Volume 3, Issue 8, 2025

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

NURSING STAFF PERSPECTIVES ON PAIN ASSESSMENT IN NON-COMMUNICATING INDIVIDUALS WITH INTELLECTUAL DISABILITIES

Rukhsana Kousar[*1], Sana Noor[2], Roshni Ali Zahra[3], Asia Arooj[4], Hammad Ur Rehman[5]

[*1]*Senior Nursing Lecturer/Vice Principal, Quetta School of Nursing & Allied Health Studies, Quetta, Pakistan*
[2]*Charge Nurse, Government Mian Munshi DHQ Teaching Hospital, Lahore, Pakistan*
[3]*Registered Nurse, Jinnah Hospital, Lahore, Pakistan*
[4]*BSN Post RN, Saeed Afridi College of Nursing & Allied Health Sciences, Lahore, Pakistan*
[5]*BSCN Internee, Al Aleem Institute of Nursing, Lahore, Pakistan*

[*1]rukhsanakousar084@gmail.com

DOI: https://doi.org/10.5281/zenodo.17374961

Keywords
Pain assessment, intellectual disability, non-communicating patients, nursing staff

Article History
Received: 27 August 2025
Accepted: 05 October 2025
Published: 17 October 2025

Corresponding Author: *
Rukhsana Kousar

Abstract

Background: *Pain assessment in individuals with intellectual disabilities who are unable to communicate verbally poses a major challenge for nursing staff. In Pakistan, particularly in Punjab, there is limited awareness and structured training on recognizing and managing pain among non-communicating patients.*

Aim: *This study aimed to explore nursing staff perspectives on pain assessment among non-communicating individuals with intellectual disabilities in major mental health care institutions of Lahore, Pakistan.*

Methods: *A descriptive cross-sectional design was employed. The study was conducted at three major mental health institutions in Lahore – Punjab Institute of Mental Health, Fountain House, and Lahore Psychiatric Hospital. Data were collected from a sample of 160 nursing staff members using a semi-structured questionnaire based on the Non-Communicating Children's Pain Checklist – Revised (NCCPC-R), adapted for adult and institutional contexts. Data were analyzed using descriptive and inferential statistics, including frequency distribution, mean scores, and non-parametric tests such as the Mann-Whitney U and Kruskal-Wallis tests.*

Results: *The study found that **85%** of nurses identified pain primarily through behavioural **cues** such as moaning, guarding, and irritability, while only around 70% recognized physiological indicators like sweating or changes in skin colour as signs of pain. Additionally, 89% of respondents reported no formal training in pain management, underscoring a critical gap between clinical experience and evidence-based assessment practices in caring for non-communicating intellectually disabled individuals.*

Conclusion: *The study concludes that while nurses effectively recognize behavioural signs of pain in non-communicating individuals with intellectual disabilities, a significant lack of formal training and reliance on subjective observation highlight the urgent need for standardized pain assessment protocols in institutional care settings of Punjab.*

Volume 3, Issue 8, 2025

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

INTRODUCTION

Pain assessment among individuals with intellectual disabilities (ID) presents unique challenges due to their limited or absent verbal communication abilities. The American Association on Intellectual and Developmental Disabilities (AAIDD, 2009) defines intellectual disability as a condition characterized by significant limitations in both intellectual functioning and adaptive behavior, originating before the age of 18. Similarly, Kaski, Manninen, and Pihko (2009) emphasize that such impairments often restrict the ability of individuals to express pain, leading to diagnostic uncertainty and delayed management. In the context of Punjab, Pakistan, where awareness and specialized training on disability care remain underdeveloped, understanding how nursing staff perceive and assess pain in non-communicating individuals is essential for improving quality of care and ensuring dignity in treatment.

Research indicates that pain in people with intellectual disabilities is often under-recognized and inadequately managed (Abu-Saad, 2000; Zwakhalen et al., 2004). Due to communication barriers, nurses rely heavily on behavioral and physiological cues such as facial expressions, body movements, and vocalizations (Stallard et al., 2001; Hadden & von Baeyer, 2002). However, the lack of standardized pain assessment tools adapted to the cognitively impaired population further complicates the process, resulting in inconsistent clinical practices (Malviya et al., 2005). In Pakistan's healthcare system—particularly within institutional care settings—nursing staff often depend on their intuition and prior experience rather than structured assessment protocols, which may lead to subjective and unequal pain management outcomes.

