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SELF-REPORTING OF PAIN IN PEOPLE WITH MILD TO MODERATE INTELLECTUAL DISABILITY: IS IT FEASIBLE?

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SUMMARY

The assessment of pain in people with intellectual disabilities (individuals with ID) represents a clinical challenge due to the variability in communicative and cognitive skills. This study explores the feasibility of pain self-reporting in individuals with mild to moderate intellectual disability using validated self-assessment scales. Our findings suggest that, under appropriate conditions, self-reporting can be a reliable and empowering method for pain evaluation in this population. This approach may foster autonomy, improve care, and counteract the undervaluation of subjective pain reports.

Key words: *pain - assessment - intellectual disabilities*

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INTRODUCTION

Pain is by its nature a subjective, complex sensory experience, modulated by organic, environmental, socio-cultural and behavioural variables (Raja et al. 2020). The revised definition of the International Association for the Study of Pain (IASP) defines pain as: “An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”. It is noteworthy to mention also the associated notes to this definition, approved by the IASP Council:

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- A person’s report of an experience as pain should be respected.
- Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain.

As widely reported in the literature, the assessment of pain in people with intellectual disabilities and communication deficits is a particularly complex clinical task (Hauer et al. 2017). People with intellectual disabilities (individuals with ID) are more susceptible to pain, perceiving it as more intense as compared to individuals without disabilities (Genik et al. 2017). In fact, individuals with ID are at higher risk of experiencing greater levels of discomfort, due to the congenital and acquired pathologies from which they suffer, and of receiving inadequate medical care for pain, due to difficulties often present in expressing it (Bambi et al. 2021; Icht et al. 2021). This can cause a voluntary or unintentional over- or under-reporting of pain episodes experienced by individuals with ID, negatively affecting their quality of life and perceived well-being (Baldridge & Andrasik 2010). Since self-assessment is the gold standard in the evaluation of pain (Crosta et al. 2017; Doody & Bailey 2017) and given the evidence regarding the possibility people with mild to moderate ID to communicate their discomfort, it is important to properly value self-assessment as a central tool in the assessment of pain among individuals with ID (Cascella et al. 2019). Furthermore, although the influence of ID in conditioning the reliability of the self-assessment of pain is undoubted, it has been demonstrated that up to 35% of individuals with ID, mostly mild and moderate, can correctly use pain self-report scales (Dillane & Doody 2019). This reinforces the belief that various self-assessment scales (pyramidal, numeric or colored visual analogue scales) could be successfully used in individuals with ID, after having verified their adequate understanding and ability to use the scale. Accordingly, it is necessary to develop and improve reliable, ecological and valid methodologies in the assessment of pain, integrated into the daily environment of individuals with ID (de Knegt et al. 2015). This would allow for an increase in the correct reporting of pain, preventing it from becoming chronic, and would promote greater self-determination and autonomy of individuals with ID, who would no longer depend exclusively on the caregiver for the recognition of their discomfort (Wilson et al. 2013). Furthermore, using self-report in people with ID would reduce the tendency to view these individuals as non-competent in their own pain assessment and change the erroneous hierarchy of pain data. In fact, clinicians tend to rely nmore on those parameters defined as "objective" or “neutral”, such as physiological evidence, compared to “subjective” data obtained through self-assessment; in other words, they tend to believe more on bodily-related data than on the information gathered from listening to individuals with ID (Berger & Baria 2022).

The Istituto Serafico is a neurorehabilitation in- and out-patient centre for children and adults affected by complex intellectual, physical and sensory disabilities. The majority (over 85%) of patients in care are affected by severe to extreme intellectual disability (ID) and absent speech. Only a minority of them display mild to moderate ID, all of them associated to genetic and acquired pathologies, with different degrees of communication or sensory impairments alongside behavioural or psychiatric disorders. We conducted a study aiming to evaluate the ability to self-report pain in adults and children with mild to moderate ID at Istituto Serafico. This was part of a wider study on pain assessment in subjects with ID, which also included a previous study to evaluate the knowledge and confidence of health and education personnel concerning the evaluation of pain in individuals with ID, after receiving specific training on the use of pain scales and on pain in general.

