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PAIN ASSESSMENT IN PEOPLE WITH INTELLECTUAL DISABILITY: IMPROVING SKILLS OF HEALTH AND EDUCATIONAL PERSONNEL AT ISTITUTO SERAFICO OF ASSISI, ITALY

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SUMMARY

Background: *Assessment of pain in people with intellectual disability (PWID) is a difficult clinical task. Poor knowledge and confidence in assessing pain in PWID result in underestimation and undertreatment. Available resources for healthcare personnel and caregivers on pain assessment in PWID are still very limited. The aim of the study was to measure the level of knowledge and confidence in assessing pain in PWID of health and education personnel at Istituto Serafico, before and after training.*

Subjects and methods: *The Istituto Serafico is a neuro-rehabilitation center caring for people with complex disabilities. Nurses, rehabilitation therapists, social health workers (SHW) and educators were invited to participate in a 4-hours theoretical and practical training. Participants were assessed through a knowledge and confidence questionnaire on pain assessment in PWID, administered before and after the training.*

Results: *123 participants attended both the theoretical and practical sessions. Median age was 43 years (range 23-67); 89 were females and 34 males. They were 10 (8%) nurses, 9 (7%) rehabilitation therapists, 77 (63%) SHW, 27 (22%) educators. Only 7 (6%) participants (5 nurses and 2 SHW) declared to have previously received formation on pain. Participants who felt "quite confident" in assessing pain increased from 28% to 73% after the training. The median score to the 24 knowledge questions raised from 15/24 correct answers (range 6-22, 62.5%) in the pre-test to 21/24 (range 11-24, 87.5%) in the post-tests (p=0.001)*

Conclusions: *The study highlights the great need of education programs for health and educational personnel working with PWID on pain assessment and the potential to improve knowledge and confidence through theoretical and practical training. A greater awareness of pain causes, clinical manifestations and consequences of untreated pain, could improve patient care, quality of life and rehabilitation goals.*

Key words: *pain assessment - intellectual disability – training - healthcare personnel - educational personnel*

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INTRODUCTION

The International Association for the Study of Pain (IASP 2020) define pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al. 2020). Pain is, by its own nature, a personal experience, thus "self-reporting" is considered the gold standard of pain evaluation (Berger & Baria 2022, Crosta et al. 2014, Doody & Bailey 2017). Patients with intellectual disability (ID) have a higher risk of experiencing pain due to their underlying conditions, frequent comorbidities and a higher risk of trauma and accidents (Bambi et al. 2021). Evaluation of pain in people with intellectual disability (PWID) is a difficult clinical task for healthcare personnel (Hauer & Houtrow 2017, Wilkinson et al. 2005). PWID are often unable to self-report pain, particularly if severe or extreme ID, associated with communication and/or sensory impairments, affects them. Numerous studies showed that the difficulties to assess pain in PWID lead to the underestimation of pain, particularly of chronic pain, and inadequate treatment (Chen-Lim et al. 2012, Kerr & Wilkinson 2006). The Italian Law N. 38 of 15 March 2010 states the right of each sick person to access palliative care and pain therapy; the law applies to all individuals (including people with severe disabilities) and to all health structures (Ministero della Salute 2020).The law envisaged the implementation of specific courses on palliative care and pain therapy in the academic courses of health-related professions. The need for formation on pain assessment and management is even more critical for staff caring for PWID who are unable to self-report. While in the past decade there has been a growing attention to education and awareness programs on palliative care and pain management in the general population, little has been done in order to equip health and educational personnel to assess pain in PWID. Few educational intervention programs targeting school nurses and health staff taking care of elderly people with dementia in nursing homes, have highlighted the great need of specific education to increase confidence and knowledge in assessing pain in PWID (Brandauer et al. 2020, Quinn & Smolinski

2018). Caregivers, health and educational personnel caring for PWID should receive an adequate training on pain and on the use of appropriate pain assessment tools, in order to improve pain management and quality of life of the persons entrusted to their care (Genik et al. 2017, 2018).

The Istituto Serafico of Assisi is a Neuro-rehabilitation Centre for persons with complex disabilities in particular with ID. It accommodates both children and adults in the Resident and Semi-resident structure. More than 85% of children and adults in care at Serafico are affected by severe or extreme ID associated, in over 85% of cases, with total absence of language or just basic verbal activity. More than 40% of them are also affected by visual impairment and/or deafness. Evaluation of pain in children and adults in care of Serafico is particularly difficult because of the complexity of sensory, intellectual and behavioral impairments. Health and educational personnel used to assess pain in PWID mainly by their personal experience and clinical observation, without having received a specific training on the use of pain scales. We conducted a study to evaluate the knowledge and confidence of the health and education personnel pre and post theoretical - practical training on evaluation of pain in PWDIs. This was the first step of a wider study on evaluation of pain in PWID at Istituto Serafico.

