Educator satisfaction, behaviour disorders and psycho-educational profile in young Indians with intellectual disabilities

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Summary

Swiss and Indian professionals have joined forces to develop better strategies for improving care of people with intellectual disability (ID). The purpose of this research is to investigate the relationship between behavioural disorders, the feelings of satisfaction that educators have about the care process, and educators' perceived effectiveness of the care for people with ID. In addition, we investigated the relationship between behavioural disorders and various life skills in people with ID. Subjects included 27 Indian adults with ID living in an institution in India. Professional educators of these adults with ID filled out visual analogue scales on their satisfaction with and perceptions of the effectiveness of care, and provided an assessment of the behavioural disorders of the subjects. The Psychoeducational Profile Revised (PEP-R; Schopler, 1990) was then used to assess subjects' social, behaviour and cognitive skills. We observed significant negative correlations between motor stereotypies and PEP-R subscales "relationships/emotions" and "play / interest in materials". A significant positive correlation was found between the "inappropriate language" behavioural disorder and educators' satisfaction of the care. Possible implications of these results are discussed.

Key words: intellectual disabilities; autism; challenging behaviour; staff satisfaction; communication and social skills; Psychoeducational Profile (PEP-R)

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Introduction

Caring for people with intellectual disability (ID) has always been a challenge for educational and health care professionals. A meta-analysis of the prevalence of psychiatric disorders in India shows that 5.4 per 1000 people have ID according to national data, but around 80% of the studies analysed by the authors indicated a prevalence of 10.5 per 1000 people [1]. Since 1995, due to the *Persons with Disabilities Act* [2], the Indian government has been committed to guaranteeing that the rights of individuals with disabilities are respected by ensuring them equal opportunities and non-discrimination. One of these fundamental rights is an appropriate education, which is crucial for these people's intellectual development and integration into society [3]. In India, stigma and misunderstanding of ID are being fought through efforts to enhance public awareness and to increase the number of educational and community interventions [4].

The present study is part of a larger longitudinal research project started in 2002 via a collaboration between the Lebenshilfe Institute at Visakhapatnam (Andhra Pradesh, India) and the University Hospitals of Geneva (HUG, Switzerland). Mrs. Saraswathi Devi Tallapragada founded the Lebenshilfe Institute in 1980 that now welcomes over 400 children and adults of various ages, regardless of diagnosis, but with the common trait of a proven ID. The purpose of this institution is to improve the quality of life for these people by helping them to regain their place in society – that is, by helping them become as active, productive, autonomous, and independent as possible.

ID is a generalised developmental disorder, appearing before adulthood, characterised by cognitive functioning impairments and deficits in adaptive behaviours. The World Health Organization International Classification of Diseases (ICD-10) defines ID as "a condition of arrested or incomplete development of the mind, which is especially characterised during the developmental period by the impairment of skills contributing to the overall intelligence level, i.e., cognitive, language, motor, and social abilities" [5, p. 202]. The diagnosis depends on the overall assessment of intellectual functioning by a skilled diagnostician and standardised intelligence tests are used to estimate the degree of ID. ICD-10 broadly classifies ID levels in four diagnostic categories: mild (IQ between 50 and 69), moderate (IQ between 35 and 49),

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severe (IQ between 20 and 34) and profound ID (IQ less than 20). In mild ID we observe learning difficulties in school but social relationships are preserved as well as the working capability. Profound ID is characterised by severe limitations in self-care, continence, communication and in mobility skills.