METHODS

Patients with mild to moderate ID were selected from all the patients being followed by the Istituto Serafico at the time of the study. The diagnosis of ID and of the degree of ID are systematically performed by the medical team (paediatric neuro-psychiatrist, neurologist, psychiatrist, and psychologist) at the time of admission and periodically thereafter. We employ a set of tests (WISC- IV, WISC-R, WIPPSI, WAIS, LEITER-R, and Raven's Progressive Matrices) or, when behavioural challenges prevent conducting a structured test, by clinical evaluation with a particular focus on adaptive skills, communication, receptive and productive language, gross and fine motor skills and social interaction.

Patients were further subdivided into subjects with verbal activity (able to construct complete sentences, though not always coherent and contextualized) or with basic verbal activity (2-3 word sentences) and nonverbal (inability to produce any words).

All patients with mild and moderate ID were tested employing a test–retest method by the research team on their ability to understand and correctly use three self-report pain scales: the Wong Baker Pain Scale (WBPS), the Numeric Rating Scale (NRS), and the Pyramid Pain Scale (Figure 1). The test-retest aimed also to select the preferred or most effectively used scale, for patients to self-report pain.

Children and adults unable to understand or use the selected self-report pain scales were excluded from the study.

Nurses, social health workers (SHW), rehabilitation therapists and educators, caring for children and adults at the Serafico, had been specifically trained on the administration of the self-report pain scales through a theoretical and practical training program administered prior to starting the study (Ciccone et al. 2023)

Episodes of directly reported or suspected pain were evaluated through the assigned (preferred) pain self-report scale administered by the personnel assisting the patient in the residential and day care settings and independently by the medical staff (nurses or doctors) within 15 minutes of the initial report, as documented in the medical record. Date, time, setting of evaluation, associated behavioural changes, reported type or cause of pain, score, type of intervention and outcome were recorded independently by the residential or day care personnel and the medical staff.

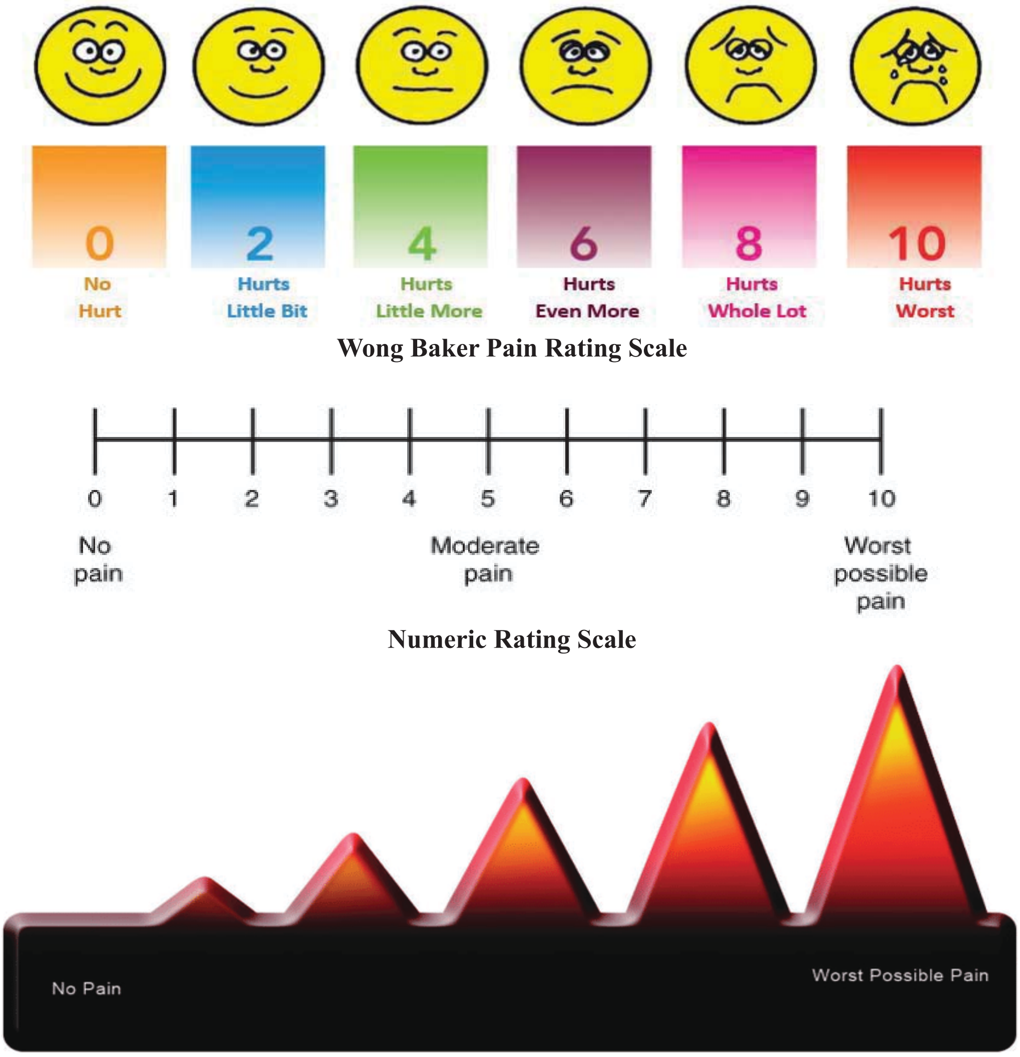
In case where participants manifested behavioural changes, such as extreme irritability and/or opposition without a known cause, for which the self-report pain scales could not be applied (e.g., refusal to speak and/or cooperate) the team was instructed to compile an observational pain scale, the revised Face, Legs, Activity, Cry and Consolability scale (r-FLACC), to score the event.