SUBJECTS AND METHODS

All nurses, social health workers, rehabilitation therapists and educators of Istituto Serafico were invited to participate in the training on "evaluation of pain in people with intellectual disability and communication impairment". The training consisted of 2 hours theory and 2 hours practical sessions. Sessions were conducted in small groups of 15-25 participants to allow all personnel to participate without disrupting the residents daily care and rehabilitation program.

The research team, consisting of pediatric neurologist, pediatric infectious disease specialist, physiatrist, psychologists, and psychiatrists of Istituto Serafico, with the support of two pediatric palliative care specialists of Bambino Gesù Pediatric Hospital, prepared and revised the training materials.

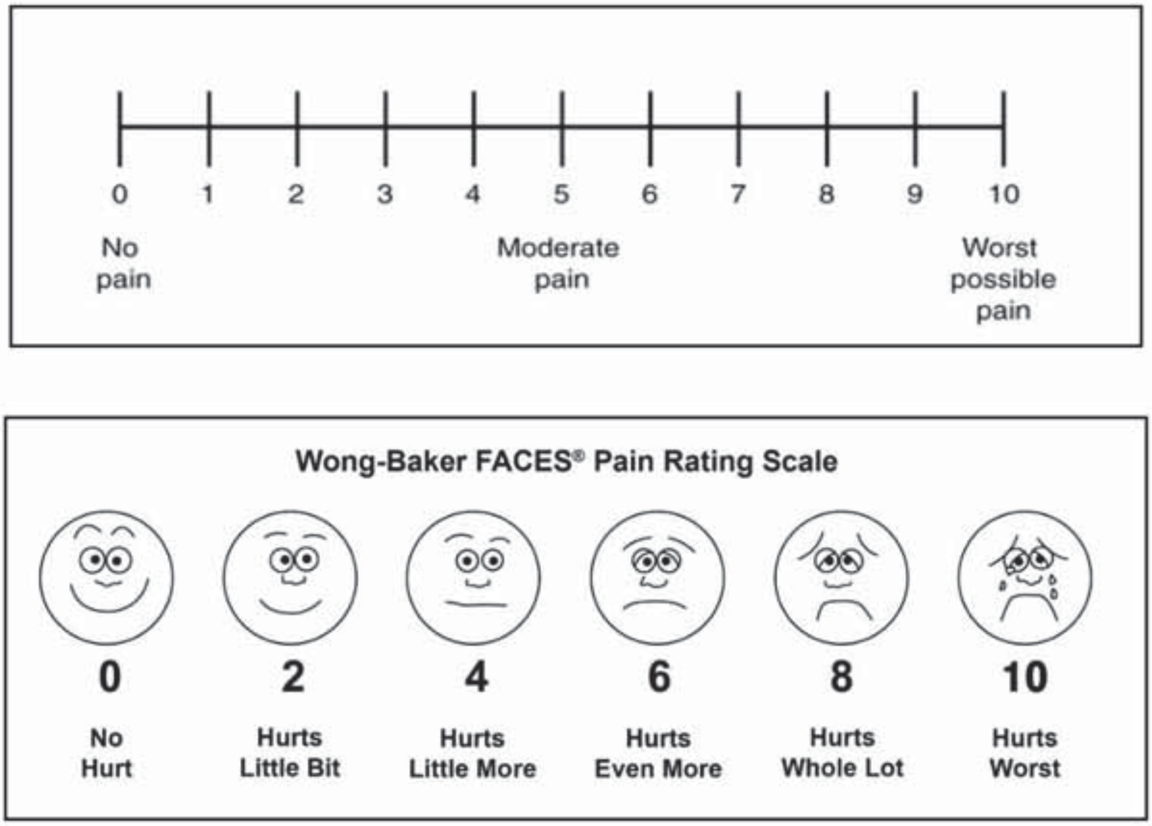
Training sessions were conducted by the pediatric neurologist and a psychologist. The theoretical sessions, which were based on a literature review, included topics on pain definition and physiopathology, pain prevalence in children and adults with cognitive and communication impairment, main causes of pain in PWID, consequences of untreated pain, methods of evaluation and validated pain scales. The practical session was based on teaching/learning the use of two self-reporting pain scales: the Numeric Rating Scale (NRS) and the Wong Baker Pain Scale (WBPS), and the Revised Face, Legs, Activity, Cry and Consolability scale (r-FLACC) (Figure 1). The trainee learned how to employ each scale through visual materials and role play among the participants.

