Assessing Challenging Behaviour in People with Hearing Impairments and Profound Intellectual Disabilities: The Development of an Individual Behaviour Observation and Recording Scale

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ABSTRACT

Background and Objective: Studies on people with both Hearing Impairments (HI) and an Intellectual Disability (ID) are rare, although in clinical practice aggressive incidents such as destructive behaviour aimed at objects or other people and self-harming behaviour are mentioned as common problems. In studies into people of both groups of people separately prevalence rates of behavioural problems vary widely and many risk factors for developing behavioural problems are mentioned. Although recognizing risk factors can contribute to the understanding of behavioural problems, empirical research is needed into relations between behaviour and several external factors to gain more insight into direct causes of behavioural problems. The aim of this article is to detect a scale with which behaviour of individuals with both ID and HI can be observed and recorded in order to study relationships between behaviour and several external factors. Six conditions for such a scale are defined.

Results: Regrettably, none of the scales we studied meets all our conditions and are therefore not suitable for our study. Because of this shortage we developed our own Individual Behaviour Observation and Rating Scale (IBORS) which is based on eight dimensions of behaviour and five levels of severity which results in a unique behavioural repertoire of each individual person.

Conclusions: Although we succeeded in the construction of a scale which meets our conditions, some remarks can be made. The construction of an individual behaviour repertoire is an extensive process in which several familiar people should be involved. Secondly, the classification of eight dimensions of behaviour was not based on a scientific theory or construct. It is recommended to do further research on these topics and especially on the psychometric properties of IBORS.

KEYWORDS

Behavioural problems, deaf, hard of hearing, intellectual disability, observation method

Introduction

Professionals working with people with both an Intellectual Disability (ID) and Hearing Impairments (HI) have frequently reported confrontations with behavioural problems1. In particular, aggressive incidents such as destructive behaviour aimed at objects or other people and self-harming behaviour are mentioned as common problems.
Little research on behavioural problems in people with a combination of both disabilities has been found. An exception is the study of Timehin and Timehin. They report that of 543 people 62% shows problem behaviour and 34% exhibits self-harming behaviour.

Much research has been done into people with ID. In this group behavioural problems frequently occur 4-9. Prevalence rates vary from less than 10% to over 40%. These results depend on the definition and terminology used to indicate behavioural problems, background and age of the population, methods of data collection used and psychiatric scales employed. Several risk factors for these behavioural problems are reported. Some studies found a gender effect in which males exhibited more behavioural problems than females 5-7,10. On the contrary, Deb, Thomas & Bright found that the rate of self-harming behaviour was significantly associated with the female gender. Emerson et al.6 and Tyrer et al.7 reported an age effect; adolescents and young adults showed more behavioural problems than other age groups. The severity of the ID is also mentioned as a risk factor by several studies 4,5,7,10. Additional problems such as sensory impairment11,12 and autism13,14 are also found as risk factors.

In people with HI similar findings were reported for the prevalence and distribution of behavioural problems24-28. Prevalence rates also vary from less than 10% to over 40%. In these studies however, the concept of behavioural problems is defined in a more general and uniform way than in studies in people with ID. The most important reason for this seems to be the use of only two diagnostic scales and check for their suitability of using them for groups separately. Furthermore it is plausible that communication difficulties form an important risk factor leading to behavioural problems in individuals with ID or HI.

From the results of the studies mentioned above we conclude that in people with ID and also in people with HI an increase of behavioural problems is found when additional handicaps occur. It is plausible that the prevalence rates of behavioural problems in people with both ID and HI are higher than in both groups separately. Furthermore it is plausible that communication difficulties form an important risk factor leading to behavioural problems in individuals with ID or HI.

Unfortunately we did not find any study on causal relations between risk factors and behavioural problems. Although recognizing risk factors can contribute to the understanding of behavioural problems, empirical research is needed into relations between behaviour and several external factors to gain more insight into direct causes of behavioural problems. When behavioural problems occur following specific external events, this could be an indication that this behaviour might be caused by these factors. In order to gain more insight into the relations between behaviour and external factors, it is necessary to use a scale with which behaviour can be observed and recorded. In this article we will first review existing behaviour observation and recording scales and check for their suitability of using them for
studying individuals with ID and HI. Our research questions are:

1. Which conditions are required for a behaviour observation and recording scale for individuals with both ID and HI?
2. Are there scales with which behaviour of individuals with both ID and HI can be observed and recorded?
3. Which scale can be used in a study to find relationships between behaviour and several external factors?