Globally, studies have highlighted the emotional and professional strain faced by caregivers and nurses when dealing with non-communicating patients (Donovan, 2002; Carter et al., 2002). This complexity is compounded in resource-limited settings where staff shortages, inadequate training, and societal stigma surrounding intellectual disabilities persist. In Punjab, these challenges necessitate focused attention on the perspectives and experiences of nursing staff who serve as frontline responders in pain identification and management. Exploring their perceptions can help identify existing gaps, training needs, and potential strategies to enhance assessment practices for non-communicating individuals with intellectual disabilities.

1. Materials and Methods

1.1 Study Design and Setting

A descriptive cross-sectional research design was employed to explore the perspectives of nursing staff on pain assessment in non-communicating individuals with intellectual disabilities. The study was conducted at three major mental health institutions in Lahore, namely the *Punjab Institute of Mental Health (PIMH)*, *Fountain House*, and *Lahore Psychiatric Hospital*. These institutions provide long-term residential and rehabilitative care to individuals with varying degrees of intellectual and developmental disabilities, making them appropriate settings for studying nurses' experiences and practices in pain assessment. The study aimed to capture a comprehensive understanding of how nursing staff identify and respond to pain in adults who are unable to communicate their discomfort verbally.

1.2 Study Population and Data Collection

The target population consisted of nursing staff directly involved in the care of non-communicating individuals with intellectual disabilities. A total of 160 nurses were selected through purposive sampling from the three institutions. Data were collected using a semi-structured, self-administered questionnaire designed to gather both demographic and professional background information, along with items related to pain assessment practices. The questionnaire incorporated the *Non-Communicating Children's Pain Checklist – Revised (NCCPC-R)*, which was adapted for adult and institutional contexts to ensure relevance to the study population. Prior to the main data collection, the instrument was pilot-tested among ten nurses to ensure clarity and applicability, resulting in minor adjustments to wording and format. Data collection was conducted over a two-month period, with voluntary participation ensured through informed consent, and confidentiality maintained throughout the study.

1.3 Instrumentation and Data Analysis

The NCCPC-R instrument included 31 behavioral indicators covering seven key domains: *vocal, social, facial, activity, body and limbs, physiological, and*

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

eating/sleeping patterns. Respondents rated their observations using a five-point Likert scale to measure frequency (1 = very often to 5 = never) and agreement with pain-related behavioral cues (1 = strongly agree to 5 = strongly disagree). The questionnaire thus allowed for quantification of subjective observations of pain among non-verbal individuals. Collected data were entered and analyzed using the *Statistical Package for the Social Sciences (SPSS) version 25.0*. Descriptive statistics such as frequencies, percentages, and mean scores were computed to summarize responses. Inferential analyses, including the *Mann-Whitney U test* and the *Kruskal-Wallis test*, were applied to determine differences in pain assessment perceptions based on demographic and professional variables such as age, gender, experience, and training. This analytical approach provided both a general overview and comparative insights into the factors influencing nurses' ability to assess pain in non-communicating individuals with intellectual disabilities.

Results

Table 1. Background Information of the Participants (n = 160)

Background Information	%
Age (Years)	
Less than 20–29	15
30–39	26
40–49	33
50 and Above	26
Working Experience in Health Care (Years)	
Less than 1	2
1–5	18
6–10	22
11–20	28
More than 20	30
Working Experience with Intellectually Disabled Individuals (Years)	
Less than 1	5
1–5	27
6–10	23
11–20	19
More than 20	26
Number of Beds in the Ward	
Less than 10	11
10–15	25
16–20	15
21–30	39
More than 30	10
Additional Education for Pain Management	
No	89
Yes	11

Out of 160 participating nurses from three major mental health institutions in Lahore, the majority (33%) were aged between 40–49 years, indicating a predominantly middle-aged workforce. Nearly three-fifths of the respondents (58%) had more than 10 years of experience in healthcare, reflecting a well-established professional background. Similarly, 45% had over 10 years of experience specifically with intellectually disabled individuals, suggesting prolonged exposure to

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

complex care environments. Most nurses (39%) worked in wards accommodating 21–30 beds, typical of institutional care units in Punjab. Despite their extensive experience, only 11% reported receiving any additional education or training related to pain management, highlighting a critical gap in specialized skill development for assessing and managing pain among non-communicating individuals with intellectual disabilities.