Statistical analysis

Descriptive analyses were computed on all variables collected in the studies, mainly focusing on frequency trends. The only parametric analysis used was the t-test to determine whether there were statistically significant differences between the mean scores of the self-assessment scales in presence of the non-medical staff and when the medical staff were present instead.

RESULTS

Among the 120 patients admitted at Serafico in residential and semi residential regime, 15 patients (3 females and12 males) with mild to moderate ID were selected for the use of self-reporting pain scales. Demographics and clinical characteristics are reported in Table 1. In the test- retest preliminary phase of the study, 3/15 participants (patients A13, A14, A15) did not meet the criteria of the self- assessment group, as they were unable to use at least one of the three proposed self-reporting pain scales, and were excluded. The first participant (A13, 37 y/old, M) affected by optic nerve hypoplasia and autism spectrum disorder with only basic verbal activity, showed anxiety and opposition to the administration of the scales; the test-retest trial was repeated in a different setting and by different caregivers with the same results. The second participant (A14, 21 y/old, M), affected by cerebral palsy and blindness, did not show any numerical competence to use the NRS. The third participant (A15, 7 y/old, M), affected by severe spastic- dystonic tetraplegia, without any verbal ability, did not demonstrate the ability to indicate, using his limbs or eyes any of the proposed pain scales. The remaining 12 patients (3 F, 9 M), with a median age of 31 years (range 15-47 years), showed a good understanding of the pain scales and the ability to



Wong Baker Pain Rating Scale

Numeric Rating Scale

Pyramid Pain Scale

Figure 1. Self Report Pain Scales

use at least one of them. The test-retest showed a good internal consistency in baseline conditions (absence of pain: rating nil in all 3 scales (and only in the NRS for participants with visual impairment). A preferred scale was assigned to each participant based on personal preference and ability to use it.

