exploration is reflected in behaviours as “positively motivate & confirm positive behaviour,” “support play,” “stimulate/encourage play/exploration,” “mirroring position/behaviour/sounds/emotions” and “move together/along.” These responsive behaviours are mostly linked to the “slightly tensed”-arousal level of the client, which suggest that the adequacy of these responses depend on the arousal level of the child. If the arousal level of the child increases, the attachment figure is the “safe haven” (Marvin et al., 2002), who helps to regulate the stress. The overview of therapist-behaviours shows concrete terms as “distract attention” and “down-regulate arousal.” If the child becomes over-aroused, the attachment figure needs to take control to comfort and protect the child from stress (Marvin et al., 2002), which is reflected in the overview in behaviours as “appease, calm down, reassure” and “take physical distance.” Comparable to the Circle of Security (Marvin et al., 2002), which can give parents and professional caregivers insight in their role in the attachment relationship, the examples of therapists’ responsive behaviours may offer guidance in direct interaction with people with severe intellectual disabilities.

Implications

Vandesande et al. (2019) remarked that the unique and subtle behaviour of people with severe intellectual disabilities are difficult to capture in the abstract item descriptions of existing observation lists of attachment behaviour. Although observing attachment behaviour is related to, but not directly the same as observing expressions of stress, the importance of the nuances in observing expressions of stress in people with severe intellectual disabilities indicated by the results of this study are in line with the remark of Vandesande and
colleagues. They suggest a coding system that includes alternative (non-locomotor) behaviours and is based on observable behaviour. A coding list of concrete behavioural descriptions was developed in this study, including the alternative and non-locomotor behaviours. All behaviours were coded and included in this behavioural catalogue, from eye movement to sounds and from head direction to foot movements. This catalogue may help to identify characteristic behaviours, including non-physical differentiations in behaviour, with regard to stress and proximity seeking in a stress-regulating relationship. Vandesande et al. also stated that existing observation lists were not able to discriminate subtlety in behaviour, because different behaviours of clients received the same score, especially at the lower end of a rating scale. Supplementing the behavioural catalogue with the adjusted Arousal & Valence-scale might assist in capturing the subtlety in behaviour with which people with severe intellectual disabilities express their stress, by giving a nuanced value to the observed characteristic behaviours.

The coding system may be used to support co-operation between parents and professional caregivers to assess multi-interpretable signals of communication. Such a common vocabulary is helpful when parents and professional caregivers discuss highly emotionally charged interactions, which also includes stress-manifestations in relation to pain and illness. In the co-operation between parents and professional caregivers, an individual stress-related behavioural pattern could be composed using the coding system, which is helpful in recognising stress in their child or client. Additionally, the examples of therapists’ responsive behaviours may be used by parents and professional caregivers to expand their own repertoire of responsive behaviours. Kruithof et al. (2020) described that parents can transfer their way of interacting with their child to professional caregivers, by letting them observe the parent–child interaction and learn from their examples. The examples of therapists’ responsive behaviours may serve as a basis to make these interactions and parental reactions concrete.

**Strengths and limitations**

Although the video-data of the ITAB-study was a good starting point to analyse stress-regulating relationships between clients with severe intellectual disabilities and their attachment therapists, the multiple case design of the ITAB-study meant that just four clients and two therapists were available for observation. This may have resulted in limited variation in behaviours. Another limitation is the generalisability of the results to daily life interactions as in this study only videos made during the ITAB-intervention were analysed. In future research with a larger sample and focused on daily life interactions the completeness of the stress-related behaviours of the clients need to be checked and supplemented if necessary, as well as the examples of responsive behaviours of the therapists and the links to the levels of arousal and valence.

Because of the severe communicative and cognitive limitations of people with severe intellectual disabilities, observation is an important method of attempting to understand their behaviour. This qualitative research was conducted in a structured and methodological way by using the Spiral of Analysis method (Boeije, 2010) and by selecting the ITAB-videos randomly. This study is unique in describing concrete behaviours and in linking these concrete descriptions to the stress level of the client. Many different coders coded videos and each video was coded twice in order to prevent personal interpretation as much as possible. In addition, the coders were students with different educational backgrounds, from university students to practical college students, as to contribute to the use of the descriptive behaviours for research as well as for practice.

**Recommendations**

The current results lay the groundwork for developing an instrument for practice, in which the behavioural catalogue may support identifying stress-related behaviour and additionally the adjusted Arousal & Valence-scale may support capturing subtle differences in behaviour. Subsequently, the examples of responsive behaviours may help parents and professional caregivers to respond adequately in order to regulate the stress. Future research should investigate whether the proposed instrument is an applicable, reliable, valid and effective tool to observe, interpret and regulate stress in people with severe intellectual disabilities.

**Conclusion**

In order to contribute to the understanding and supporting of stress regulation by parents and professional caregivers in people with severe intellectual disabilities, concrete behaviours of clients were categorised as stress-specific, non-stress-specific, and client-specific behaviour. Additionally, examples were described of responsive behaviour of attachment therapists in relation to the level of arousal and valence of the client.

The behavioural catalogue generated in the study introduces an extensive overview of the characteristic behaviour of people with severe intellectual disabilities
in a stress-regulating relationship, which could not be scored in existing coding systems thus far. In addition to the behavioural catalogue, a rating scale using arousal and valence parameters might capture subtlety in behaviour in relation to stress. Developing a tool could support parents and professional caregivers of people with severe and profound intellectual disabilities in building stress-regulating relationships by being sensitive and responsive, and moreover may serve as a tool to support the co-operation between parents and professional caregivers. Regulating stress of people with severe and profound intellectual disabilities will prevent or decrease behavioural problems, stimulate desired behaviour and provide more opportunities for positive development.

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