The self-evaluation scales had to be used in children and adults with mild intellectual disabilities, able to self-report. The NRS (score 0-10) had been previously tested in Serafico patients with mild-to moderate ID, who had a sufficient conceptualization of numbers and had shown the ability to understand the scale and use it correctly. The scale was found to be particularly useful in blind patients. The WBPS, which is based on identification of face expressions (scored 0 to 10), had been used successfully in a group of patients with mild to moderate ID, with verbal or non-verbal abilities, capable of communicating pain/discomfort through pointing or eye gaze. Trainees were educated to explain to the patients how to use the scales each time before administration and to test their understanding and ability to use them correctly. The r-FLACC is a validated observational tool based on the Face, Legs, Activity, Cry and Consolability scale (FLACC) used to measure pain in small preverbal children (Merkel et al. 1997). The FLACC scale was subsequently revised to adapt it to children with ID. It has been shown to be a reliable and easy to use tool in clinical practice for children with cognitive impairments unable to communicate (Pedersen et al. 2015). The Italian version has shown a good inter-rater reliability and internal consistency (Destrebecq & Terzoni 2013).

The r-FLACC has been shown to be a valid and reliable tool also in adults with severe ID (Faraldo et al. 2016). Among the validated observational scales, we choose to adopt the r-FLACC in order to employ only one tool for both children and adults with severe ID at the same Institution.

A pre-training questionnaire, consisting of 24 knowledge questions and 6 questions about previous formation and confidence in assessing pain in PWID was administered at the beginning of the training. The knowledge questions consisted in 13 multiple choice (MC) and 11 true or false (TF) questions. A post-training questionnaire consisting of the same 24 knowledge questions and 3 confidence questions was administered at the end of the theoretical and practical session to evaluate the acquired knowledge and confidence in the use of the scales by all the participants. The participants were also tested for their ability to administer the scale correctly through role-play. The answers to the pre and post-test questionnaires were entered in Google Forms. The pre and post training questionnaire is available upon request to the corresponding author.

Ongoing supervision and support on the actual and correct use of the pain scales was continued throughout working hours in the following months.



Categories	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested, **sad, appears worried**	Frequent to constant quivering chin, clenched jaw, **distressed looking face, expression of fright/panic**
Legs	Normal position or relaxed, **usual tone & motion to limbs**	Uneasy, restless, tense, **occasional tremors**	Kicking, or legs drawn up, **marked increase in spasticity, constant tremors, jerking**
Activity	Lying quietly, normal position, moves easily, **regular, rhythmic respirations**	Squirming, shifting back and forth, tense, **tense/guarded movements, mildly agitated, shallow/splinting respirations, intermittent sighs**	Arched, rigid or jerking, **severe agitation, head banging, shivering, breath holding, gasping, severe splinting**
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint, **occasional verbal outbursts, constant grunting**	Crying steadily, screams or sobs, frequent complaints, **repeated outbursts, constant grunting**
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort, **pushing caregiver away, resisting care or comfort measures**

Figure 1. Numeric Rating Scale, Wong Baker Pain Rating Scale, Revised FLACC Pain Scale