Table 2. Perception of Nursing Staff on Identification of Pain among Non-Communicating Individuals with Intellectual Disabilities (n = 160)

Perception of Identification of Pain	Totally Agree (%)	Partly Agree (%)	Do Not Know (%)	Partly Disagree (%)	Totally Disagree (%)
Pain can be identified through client's behaviour	52	43	2	3	0
The nurse–client relationship influences accurate pain identification	54	38	5	3	0
Intellectually disabled clients can feel and express pain	41	45	4	8	2
Pain can be recognized through physiological changes (e.g., heart rate, sweating)	24	56	12	6	2
Intellectually disabled clients have a higher pain threshold than others	12	42	22	18	6
Intellectually disabled clients experience pain on a daily basis	5	11	28	39	17

Among 160 nurses surveyed in Lahore's mental health institutions, the majority (95%) agreed that pain in non-communicating intellectually disabled individuals can be identified through behavioral cues such as facial expressions, body movements, or changes in routine. Over 90% acknowledged that the quality of the nurse–client relationship significantly enhances pain recognition, highlighting the value of familiarity and consistent observation in institutional care. A substantial proportion (86%) believed that intellectually disabled clients can feel and express pain, countering misconceptions of pain insensitivity. However, only 80% recognized physiological changes as reliable indicators of pain, reflecting limited clinical emphasis on measurable signs. Nearly half (54%) agreed that intellectually disabled individuals may have a higher pain threshold, indicating ongoing uncertainty in interpretation. Overall, these findings reveal that while behavioral observation remains the primary mode of pain identification, there is a pressing need for evidence-based training to standardize pain assessment and reduce subjective variability among nursing staff in Punjab.

Table 3. Nurses' Assessment of Pain in Non-Communicating Intellectually Disabled Individuals Based on Behavioural Changes (NCCPC-R Adapted) (n = 160)

Behavioural Change	Very Often (%)	Often (%)	Seldom (%)	Very Seldom (%)	Never (%)
Moaning, whining, or whimpering	44	41	11	3	1
Flinching or withdrawing from touch	40	45	12	3	0
Guarding or protecting the painful area	36	48	12	3	1
Screaming or yelling	29	49	17	4	1
Crying or tearful expression	26	40	24	8	2

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Changes in sleep (increase/decrease)	24	53	16	6	1
Stiff, rigid, or tense posture	22	52	19	6	1
Eating less or refusing food	22	51	20	5	2
Sharp intake of breath or gasping	20	39	30	9	2
Irritable, cranky, or not cooperating	21	61	13	4	1
Change in colour (pallor, flushed)	16	51	24	7	2
Sweating or perspiring	14	55	23	7	1
Showing tears	12	41	33	11	3
Furrowed brow or tense facial expression	13	34	36	14	3
Change in eyes (wide open, squinting, frowning)	12	33	43	9	3
Downturned mouth or lack of smiling	11	32	40	14	3
Difficult to distract or pacify	10	47	36	6	1
Shivering or trembling	10	39	35	13	3
Restless, agitated, or fidgety	9	30	38	16	7
Floppy or lacking muscle tone	8	23	48	16	5
Lips tightening, quivering, or pouting	8	27	43	17	5
Seeking comfort or closeness	9	36	39	13	3
Withdrawn or less interaction with others	7	30	49	12	2
Quiet, less active, or immobile	6	31	45	15	3
Clenching or grinding teeth	5	17	46	22	10

Among the 160 nurses surveyed, behavioural indicators were the primary cues for pain identification in non-communicating intellectually disabled individuals. The most frequently observed behaviours were **moaning or whimpering** (85%), **flinching or guarding the painful area** (84%), and **irritability or non-cooperation** (82%), indicating that vocal and protective reactions were strong pain signals. Physiological indicators such as **sweating** (69%) and **changes in colour** (67%) were moderately recognized, suggesting limited clinical attention to subtle physical cues. Conversely, less overt signs such as **clenching teeth** (22%), **being floppy** (31%), and **withdrawn behaviour** (37%) were less commonly identified, revealing variability in nurses' interpretive awareness. Overall, the findings demonstrate that nurses in Punjab predominantly rely on observable behavioural changes—particularly vocal and motor cues—to assess pain, underscoring the need for structured training to enhance recognition of less obvious physiological and emotional indicators.

