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IMPLEMENTATION OF PAIN SCALE USE IN PEOPLE WITH INTELLECTUAL DISABILITIES IN CLINICAL PRACTICE: A POST-STUDY FOLLOW-UP

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SUMMARY

Assessing pain in people with intellectual disabilities (PWID), particularly those with multiple sensory and motor impairments, is a complex clinical challenge often overlooked, leading to the risk of underestimating pain. The Serafico Institute in Assisi investigated pain assessment in this population using the revised Face, Legs, Activity, Cry, Consolability (R-FLACC) scale and self-report tools. This follow-up study examined the reporting of unexplained behavioral changes and the use of pain scales in routine clinical practice one year after the initial research. A total of 110 participants (72% male; mean age 27 years, range 2-54) were enrolled, including 27 children (25%) and 83 adults (75%). Over seven months, 252 episodes of unexplained behavioral changes were recorded: 227 (90%) assessed with R-FLACC and 25 (10%) via self-report. Of these, 148 (59%) were classified as pain-related, 83 (33%) as distress episodes, and 21 (7%) remained unexplained. The number of episodes reported and consistent use of pain scales, indicate heightened awareness among healthcare and educational staff towards unexplained behaviors that might signal pain, prompting appropriate evaluation and treatment. Pain assessment has now become an integral component of Serafico Institute's clinical practice and operational guidelines for PWID.

Key words: *pain – assessment – complex – disabilities – behavior - distress*

Abbreviations: *PWID: people with intellectual disabilities; ID: intellectual disability; MS: medical staff; NMS: non medical staff*

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INTRODUCTION

Pain assessment in people with intellectual disabilities (PWID) presents significant clinical challenges due to frequent impairments in verbal communication and the presence of behavioral or psychological disturbances (Enninga et al. 2023). Self-reporting is considered the gold standard for pain evaluation; however, many PWID - particularly those with severe or multiple impairments - are unable to self-report (Berger & Baria 2022; Crosta et al. 2014; Doody & Bailey 2017; Hauer & Houtrow 2017; Raja et al. 2020). Nevertheless, PWID experience pain, often more frequently than the general population, yet their pain frequently remains unrecognized and untreated (Bembich et al. 2021; Benromano et al. 2017; El-Tallawy et al. 2023; Riquelme et al. 2021). Expressions of pain in this population are commonly misinterpreted by healthcare workers or caregivers as behavioral or psychiatric issues rather than pain (Tosato et al. 2012; Wilkinson et al. 2005). Because verbal self-reporting is often not feasible, the use of observational pain scales is strongly recommended to identify potential indicators of pain, providing a systematic and structured approach to guide appropriate treatment (Chen-Lim et al. 2012).

The Serafico Institute of Assisi is a neurorehabilitation center that provides care for PWID with multiple sensory and motor impairments. The Institute has conducted research to enhance the ability of healthcare and educational staff to detect pain in PWID. The first phase of the study involved training all personnel in pain recognition and the use of validated pain assessment scales (Ciccone et al. 2023). Over the following six months, data were collected on episodes of unexplained behavioral changes through the completion of pain scales and clinical assessments (manuscript under review). The present study is a follow-up investigation designed to evaluate pain assessment practices at the Serafico Institute one year after the initial data collection, with the goal of assessing the integration of pain scale use into routine clinical practice.

SUBJECTS AND METHODS

This observational study was conducted among residents and semi-residents receiving care at the Serafico Institute of Assisi. Participants with intellectual disabilities (ID) who were unable to self-report were assessed using the revised Face, Legs, Activity, Cry, Consolability (R-FLACC) scale, while those with mild to moderate ID were evaluated with self-report pain scales, including the Wong-Baker Pain Scale (WBPS) and the Numeric Rating Scale (NRS). Episodes of unexplained behavioral changes or suspected pain-related behaviors were evaluated by non-medical staff (NMS) and/or medical staff (MS) to identify potential causes or antecedents. Pain assessments were recorded digitally through the Institute's electronic medical

record system. Pain scales were completed by NMS and MS spontaneously, without prompting from the research team, to capture real-world clinical practice without interference. Data were collected between February and October 2024. The primary objective of the study was to evaluate the extent to which pain scale use had become integrated into routine practice at the Institute, following the 2023 pain assessment study in PWID. All data were analyzed descriptively. The study was approved by the Regional Ethics Committee of Umbria. Informed consent was obtained from the guardians of minors and adults unable to consent, and verbally from participants able to express themselves. Participant anonymity was maintained. All procedures adhered to good clinical practice guidelines, national regulations, and the principles of the Declaration of Helsinki.

RESULTS

A total of 110 participants were enrolled in the study, including 79 males (72%) and 31 females (28%), with a mean age of 27 years (range: 2–54 years). Of these, 27 participants (25%) were children (<18 years), and 83 (75%) were adults. Eighty-six participants (79%) were residents of the Institute, while 24 (22%) attended the semi-residential center. Most participants (93, 85%) had severe to profound intellectual disability (ID), and 17 (15%) had mild to moderate ID. The majority were non-verbal (67, 60%), while 27 (25%) had only basic verbal ability (BVA), and 16 (15%) were fully verbal. Only 4% of participants had isolated ID, whereas 106 (97%) presented with at least one additional functional impairment; among these, 73% had two or three associated disabilities. The clinical characteristics of participants are summarized in Table 1.