The social integration of people with ID is achieved via the attenuation of the elements that separate them from their familiar, cultural, and social environments. These can include deficits in communication, frequent behavioural disorders, and lack of understanding; these deficits are even more marked when the individuals with ID have co-occurring autistic tendencies, which makes their integration into residential areas or occupations even more difficult. Sigafoos, Arthur and O'Reilly [6] showed that up to 40% of people with ID may have one or more types of dysfunctional behaviour. Indeed, ICD-10 [4] states that ID is often recognised, amongst other factors, by presenting various behavioural disorders and learning impairment. The behavioural disorders include aggression, self-mutilation, destructive behaviour, grasping behaviour, motor stereotypies, echolalia and stereotyped language, hyperactivity, and irritability. One can also add dysfunctional social relations, including social inhibition, isolation, and inappropriate sexual behaviour [7, 8]. Authors reported as well that the prevalence of behavioural disorders increases with the severity of ID. Another study shows that 91.7% of studied Indians with ID present severe behavioural problems, against the 18.2% of those with mild mental retardation [9]. Although a large number of individuals with ID do not present aggressive behaviour, even the less severe forms of dysfunctional behaviour can be a barrier to their integrating into educational, residential, social, or professional settings [10]. Matson and Rivet [11] argued in turn that the frequency of behavioural problems increases with the severity of autistic traits. Researches showed that these dysfunctional behaviours are associated with poor language skills and quality of social interaction for people with ID or autism [12]. Thus, a perspective for the management of behavioural problems is to consider them as behaviours that have some communicative function, but the individuals have no skills to express their messages or needs [13–15].

To assist people with ID, autism, or both, it is therefore necessary to help them reduce their behavioural problems and improve the skills that would allow them to successfully integrate into society. This can be done through suitable structured activities and projects tailored to each individual [16, 17]. Indeed, educators who supervise and support people with mental disabilities or autism are involved in this effort on a daily basis.

The interest of Indian educators in various psychological assessment tools began an international exchange of research to understand what individuals with ID must actually face. Their interest has been mainly directed towards developing quick and effective methods for assessing behavioural disorders, as these constitute a major problem in their daily care activities [18]. To quantify and qualify these behavioural problems, researchers developed the Aberrant Behavior Checklist scale (ABC scale), which is a remarkable assessment tool because it is easily applicable and allows for the observation of possible improvements over time [19–23]. The sensitivity of the ABC for an Indian population with ID has already been established and the results were comparable with the original [24]. Thanks to the collaboration of Swiss and Indian professionals, this questionnaire has been translated from English to Telugu, the national language in Andhra Pradesh, creating a stable and efficient tool for use by any Telugu-speaking professional in the Lebenshilfe Institute [18].

The presence of two HUG psychologists at the Lebenshilfe Institute has also allowed the training of ten Indian professionals in using the Psychoeducational Profile-revised (PEP-R) [25]. This tool is used for the evaluation of various skills, communication competencies, and appropriate behaviours, as well as the assessment of the specific needs of people with ID and/or autism.

Researchers in Geneva were also interested in the observation of the subjective feelings of Indian educators about their satisfaction with the process of caring for and educating individuals with ID and how effective they think these efforts are. They proposed the use of simple visual analogue scales (VAS) for these assessments. The purpose of this investigation was to enable educators at the Lebenshilfe Institute to visibly judge the success or failure of their care while taking into account the efforts being deployed to ensure its success. This would allow for easier investigation of educators and preventing possible exhaustion of the educational team due to negative perceptions of their care. Furthermore, it examines the effectiveness of the strategies that have been adopted so far.

Finally, the aim of this study was to determine whether there is a relationship between the skill levels (PEP-R) and the severity of the behavioural disorders (ABC) in people with ID. In addition, we investigated whether there is a relationship between behavioural disorders (ABC) and the self-evaluation of the educators on their satisfaction with and perceived effectiveness of their care (VAS).

Methods

Measurements

Aberrant Behaviour Checklist (ABC)

The ABC is a qualitative and quantitative assessment of behavioural disorders. It is completed by a proxy (family member or caregiver), and contains 58 items rated on 4-point scales ranging from 0 ("no problem at all") to 3 ("very serious problem") [19–22]. The 58 items are divided into five subscales: 15 items for the "irritability" (score from 0 to 45), 16 items for "lethargy" (score from 0 to 48), 7 items for "stereotypy" (score from 0 to 21), 16 items for "hyperactivity/non-compliance" (score from 0 to 48) and 4 items for "inappropriate language (score from 0 to 12). The questionnaire was translated into the official language in Visakhapatnam – Telugu – through the standard back translation procedure. The authors of ABC have approved the Telugu version of the ABC. All nursing staff who took the ABC was therefore able to read and answer questions in their native language.