Because we did not find any suitable scales for our study, we describe the development of an Individual Behaviour Observation and Recording Scale (IBORS) in the second part of this article.

**Method**

The required conditions of a behaviour observation and recording scale

The aim of our study is to detect certain relations between behavioural problems and external factors. Therefore it is necessary to collect observations of specific defined behaviour as well as descriptions of circumstances in which this behaviour occurs. In this article we concentrate on the description of (problem) behaviour.

Our research will take place in institutional settings for people with both ID and HI. These people are needy and dependent in their daily care because of the complexity of their handicaps. They do not have the ability to communicate verbally and depend on non-verbal communication. Moreover, they are not able to read or write. They are assisted by several familiar carers throughout the day for their daily care. In the interaction between carers and people with ID and HI carers have to be able to determine and interpret the non-verbal communication of their pupils. Watzlawick, Beavin and Jackson describe several dimensions of human communication. Communication is not only what we say but rather what we don’t say. In their first axioma they formulate that it is impossible to not communicate. Every act, including doing “nothing” has a certain influence on the environment. Every behaviour is a form of communication. Granlund & Olsson state that even such behaviour as licking, squeezing, smiling, crying, hitting, or smearing with faeces should be seen as communicative signals. These communicative signals have been developed as a result of a combination of an individual’s predispositions (nature) and learning experience (nurture).

As a part of their daily routine, professional carers of people with ID and HI have to observe and record behaviour of their pupils. Therefore, it is necessary to use a scale in which non-verbal signals can be observed and recorded if we want to study the behaviour of this group. Several studies conclude that it is possible to determine and interpret motives of people who depend on non-verbal communication by using systematic observation of non-verbal signals.

With the experience of daily practice, combined with the first axioma of Watzlawick, we might be able to give an answer to our question “Which conditions are required for a behaviour observation and recording scale for individuals with both ID and HI?”

**Results**

Our first condition is that it is necessary to observe and record a variety of (non-verbal) behaviour. It is our purpose to study a wide range of behaviour and do not focus on specific aspects of behaviour.

Our second condition is related to the fact that each person tends to react in an individually determined way based on his personal history, limitations and abilities. In a recording scale of behaviour which is suitable for our study there should be room for measuring specific behavioural patterns that are characteristic of and personal to the individual. So we must be able to personalize the recording scale.

The third condition for our scale is to differentiate between degrees of severity of problem behaviour. Because the purpose of our study is to gain insight into relations between behavioural problems and external factors it is necessary to make quantitative records of the severity of behaviour which is defined as a behavioural problem. It is also necessary to make records of behaviour of the same individual which is not experienced as a behavioural problem. This will make it possible to draw conclusions about circumstances in which behavioural problems do and do not occur and to which extent they occur.

Our fourth condition is that it should be possible to carry out several daily recordings of observed behaviour during a specific period. This could increase the possibility of gaining insight into specific relations between behaviour and external factors.

A fifth condition is that it enables each professional carer to use the scale. First of all, it is not likely that people with ID and HI are able to read and write or to
make records of their own behaviour. Secondly, if outsiders were to do the recording it could disrupt the daily routine, especially because it is our aim to collect records over an extended period of time. It would require a lot of time to have outsiders make these recordings. A third argument in favour of letting the carers do the recording for our study is that they are quite able to recognise behavioural patterns because they are familiar with the client.

A final condition is that such a scale should not be highly time consuming. Because carers are on duty, it is not acceptable for them to invest more than five minutes in recording behaviour. With the use of a scale which fulfills these conditions, it will be possible to determine differences in behaviour over a period of time in order to relate them to changing circumstances.

In summary, the observation and recording scale should meet the following conditions:

1. A variety of non-verbal behavioural aspects must be measurable;
2. There must be room for individual behavioural descriptions;
3. The severity of problem behaviour must be measurable;
4. There should be room for several records per day;
5. It should be filled in by professional carers;
6. It must be efficient and easy to use for every carer;

Method

With these six conditions in mind we have searched for suitable scales.