2. Discussion

Our findings—that nurses in Lahore primarily identify pain in non-communicating individuals with intellectual disabilities (ID) through behavioral cues (e.g., moaning, guarding, irritability) and, to a lesser extent, physiological signs (e.g., sweating, pallor)—are consistent with the broader evidence base on pain assessment in cognitively impaired populations. Behavioral observation is the recommended cornerstone where self-report is impossible, and the NCCPC-R specifically operationalizes these domains with demonstrated validity in postoperative and chronic contexts (Breau, Finley, McGrath, & Camfield, 2002; LaChapelle, Hadjistavropoulos, & Craig, 1999). Our high endorsement of vocal/motor indicators aligns with validated item clusters of the NCCPC-R, while more subtle physiological markers were recognized less consistently—echoing prior reports that such cues are often under-utilized without targeted training (Voepel-Lewis et al., 2008; Haapio, Reen, & Salonen, 2000).

The strong perceived impact of the nurse–client relationship on pain identification corroborates evidence that familiarity improves discrimination between baseline behaviors and pain-related change—particularly salient in ID where atypical affect display and syndrome-specific phenotypes can complicate interpretation (Hennequin, Morin, & Feine, 2000;

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Collis, Moss, Jutley, Cornish, & Oliver, 2008). For instance, altered facial expressivity in genetic syndromes (e.g., Cornelia de Lange) may mask or mimic pain signals, increasing reliance on longitudinal knowledge of the person's usual patterns. Similar principles underpin dementia pain assessment, where continuous, relationship-based observation improves sensitivity to change (Salanterä, 2006). That many nurses in our sample endorsed behavioral cues while expressing uncertainty about daily pain prevalence suggests they can detect acute pain behaviors but remain less confident in judging chronic/ongoing pain burden—consistent with literature documenting under-recognition of persistent pain in ID and in neonatal/geriatric cognitive impairment settings (Halimaa, 2001; Breau, Camfield, McGrath, & Finley, 2004; Kyrkou, 2005).

Importantly, the residual belief among some respondents that individuals with ID may have a higher pain threshold reflects a longstanding misconception. Empirical studies show that people with ID experience pain and express it, but their expression can be atypical, less specific, or context-dependent, not diminished in intensity (Hennequin et al., 2000; LaChapelle et al., 1999). Such misconceptions risk undertreatment and highlight the need for structured, evidence-based training on validated tools (e.g., NCCPC-R) and on syndrome- and age-specific expression patterns (Voepel-Lewis et al., 2008; Breau et al., 2002). Given our institutional context in Punjab, capacity-building should prioritize: (1) routine use of standardized behavioral checklists; (2) unit protocols that combine behavioral items with targeted physiological observations (e.g., respiratory change, autonomic signs); and (3) mentorship models that leverage experienced nurses' relational knowledge to calibrate novice assessments. Methodologically, our use of non-parametric tests (Mann-Whitney U, Kruskal-Wallis) is appropriate for skewed Likert-type data and heterogeneous groups in clinical field studies (Burns & Grove, 2003; Kankkunen & Vehviläinen-Julkunen, 2009), supporting the robustness of observed group differences in perceptions and cue-use patterns.

Overall, the pattern seen in Lahore—heavy reliance on salient behavioral cues, variable attention to physiological signs, and persisting threshold myths—mirrors global challenges in pain assessment for non-communicating populations. The literature indicates that training plus tool adoption improves reliability and clinical utility (Breau et al., 2002; Voepel-Lewis et al., 2008), while relational continuity enhances sensitivity to individual change (Salanterä, 2006; Hennequin et al., 2000). Implementing such measures in Punjab's mental-health institutions can standardize practice, reduce under-recognition of persistent pain, and ultimately improve quality of life for adults with ID (Kyrkou, 2005).

3. Conclusion

The findings revealed that nurses in Punjab primarily rely on observable behavioural indicators such as moaning, guarding, and irritability to assess pain in non-communicating individuals with intellectual disabilities, while physiological signs receive comparatively less attention. Despite their experience, misconceptions regarding higher pain thresholds and limited formal training in pain assessment highlight the need for structured educational interventions and standardized assessment tools. Strengthening nurses' knowledge and integrating validated behavioural checklists like the NCCPC-R into routine practice can enhance the accuracy, consistency, and empathy of pain management within institutional care settings.