During the 6-months study period (February to July 2023), a total of 60 episodes of self-reported pain were recorded. Thirty-eight (63%) events were evaluated both by the educators/SHW and by nurses/doctors: in 30 events, the score was recorded independently by the educators/SHW and the medical staff. In three cases, the medical staff compiled the r-FLACC due to a lack of cooperation from the participant, while in five cases there was a medical intervention without any pain scale being scored. Only the medical staff assessed fourteen events (23%); solely the educational staff evaluated eight events (21%), without reporting them to the medical staff, as they were considered not reliable. The number of events reported for each patient ranged from 0 to 16 (Table 1).

Twenty-one events (30%) involved only verbalized pain without associated behavioural symptoms, while 42 episodes (70%), were associated with irritability (16 events), crying (12), self and hetero-aggression (7), opposition (5), mutism (1), and refusal to eat (1). There was no significant difference in the mean score of the verbalized pain episodes (M= 7.8, range 2-10), as compared to the mean score of the episodes associated with behavioural symptoms (M= 7.2, range 2-10), as recorded by the educators/SHW.

Interestingly, participants were able to report intermediate scores and not just indicate the absence or presence of pain. Participants also demonstrated good intra-rater consistency when reporting the same pain events to different providers ($M = 0.3$, $SD = 2.66$), $t(29) = 1.0$, $p < 0.05$.

The most frequent complaint was musculoskeletal pain, followed by sore throat (pharyngodynia), malaise, headache, menstrual pain, abdominal pain, pain related to trauma, otalgia, and urogenital pain (Figure 2). Individual patients' complaints are reported in figure 3.

Table 1. Demographics and clinical characteristics

Code	Sex	Age	R/S	Pathology	ID	S&L	Sensory D	Motor D	Beh/Psych Disorders ICD-10	ASD	N. Events
A1	M	44	R	FXS	M	V			F07		5
A2	M	33	R	TBI	M	V		Tetraparesis	F07. 9		0
A3	M	24	R	PDD-NOS	L	V			F39 + F42		6
A4	M	24	R	Impulsive-type EUPD	M	V					10
A5	M	43	R	CBM	M	V	Visual impairment				1
A6	F	27	R	ROP	L	V	Blindness			X	5
A7	F	27	R	Oligohydramnios	L	V		DCD*	F63		16
A8	M	37	R	FXS	M	V			F07		1
A9	M	25	R	ROP	M	V	Blindness			X	0
A10	F	31	R	TSC	M	V			F63	X	16
A11	M	47	S	Astrocytoma surgery outcome	L	V	Visual impairment + deafness	Ataxia + right hemiparesis			0
A12	M	15	S	LNS	M	BVA		Tetraparesis			0
A13	M	37	R	ONH	M	BVA	Blindness		F71.1	X	NA
A14	M	21	S	CP	M	BVA	Blindness	Tetraparesis			NA
A15	M	7	S	CP	M	NV		Tetraparesis			NA

Legend: *Pathology: FXS: Fragile X Syndrome; TBI: Traumatic Brain Injury; PDD-NOS: Pervasive Developmental Disorder-Not Otherwise Specified; EUPD: Emotionally Unstable Personality Disorder; CBM: Congenital Brain Malformation; ROP: Retinopathy of Prematurity; TSC: Tuberous Sclerosis Complex; LNS: Lesch Nyhan Syndrome; ONH: Optic Nerve Hypoplasia; CP: Cerebral Palsy; DCD: Developmental Coordination Disorder; OCD: Obsessive Compulsive Disorder; EUPD: Emotionally Unstable Personality Disorder; IED: Intermittent Explosive disorder.
**Beh/Psych Disorders ICD-10F07: Unspecified personality and behavioral disorder due to known physiological condition; F07. 9: Psycho Organic Syndrome; F39: Mood Disorder; F42: Obsessive-Compulsive Disorder; F63: Impulse Control Disorders; F71.1: Moderate mental retardation: Significant impairment of behaviour.