A literature study was carried out in March 2013 using “PsychInfo”, “Medline” and “Web of Science” with the following search terms and limited to publications after 1999:

1: Questionnaires or Observation Methods or Diagnostic interview Schedule
2: Behaviour or Behavioural assessment.
3: The combination and/or of the two groups of search terms.

Results

This resulted in 169 publications in which was referred to behaviour description scales, questionnaires, observation methods or diagnostic interview schedules. After initial inspection, this resulted in 27 different scales. Our first condition is that it is necessary to observe and record a variety of non-verbal behaviour. Some of these scales however are used to diagnose psychiatric disturbances and are therefore not suitable: Rutter Children's Behaviour Questionnaire$^{29}$, Psychopathology checklist for Adults with Intellectuel Disability$^{45}$, Psychopathology Inventory for Mentally Retarded Adults$^{46}$, Gedye's Compulsive Behaviour Checklist$^{47}$, Diagnostic Criteria for Psychiatric Disorders in Adults with MR/Learning Disorders$^{48}$, Clinical Global Impression$^{49}$, The scale for Assessing Severity of the psychopathology in children$^{50}$, The Diagnostic Assessment for the Severely Handicapped$^{51}$, The Psychiatric Assessment Schedule for Adults with a Developmental Disability$^{52}$, Reiss Screen$^{53}$, Brief Symptom Inventory$^{54}$.

Another group of behavioural observation scales is not suitable because these scales are aimed at specific aspects of behaviour such as motivation$^{55}$, depression$^{56}$, social skills$^{57}$, playing skills$^{58}$, anxiety$^{59}$ or temperament$^{60}$.

After this selection ten scales remained. Unfortunately, in none of these scales is there room for individual behavioural descriptions, which is our second condition. We may already assume that a scale which meets all our conditions does not seem to exist. Yet we will review our other conditions and assess the ten remaining scales. Some of these scales take a lot of time for carers to complete (Condition 6). Examples are The Aberrant Behaviour Checklist$^{61}$, the Child Behaviour Checklist$^{30}$, Developmental Behaviour Checklist$^{62}$, Child Behaviour Rating Form and Nisonger$^{63}$. Some of these scales are not appropriate to our study because recording should not be done by professional carers (Condition 5). The Self-Efficacy Questionnaire for Children$^{64}$ is a self-evaluating method and the Children’s Global Assessment Scale$^{65}$ should be used by doctors and clinicians.

Four scales remained: The Behaviour Problems Index (BPI)$^{66}$, Strengths and Difficulties Questionnaire (SDQ)$^{67}$, Storend Gedragschaal voor Zwakzinnigen (Disturbed Behaviour Scale for the Mentally Handicapped) (SGZ)$^{68}$ and Questions About Behavioral Function (QABF)$^{69}$. These four scales all measure a certain degree of severity of problem behaviour, which is our third condition. These scales all are designed to identify aberrant behaviour and develop hypotheses about its function. As a result it should be possible to formulate and carry out suitable
interventions in order to decrease the occurrence of this behaviour while increasing adaptive skills to increase more desirable behaviour. To complete the BPI, SDQ, SGZ and QABF however, the informant has to make judgements about behavioural aspects during the most recent months. In Condition 4, we formulated that it should be possible to make several records per day. Making several records with these scales will not increase the possibility of gaining insight into specific relations between behaviour and external factors.

We thus come to the conclusion that none of the scales are suitable for our study. Our main objections are that there does not seem to be a questionnaire in which there is room for individual behavioural descriptions and that making several records per day does not give extra information. These conditions are essential if we want to draw conclusions about circumstances in which individuals behave in a specific way.