Psychoeducational Profile Revised (PEP-R)

The PEP-R is a skill assessment tool for adults with ID and/or a pervasive developmental disorder [25]. The test consists of 131 items of varying complexity, which evaluate the developmental dimension. Moreover, the behavioural dimension is measured by 32 items based on the observation of the candidate during structured and non-structured moments of the evaluation.

The developmental scale consists of seven subscales assessing different skills: "imitation," "perception," "fine motor function," "coarse motor function," "hand-eye coordination," "cognitive performance," and "verbal cognition." These items are rated according to three levels: competence is fully "acquired," "emerging," or "failed." An "emerging" skill is one that has not yet been acquired, but could be acquired with appropriate educational support. For the quotation 1 point is attributed to the "acquired" skills and 0 points to the "emerging and failed" skills. Conforming to the authors, a "total score" for the developmental scale is calculated by summing all the points of the seven subscales. For the statistical analysis we decided to use the "total score" instead of the seven individual subscales. This "total score", ranging between 0 and 131 points, is a good assessment of cognitive functioning: the higher the "total developmental score", the more cognitive skills are acquired.

The behaviour scale consists of four subscales assessing different types of behaviour: "relationships and emotions" (0–8 points) "play and interest in materials" (0–6 points) "sensory responses" (0–7 points) and "language" (0–11 points). Each item is rated according to three levels: behaviour is "appropriate," "slightly problematic," or "severely problematic." For the quotation 1 point is attributed to the "appropriate" behaviours and 0 points to the "slightly and severely problematic" behaviours. Therefore, the higher the score in the four subscales, the more adaptive behaviours are acquired.

Visual Analogue Scale (VAS)

Two VASs were used to assess nursing staffs' subjective feelings on the "effectiveness" and "satisfaction" of their care of people with ID in their institution. Scales ranged from 0 (no effectiveness/satisfaction of the care process) to 10 (high effectiveness/satisfaction of the care process).

Table 1 Demographic data for each subject: gender, age, ID level and secondary diagnosis according to the ICD-10.

Subject	Gender	Age	ID level	Second diagnosis
1	m	32	Moderate	
2	m	39	Profound	Autism
3	m	25	Moderate	
4	m	36	Profound	Autism
5	m	29	Severe	
6	m	35	Severe	Autism
7	m	32	Moderate	
8	m	22	Severe	Autism
9	m	32	Moderate	
10	m	31	Profound	Autism
11	f	20	Mild	
12	m	22	Moderate	Autism
13	m	26	Severe	Autism
14	m	25	Profound	Autism
15	m	21	Severe	Autism
16	m	32	Moderate	
17	m	22	Moderate	
18	m	27	Severe	
19	m	33	Profound	Autism
20	m	23	Severe	Autism
21	m	31	Mild	
22	m	30	Severe	
23	m	16	Profound	Autism
24	m	29	Severe	Autism
25	m	24	Profound	Autism
26	m	50	Mild	
27	m	30	Mild	

Procedure

When we recruited participants, we met with the legal representatives (i.e., parents or guardians) of the participants or the participants themselves if they were capable of discernment. They were all informed about the progress and purpose of this study. If they chose to participate, the legal representatives signed an informed consent form. We collected 30 signed forms but were unable to consider three participants because they lacked PEP-R test data. All subjects were assessed using the same questionnaires and scales. Participants whose legal representatives did not provide consent were excluded from the study.

Once recruitment was completed, in the first week of June 2006 the nursing staff answered the questions of the ABC and of the VAS for each participant. At the same time, two HUG psychologists, who were qualified for the PEP-R, started to perform the test with each participant. Participants were evaluated in 1 to 3 sessions depending on their fatigability. All participants had passed the PEP-R test at the end of June 2006.