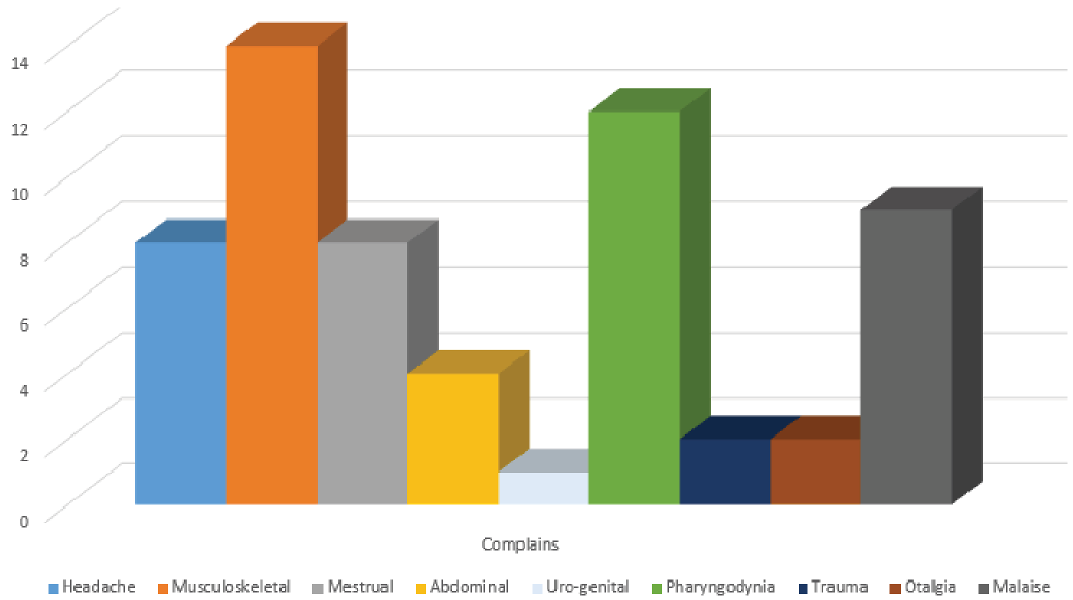


Figure 2. Complained symptoms

Pain complaints were managed with pharmacological interventions in 42 cases, of which 40 included analgesics (paracetamol alone: 29, non-steroidal anti-inflammatory drugs (NSAIDs): 7, topical pain medications: 4). Two patients required additional drugs to relieve the condition causing discomfort. The remaining 10 events reported to the nursing staff were managed with non-pharmacological interventions, as they were judged as behavioural episodes. All the events treated pharmacologically resolved within 1 hour, while two of the 18 events considered psycho- behavioural did not resolve after non-pharmacological interventions and required a MS revaluation.