**Behaviour Description Plans**

Nowhere in our search in the above-mentioned databases did we find any scale that is suitable for our study. Therefore we explored behaviour observation scales that are not internationally published, but already used in (Dutch) clinical practice. One of the scales we found is “behaviour description plans” which is commonly being used in several psychiatric hospitals. This method was originally presented by Van der Werf, Goedhart and Huiberts70. Basically this scale is meant as an intervention method. The main aim of this method is to make plans jointly with the client, enabling carers to intervene appropriately in critical situations. In order to decide which intervention is the most applicable, carers must be able to recognise warning signals, or behavioural patterns of a client. As a result, carers can offer the conditions needed to decrease tension within the client. The premise of this method is that behavioural patterns of each individual vary with one’s state of mind. Behavioural patterns are therefore described in several different moods, representing different states of mind. These states of mind are rated in levels varying from relaxation to loss of control. For every person an individual behavioural repertoire is described with which it is possible to make judgements on an individual’s mood at any given time. In the method of Van der Werf, Goedhart and Huiberts it is possible to describe a variety of non-verbal behavioural aspects (Condition 1). This method is intended to define individual determined behaviour (Condition 2) in which it is possible to describe the severity of (problem) behaviour (Condition 3). With this method it is possible to make several records per day (Condition 4), it is suitable to be filled in by carers (Condition 5) and it is not too time-consuming and therefore efficient and easy to use (Condition 6). In the next section we will assess the possibility of using this method as a behaviour observation and recording scale for our study.