Statistical analysis

Participant characteristics were described using mean and standard deviation (SD). The results of the ABC, PEP-R and VAS tests were presented using descriptive statistics (mean, SD, median, minimum and maximum). In order to explore relationships between ABC and PEP-R, and between ABC and VAS, we used Spearman's rho correlation test, as the outcome data were skewed. The correlation was considered showing statistical significance at the 0.05 level (2-tailed), and strong statistical significance at 0.01 level (2-tailed). The Statistical Package for the Social Sciences (IBM SPSS Statistics 19.0, 2010) has been used for the statistical analysis.

Table 2 Mean standard deviation (SD) and median score for the Aberrant Behaviour Checklist (ABC), Psycho-educational Profile Revised (PEP-R) and satisfaction / effectiveness Visual Analogue Scale (VAS).

		N	Mean	SD	Median	Min	Max
ABC	Irritability	27	4.74	4.793	3	0	15
	Lethargy	27	5.26	5.565	3	0	20
	Stereotypy	27	2.15	4.400	0	0	16
	Hyperactivity/ noncompliance	36	5.44	5.430	5	0	16
	Inappropriate speech	19	2.16	3.371	0	0	11
PEP-R							
Behaviour scale	Relationships/emotions	27	8.07	4.066	10	0	12
	Play/interest in materials	27	5.30	2.933	6	0	8
	Sensory responses	27	9.07	3.802	11	0	12
	Language	19	5.95	3.922	7	0	11
Developmental scale	Total score	207	63.04	33.198	69	2	118
VAS	Satisfaction	27	4.26	1.583	5	2	8
	Effectiveness	27	5.07	1.615	5	2	8

Results

Participants

The participants in this study were 27 adult residents of the Lebenshilfe Institute at Visakhapatnam (Andhra Pradesh, India). These people were all undergoing the same care, although they participated in different educational activities offered by the institution. Demographic data for each subject are reported in table 1. The participants were aged between 16 and 50 years (M = 28.7; SD = 6.9). The participants had a clinical diagnosis performed by a psychiatrist MD from the University Hospitals of Geneva, following the ICM-10 classification. Four participants (14.8%) were diagnosed with mild ID, seven (25.9%) with moderate ID, and 16 (59.3%) with severe to profound ID. It is important to note that some people diagnosed with severe to profound ID suffer from psychiatric comorbidity; in our study, 14 (52%) participants had a secondary diagnosis of autism. Out of the 27 participants, only one was a woman. Finally, eight participants (29.6%) could not speak. Indeed, for the ABC "inappropriate speech" and the PEP-R "language" subscales only 19 participants were taken into account for the statistical analysis. For the 8 participants who did not develop language the two tests subscales were not administrated.

Descriptive statistics

Descriptive statistics are summarised in table 2. Despite the considerable heterogeneity of responses for each participant, we observed rather low levels of behaviour problems overall. The dysfunctional behaviour most often observed is "hyperactive/non-compliance" (M = 5.44; SD = 5.43), "stereotypy" is the less quoted (M = 2.15; SD = 4.40).

Correlations

For the Spearman's correlations (table 3) between the ABC and PEP-R, we observed two negative correlations between the "stereotypy" and the "relationships/emotions" subscales ($\rho = -0.574$, $p \leq 0.01$), and "stereotypy" and "play / interest in materials" ($\rho = -0.666$, $p \leq 0.01$): while stereotypical behaviours increase, adaptive social behaviours, emotional skills and functional use of tools decrease. The "hyperactivity/non-compliance" subscale was also negatively correlated with the "play/interest in materials" subscale ($\rho = -0.406$, $p \leq 0.05$), whereas hyperactivity and oppositional behaviours increase, interest in playing games and functional use of tools decrease.

Then, we observed a positive correlation between satisfaction with care quality of the VAS and the "inappropriate

Table 3 Spearman's correlations between Aberrant Behaviour Checklist (ABC), Psychoeducational Profile Revised (PEP-R) and satisfaction/ effectiveness Visual Analogue Scale (VAS).