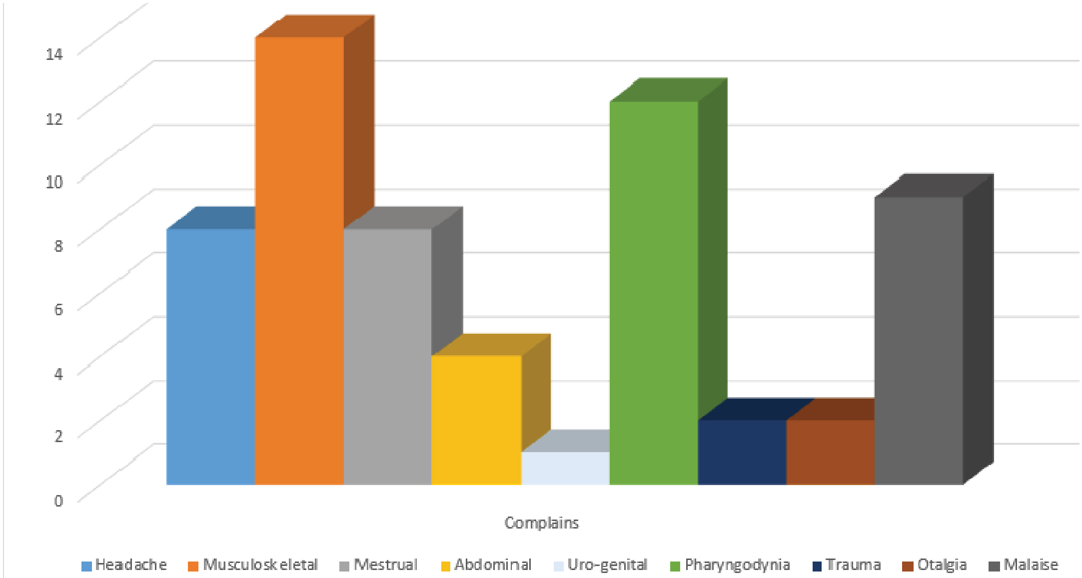


Figure 3. Complains by each participant

DISCUSSION

The aim of this study was to evaluate the feasibility of self-reporting pain in adults and children with mild to moderate ID at Istituto Serafico di Assisi. The positive results of the study support the assumption, already reported in the literature, that self-reporting is the gold standard in pain assessment. It allows for an increase in and improvement of correct pain treatment, making it personalized and accurate; however, there may be limitations and complications in the application of self-report tools in individuals with ID (Berger & Baria 2022). Some difficulties were encountered in discriminating and distinguishing physical pain from emotional pain. This was also a common finding in the literature regarding this topic; in fact, a study by Benromano and colleagues (2017) found difficulties in discerning whether atypical behavioural responses were caused by anxiety and stress or specific pain. For this reason, the study states that it is particularly challenging for the caregiver to quantify and adequately treat pain, even in self-report situations.

In patients where early development is characterized by significant trauma and/or neglect, it is likely that the temperament becomes dominated by an inner sense of undifferentiated psychic pain that lies outside the sphere of verbally accessible memory, in implicit memory systems (Van Der Kolk 1996). Even in people with intellectual disabilities, personality disorders can coexist, and discriminating psychic pain seems to be particularly challenging among those patients originally grouped as borderline personality disorders with histrionic personality disorder, predicting high Novelty Seeking (NS), low Harm Avoidance (HA), and high Reward Dependence (RD), according to Cloninger's model of temperament (Cloninger 1987).

Having typically experienced significant early trauma and dysfunctional attachments, these patients may find themselves in a situation of approach-avoidance conflict where social relatedness is painful and where the dominant experience of emotional pain may have interfered with the normal development of emotional modulation (Korner et al. 2007). The demonstration of hypometabolism in the rostral anterior cingulate cortex may be relevant to borderline personality disorders, particularly as this area is thought to be important in the integration of pain experience (Mayburg et al. 1997). It is particularly difficult to demonstrate pain as a conversion (or somatoform) symptom. It can probably only be partly shown by demonstrating that there is a major emotional problem and that the pain goes away when the problem is resolved (Merskey 2004). The most common mistake made by caregivers of people with intellectual disability and a borderline or histrionic personality disorder, is to regard the event reported as painful as an act of manipulation or as an act of exaggeration of the symptom intended to demand attention. If an individual meets the criteria for either borderline or histrionic personality disorder, it indicates that he or she possesses such an intellectual level that could not be properly approached by a behavioural therapy based only on bottom-up modification of procedural automatisms, but would also require a cognitive-behavioural approach, including top-down techniques as well. Thus, using extinction, ignoring the request does not prove to be an effective method. One must, be from time to time, validate the person's experience of pain and then help this person reflect on the reasons for why he/she made this request.

CONCLUSIONS

Our study suggests that, under suitable circumstances, self-reports can provide a reliable and empowering means of evaluating pain in people with mild to moderate ID. Such an approach may promote autonomy, improve quality of care, and address the frequent undervaluation of subjective pain experiences.

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Contribution of individual authors:

Ornella Ciccone, Alessandro Lepri, Olga Zaffini, Guido Camanni, Massimo Vallasciani, Antonella Baglioni, Chiara Tinarelli, Alessandro Jenkner, Michele Salata & Sandro Elisei: the study conception and design.

Ornella Ciccone, Alessandro Lepri & Olga Zaffini: acquisition, analysis and interpretation of the dana, have written the manuscript

All authors approved the final manuscript.

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