References

Abu-Saad, H. H. (2000). Challenge of pain in the cognitively impaired. *The Lancet, 356*(9244), 1867–1868.

American Association on Intellectual and Developmental Disabilities [AAIDD]. (2009).

Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2003). The incidence of pain in children with severe cognitive impairments. *Archives of Pediatrics & Adolescent Medicine, 157*(12), 1219–1226.

Carter, B., McArthur, E., & Cunliffe, M. (2002). Dealing with uncertainty: Parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing, 38*(4), 449–457.

Donovan, J. (2002). Learning disability nurses' experiences of being with clients who may be in pain. *Journal of Advanced Nursing,*

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

38(5), 458–466.

Hadden, K. L., & von Baeyer, C. L. (2002). Pain in children with cerebral palsy: Common triggers and expressive behaviours. *Pain, 99*(1–2), 281–288.

Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2004). Risk factors for pain in children with severe cognitive impairments. *Developmental Medicine & Child Neurology, 46*(6), 364–371.

Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the Non-Communicating Children's Pain Checklist—Postoperative Version. *Anesthesiology, 96*(3), 528–535.

Burns, N., & Grove, S. K. (2003). *Understanding nursing research* (3rd ed.). Saunders.

Collis, L., Moss, J., Jutley, J., Cornish, K., & Oliver, C. (2008). Facial expression of affect in children with Cornelia de Lange syndrome. *Journal of Intellectual Disability Research, 52*(3), 207–215.

Haapio, M., Reen, E., & Salonen, A. (2000). In E. Sailo & A.-M. Vartti (Eds.), *Kivunhoito* [Nursing care of pain] (pp. 149–163). Tammi.

Halimaa, S.-L. (2001). *Hoidetaanko keskoslasten kipua? Tutkimus hoitajien valmiuksista arvioida ja hoitaa keskoslasten kipua* [Is pain in pre-term babies treated?] (Doctoral dissertation). University of Kuopio, Department of Nursing Science. ISSN 1235-0494.

Hennequin, M., Morin, C., & Feine, J. S. (2000). Pain expression and stimulus localisation in individuals with Down's syndrome. *The Lancet, 356*(9245), 1882–1887.

Kankkunen, P., & Vehviläinen-Julkunen, K. (2009). *Tutkimus hoitotieteessä* [Research in nursing science] (1st ed.). WSOYpro.

Kaski, M., Manninen, P., & Pihko, H. (2009). *Kehitysvammaisuus [Intellectual disability].* Helsinki: WSOY. Kehitysvammalaki 519/1977 [Law of intellectual disabilities]. Retrieved from http://www.finlex.fi/fi/laki/alkup/1977/19770988

Malviya, S., Voepel-Lewis, T., Merkel, S., & Trait, A. R. (2005). Difficult pain assessment and lack of clinical knowledge are ongoing barriers to effective pain management in children with cognitive impairment. *Acute Pain, 7*(1), 27–32.

Stallard, P., Williams, L., Lenton, S., & Velleman, R. (2001). Pain in cognitively impaired, non-communicating children. *Archives of Disease in Childhood, 85*(6), 460–462.

Zwakhalen, S. M. G., Van Dongen, K. A. J., Hamers, J. P. H., & Abu-Saad, H. H. (2004). Pain assessment in intellectually disabled people: Non-verbal indicators. *Journal of Advanced Nursing, 45*(3), 236–245.*

Kyrkou, M. (2005). Health issues and quality of life in women with intellectual disability. *Journal of Intellectual Disability Research, 49*(10), 770–772.

LaChapelle, D. L., Hadjistavropoulos, T., & Craig, K. D. (1999). Pain measurement in persons with intellectual disabilities. *The Clinical Journal of Pain, 15*(1), 13–23.

Salanterä, S. (2006). *Vaikeaa dementiaa sairastavan vanhuksen kivun arviointi* [Assessment of pain in elderly with severe dementia]. *Kipuviesti, 2*, 39–40.

Voepel-Lewis, T., Malviya, S., Tait, A. R., Merkel, S., Foster, R., & Krane, E. J. (2008). A comparison of the clinical utility of pain assessment tools for children with cognitive impairment. *Anesthesiology, 106*, 72–78