		ABC				
		Irritability	Lethargy	Stereotypy	Hyperactivity/non-compliance	Inappropriate speech
PEP-R						
Behaviour scale	Relationships/emotions	−0.255	−0.255	−0.574**	−0.352	−0.297
	Play/interest in materials	−0.333	−0.216	−0.666**	−0.406*	−0.400
	Sensory responses	0.013	−0.002	−0.355	0.000	−0.212
	Language	0.053	−0.030	−0.336	−0.172	−0.142
Developmental scale	Total Score	−0.213	−0.219	−0.355	−0.337	−0.116
VAS	Satisfaction	0.092	−0.215	−0.056	0.080	0.539*
	Effectiveness	−0.070	−0.242	−0.059	−0.057	0.383

* $p \leq 0.05$ level; ** $p \leq 0.01$ level.

language" subscale of the ABC ($\rho = 0.593$, $p \leq 0.05$): increasing in inappropriate language (i.e., echolalia, stereotypical language) is associated with increasing in staff's satisfaction with their care.

Discussion

The purpose of this study was to determine whether there is a relationship between the level of skills (as assessed by the PEP-R) of people with ID and their behavioural disorders (as assessed by the ABC). We also sought a link between behavioural troubles and educators' feelings about the effectiveness of and satisfaction with their care (VAS).

Most people with ID were found to have developed skills in the "relationships/emotions" and "play/interest in materials" subscales of the PEP-R, unless they have behavioural problems such as motor stereotypies. In addition, people with ID with higher scores on the "play/interest in materials" subscale were less likely to react with inappropriate behaviour such as "hyperactivity/non-compliance."

It is interesting to note that the identified correlations show a link between relational skills and behavioural disorders related to the isolation of the individual. Indeed, motor stereotypies often inhibit social interaction because they lead people with ID to withdraw into themselves. However, we noted that the higher the relational skills scores, the less apparent are the isolation behaviours. As a possible relationship, interventions targeting interpersonal skills through activities inspired by the PEP-R items "play/interest in materials" and "relationships/emotions" may be relevant in reducing stereotypies. Such interventions are even more important for people with comorbid ID and autism, which amounted to 52% of our sample. Research showed that care via structured programmes can decrease stereotypies and improve the quality of life of people with ID and autism [26]. The results of the PEP-R allow educators to create exercises and activities structured and tailored to each person with ID [25–27]. These people will then be stimulated by tasks suited to their needs and skills, which according to our exploratory results may potentially reduce their stereotypical behaviours. The correlation we identified between the "play / interest in materials" and "hyperactivity/non-compliance" subscales presumably goes in this direction.

These results point to the relationship between occupational therapy and behavioural disorders. Authors [28] claimed that stereotypical attitudes are more likely to occur in people with low stimulation, while they are less likely to occur in people with high levels of social interaction. Furthermore, Wurbel [28] argued that in a population of people with ID and autism, an impoverished environment is often associated with repetitive behaviours, whereas engagement in stimulating activities helps decrease these repetitive dysfunctional behaviours [29, 30]. Our results might go in the same direction because they show that while skills on an activity, whether manual, relational, or educational, increase the level of inappropriate or stereotypical behaviour decrease.

Regarding the correlation between "hyperactivity/non-compliance" and "play/interest in materials," it is interesting to note that as the former decreases, the latter increases. In fact, play has a relational dimension, in that people must be able to accept others and their shared understanding of the rules of the play; in contrast to the more solitary aspect of play, the rules are fixed by the individual, and they merely require curiosity or imagination. Furthermore, playing often involves being able to connect with an object. Thus, it appears that using games tailored to individuals may allow people with ID to learn various rules – whether they be structural, relational, or social. This may have a possible influence on "hyperactivity/non-compliance" scores. There is some previous evidence to support our exploratory findings. A study [12] found that behavioural problems are much more pronounced in people with poor language skills and poor quality of social interactions. Moreover, Kevan [31] showed in his meta-analysis that expressive communication skills in people with ID and behavioural disorders should be promoted to reduce the severity of these disorders. They found that this could be done through targeted exercises to enhance the skills of people with ID, or by changing their communication environment (e.g., the staff revised their communication by reducing the amount of verbal communication and increasing non-verbal communication, such as using visual programmes with pictograms).