Table 1. Demographic and clinical characteristics of participants

Variable	n	Percent
Age		
Adults	83	75%
Children	27	25%
Sex		
Male	79	72%
Female	31	28%
Intellectual Disability		
Mild - Moderate	17	15%
Severe – Profound	93	85%
Communication		
Verbal	16	15%
Basic verbal activity	27	25%
Non-Verbal	67	60%
Associated Impairments		
Motor Disabilities	45	41%
Sensory Disabilities	51	47%
Epilepsy	44	40%
Psycho-Behavioural Disorders	81	74%

During the seven-month data collection period, 252 episodes of unexplained behavioral changes were recorded. Of these, 227 events (90%) were assessed using the R-FLACC scale, and 25 events (10%) using self-report scales. Most episodes (147, 58%) were evaluated solely by medical staff (MS), 54 (22%) solely by non-medical staff (NMS) in the residential units, and 51 (20%) by both MS and NMS.

Among the 252 events, 148 (59%) were classified as pain-related by MS, 83 (33%) as distress-related, and 21 (7%) remained undetermined. Forty participants (54%) experienced at least one pain-related episode, with a frequency ranging from 1 to 23 events per participant. A definitive cause of pain was identified in 86 episodes (58%), with the most frequent being menstrual pain (27, 18%), followed by musculoskeletal, abdominal, and dental pain. In 62 episodes (42%), the pain source could not be identified. A summary of the clinical causes of all events is provided in Table 2.

Table 2. Causes of pain-related events

Pain	n	Percent
Menstrual pain	27	18%
Musculoskeletal pain	11	8%
Abdominal pain	10	7%
Dental pain	9	6%
Headache	8	6%
Trauma	7	5%
Others*	14	9%
Not identified	62	42%

*Pharyngodynia /Otalgia, testicular pain, cutaneous lesions, post-ictal malaise

Analgesics were administered in 114 pain-related episodes (77%), medications targeting the underlying cause (e.g., antacids) in 7 episodes (5%), and a sedative in one episode. Non-pharmacological procedures, such as evacuative enemas or rectal probes, were performed in 5 events (3%). In 21 episodes (14%), pain was managed exclusively with non-pharmacological interventions provided by MS or NMS. Most episodes (120, 81%) resolved or improved within one hour without requiring further treatment.

DISCUSSION

The results of this follow-up study indicate that pain assessment in people with intellectual disabilities (ID) who exhibit unexplained behavioral changes or behaviors suggestive of pain has now become an integral part of the Serafico Institute's operational guidelines and clinical practice. The number of episodes reported, together with the systematic use of pain scales, demonstrates that both educational and health-

care staff have become increasingly aware that behavioral changes without an identifiable cause may indicate pain, prompting investigation and timely intervention. This applies to the use of the R-FLACC scale for individuals with severe to profound ID who are unable to self-report, as well as self-report scales for those with mild to moderate ID capable of expressing their pain.

Despite these encouraging findings, some episodes of pain may still go unrecognized and untreated. Approximately half of the participants experienced at least one pain-related episode over the seven-month observation period, suggesting that undetected pain might persist in the other half. Menstrual pain, for instance, was documented 27 times among 31 menstruating women within seven months - an improbably low frequency that likely reflects underreporting, as also suggested in the literature (Çınar et al. 2023). During the study period, analgesics and sedatives were never administered together, despite the ongoing challenge of differentiating pain from distress. Identifying the underlying cause of pain also remained difficult, with 42% of cases lacking a definitive etiology. This underscores the need for tools that not only detect pain but also assist in determining its source (Lotan & Icht 2023).

Recent research has further dispelled the long-standing misconception that people with ID are insensitive to pain or possess a higher pain threshold. (El-Tallawy et al. 2023; Berger & Baria 2022). Current evidence indicates that people with ID not only face a higher risk of experiencing pain than the general population but may also perceive pain more acutely (Riquelme et al. 2021; Benromano et al. 2017, McGuire et al. 2015). In light of these insights, continued implementation of education and training programs for healthcare and educational staff is essential, particularly for assessing pain in individuals unable to self-report. Failing to recognize and adequately treat the pain of these vulnerable individuals constitutes a violation of fundamental principles of justice, equity, non-discrimination, and the right to the "highest attainable standard of health."

CONCLUSION

In this study, the frequency of reported behavioural changes, coupled with the systematic use of validated pain scales, underscores the growing awareness among educational and healthcare professionals that unexplained behavioural changes may signal the presence of pain. Pain assessment in PWID presenting with unexplained behavioral changes or indicators suggestive of pain has now become an integral part of the Serafico Institute's operational guidelines and clinical practice.

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Contribution of individual authors:

Ornella Ciccone: study design, literature searches, manuscript writing, reviewed.

Olga Zaffini & Alessandro Lepri: literature searches, manuscript writing, reviewed.

Guido Camanni, Massimo Vallasciani Antonella Baglioni, Chiara Tinarelli & Sandro Elisei: reviewed and approved the manuscript.

All authors approved the final manuscript.

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