**The construction of an Individual Behaviour Observation and Rating Scale (IBORS)**

The method of Van der Werf, Goedhart and Huiberts distinguishes levels of behaviour. In constructing our Individual Behaviour Observation and Rating Scale (IBORS), several steps were taken. Parents of people with ID and HI, who all live in a specialised residential setting in Amsterdam, the Netherlands, were invited to contribute in this process. Fifteen of them cooperated. These parents were asked to describe specific behaviour of their child in different moods, from relaxation to loss of control. The same was asked of professionals of different disciplines (staff, communication therapist, physiotherapist, psychologist) who were familiar with these people. Most contributors recognised five different levels of behaviour in all individuals. These levels were defined as “relaxation”, “slight restlessness”, “tension”, “threat” and “loss of control”. This first step in the process resulted in very divergent descriptions. The next step was to divide these behaviour descriptions of all fifteen people into a few behaviour categories. After studying these descriptions professionals agreed to distinguish eight dimensions of behaviour: “making sounds”, “locomotion”, “facial expression”, “object manipulation”, “body manipulation”, “concentration”, “expressive communication” and “receptive communication”. The third step was to combine each of the eight dimensions of behaviour with the five different levels of behaviour as above. By following this step forty unique behavioural descriptions of each individual are needed to fill the scale (see Table 1).
<table>
<thead>
<tr>
<th>Behavioural aspect</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
<th>Level 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making Sounds</td>
<td>Speaks at the appropriate volume, giggles</td>
<td>Speaks monotonously and abruptly, asks obvious question</td>
<td>Speaks loudly and urgently, sighs out loud.</td>
<td>Heavy breathing patterns</td>
<td>Cries, shouts, uncontrolled screaming.</td>
</tr>
<tr>
<td>Locomotion</td>
<td>Walks relaxedly, fluid movements</td>
<td>Moves restlessly, paces back and forth.</td>
<td>Walks in a stereotypical manner, appears tense.</td>
<td>Many restless arm movements, shakes the head, avoids others.</td>
<td>Tense and rigid arm and leg movement of.</td>
</tr>
<tr>
<td>Facial expression</td>
<td>Relaxed, laughing</td>
<td>Neutral</td>
<td>Eyes darting about restlessly.</td>
<td>Panting, anxious eyes, checks that no one comes too close, lips may turn blue.</td>
<td>As 4 but to a greater extent.</td>
</tr>
<tr>
<td>Object manipulation</td>
<td>Tidy, quiet, careful</td>
<td>Functional</td>
<td>Rough, unco-ordinated, sets chairs down forcefully.</td>
<td>Throwing and shaking objects, rough.</td>
<td>None</td>
</tr>
<tr>
<td>Body Manipulation</td>
<td>Good, flowing movements</td>
<td>Occasional tidying his hair, straightening his spectacles, consulting his watch, straightening his clothes.</td>
<td>As 2 but to a greater extent.</td>
<td>As 2 but compulsively and violently, scratching hands until they bleed.</td>
<td>Tense, aggressive</td>
</tr>
<tr>
<td>Concentration</td>
<td>Good, lives peacefully, colours in colouring books, watches television.</td>
<td>Distracted now and then but does not require assistance.</td>
<td>Cannot carry out his activities on his own, requires drawing back into reality, impatient, forgetful.</td>
<td>Must be put in his own room until he calms down.</td>
<td>No concentration whatsoever.</td>
</tr>
<tr>
<td>Expressive</td>
<td>Calmly speaks, signs, finger spells (also to himself)</td>
<td>Asks unnecessary questions, fingerspelling and signing very fast.</td>
<td>Spells and speaks urgently, seeks attention, often repeats.</td>
<td>Speaks/shouts very loudly, can resort to hitting/kicking.</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>Fingerspelling, signing, understands pictorial instructions, demonstrates patience.</td>
<td>As 1, but does not react well to signing</td>
<td>Clear, slow finger spelling and understands pictorial instructions.</td>
<td>Limited finger spelling, requires support in understanding pictorial instructions</td>
<td>Doesn’t accept things lightly</td>
</tr>
<tr>
<td>Receptive</td>
<td>Fingerspelling, signing, understands pictorial instructions.</td>
<td>As 1, but does not react well to signing</td>
<td>Clear, slow finger spelling and understands pictorial instructions.</td>
<td>Limited finger spelling, requires support in understanding pictorial instructions</td>
<td>Doesn’t accept things lightly</td>
</tr>
</tbody>
</table>
Behaviour in Level 1 is described in terms of relaxation. Some examples are: “makes adequate contact, communicates in sign language, plays with his toys”. In the second level restless behaviour is described. Some examples are: “wants to arrange all his toys, communicates only in sentences of two signs, claims attention, stands up from his chair while having dinner but returns of his own accord, laughs extra loudly, walks restlessly in circles, rubs toys softly against his face, shows some stereotypical movements”. In Level 3 behaviour is described as tense. This behaviour becomes problematic because it requires active intervention of the carers in order to prevent further escalation. Examples are: “hits himself, spits and smears, steals food, is continuously making screaming sounds, is unapproachable, bites, hits and kicks wildly, is incessantly restlessly going in circles, rubs face, occasionally beats his head against the wall, pokes his finger hard into his nose, throws himself deliberately onto the ground, threatens to hit, kick or bite others, hits windows and doors with force, ignores all communication”. Level 5 behaviour reflects a highly escalated situation. Examples are: “tears his fingernails until they bleed, throws objects at others, bites himself hard in the arms, beats his head constantly against the wall, is unapproachable, bites, hits and kicks wildly, is incessantly destructive”. Behaviour at Level 3 or higher requires active intervention by carers. We therefore agree with Emerson et al.6 and Holden and Gitlesen9 in using the term “challenging behaviour” for describing behavioural problems and propose to define behaviour representing Level 3 or higher as challenging behaviour.

Discussion

This article describes how we endeavoured to find a behaviour observation and recording method suitable for use in people with ID and HI that can be used to relate behaviour to several external factors and (challenging) behaviour. To gain insight into this topic, it was necessary to use a method with which individually determined behaviour could be recorded. We defined conditions for such a method but none of the 27 scales we evaluated fullfilled all six conditions. Because we did not find any suitable method, we explored the possibility of using an Individual Behaviour Observation Rating Scale (IBORS) based on the intervention method of behaviour description plans70. We described above the development of IBORS. IBORS does fullfill our six conditions for a behaviour observation and recording scale. There are however several remarks to be made.

A first remark concerns the construction of an individual behaviour repertoire. This is an extensive process in which several people familiar to each individual should be involved. A second remark can be made about the eight behaviour categories. These categories are chosen after gathering and combining several behavioural descriptions and are not based on a scientific theory or construct. The most important critical remark on this topic concerns the psychometric properties of IBORS. The development of a behaviour observation and recording scale is not the main goal of our future research, which is aimed on relationships between challenging behaviour and internal and external factors. It is however necessary to achieve an indication of the reliability and validity of IBORS if we are planning to use it in order to do our research. Therefore we will focus on that topic in future research.

References


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