Improving interpersonal skills ("relationships/emotions" and "play/interest in materials") might lead to a decrease in problematic behaviours ("stereotypy" and "hyperactivity/non-compliance") that prevent people with ID from forming strong relationships with others. A practical way to address these issues in the field would be to help people with ID engage in occupational activities and improve their understanding of social interaction. However, to achieve this, educators must be able to establish a connection with the patient with ID and find a suitable means of communication; then, with the support of assessment tools such as the PEP-R and ABC, they can specifically address his or her problems and needs.

Regarding our second hypothesis, we found that neither educators' satisfaction with their care nor their perceptions of its effectiveness are correlated to the first four subscales of the ABC. Thus, we cannot validate our initial hypothesis that aimed to demonstrate possible relationships between educators' satisfaction with care and their perceptions of its effectiveness and the intensity of behavioural disorders. In contrast, we observed a possible relationship between satisfaction with care and the "inappropriate language" subscale. Specifically, satisfaction increases with increasing of inappropriate language. However, the observed correlation is difficult to interpret, unless we consider that Indian professionals might not perceive inappropriate language as an obstacle in their care. This could suggest that the presence of language in people with ID is a possible factor that improves educators' satisfaction, regardless of the appropriateness of the language itself. However, several studies have shown that staff tends to overestimate their ability to understand people with ID and to use more verbal communication than would normally be understood by these patients [32, 33]. Since communication involves a transmitter and a receiver, staff tends to be lulled by the illusion of good verbal communication from a person with ID, which leads them to answer

in that same modality despite the real capacities of the people with ID they are addressing. Thus, the illusion of communication through language might be sufficient to create a sense of satisfaction in the educator regarding his or her care. Thus, it might be valuable to pursue an extension of this line of thought – would this feeling of satisfaction remain high if educators were required to use non-verbal modes of communication? The question is particularly relevant for the care of people who are unable to communicate at all, that is those with the lowest skill levels.

Assessing the skills of people with ID using the PEP-R allows the implementation of personalised educational strategies aimed at improving emerging skills. As demonstrated by two longitudinal studies [26, 34], these programmes serve to reduce behavioural problems and therefore improve the quality of life of people with ID and autism. For people with ID who have very low skill levels, it is important that educators keep realistic expectations so that they remain motivated in helping people with ID. Thus, providing support and awareness of these issues through training programmes which can help reduce burnout in the nursing staff. Indeed, staff working with people with ID has a high risk of burnout, especially when those people with ID present severe behavioural disorders [35, 36]. However, negative emotions have been found to mediate the relationship between behavioural disorders and burnout [37], meaning that regular assessment of educator satisfaction via measures such as the VAS would help identify those at the greatest risk of burnout. Further, authors showed that job satisfaction is an indicator of the health and well-being of personnel [38].

In conclusion, we identified possible relationships between behaviour disorders in a group of young Indians with ID, their skills levels, and educator satisfaction of the care. A longitudinal study with a larger sample of participants would indeed be a more appropriate experimental design for the investigation of the causal relationships between these variables. Our results highlight the importance of furthers studies in order to demonstrate that implementing educational strategies specific to each person with ID or autism can improve their interpersonal, social, and communication skills and reduce their behavioural problems. Communication skills and mode of communication were found to be vital to the quality of care for people with ID and therefore to educators' feelings of satisfaction with their efforts. The implications of these communication factors on educator self-assessments must be further investigated. Preventing staff burnout should not be overlooked, especially in conditions where the level of development of people with ID is low and it is difficult for them to acquire new skills.

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