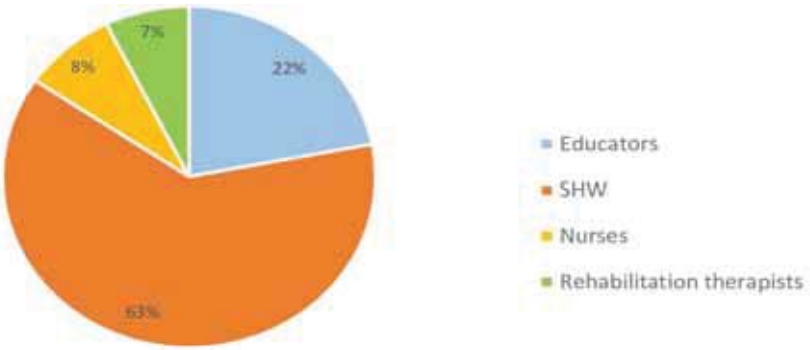


Figure 2. Trainees' Professional categories

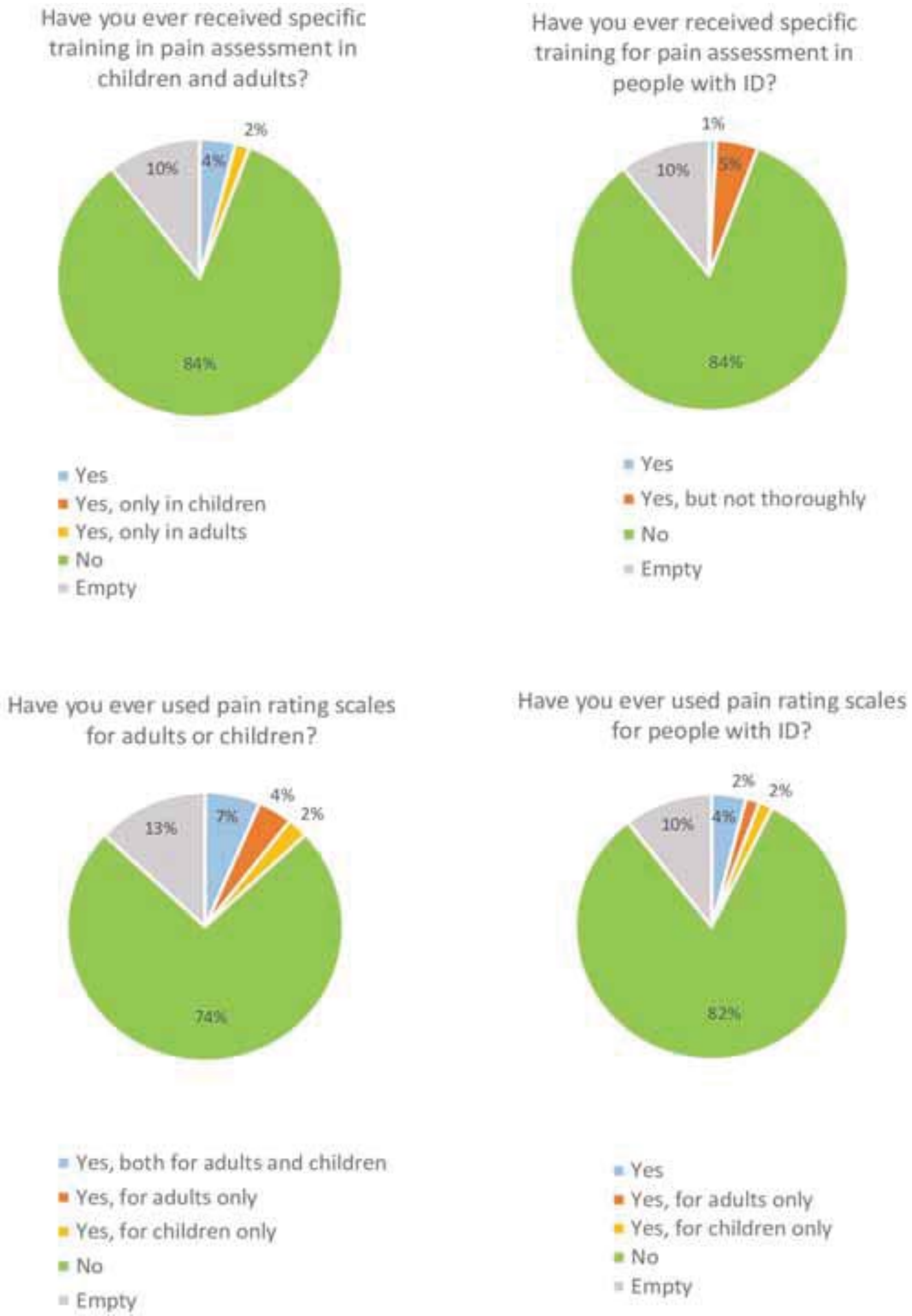


Figure 3. Answers to questions on previous formation on pain and use of pain scales

Statistical Analysis

Descriptive and frequency analyses were computed to investigate the variables of the socio-anamnestic questionnaire. A paired t-test was computed to investigate whether the test score averages of the operators were significantly higher after they had taken the training.

SQUIRE guidelines were used for the present publication; interventions were described according to the TIDIER checklist. The study was approved by the Regional Ethic Committee (Umbria) and anonymization of personal data was assured.

RESULTS

Participants characteristics

Among 135 employees who were invited to participate in the training, 126 attended the theoretical session and a total of 123 (91%) attended both the theoretical and practical sessions. Median age was 43 years (range 23-67); there were 89 females and 34 males. They were 10 nurses (8%), 9 rehabilitation therapists (7%), 77 social health workers (SHW) (63%), 27 educators (22%) (Figure 2). 85/135 participants (69%) had obtained their diploma/degree between 2010 and 2020, while only 28 (23%) and 10 (8%) before 2010 and after 2020, respectively.

Pre-training formation

One hundred and three (84%) of the responders declared they had not received a specific formation on the evaluation of pain; only 7 (6%) participants (5 nurses and 2 SHW) declared to have received formation of which 2 only in adults; 13 (11%) empty answers were mainly due to delay in participating in the training. Sixteen participants (13%) (5 nurses, 9 SHW and 2 rehabilitation therapists) had previously used pain scales for children and/or adults. Only 7 (6%) employees (3 nurses and 4 SHW) answered affirmatively to the question whether they had received a specific formation on evaluation of pain in PWID, of which 6 said that it had not been an "in-depth" training. Nine (7%) participants (3 nurses and 6 SHW) answered that they had used pain scales in PWID (Figure 3). The scale most frequently used were the NRS followed by WBPS, r-FLACC and PAINAD scales.

Pre- and post-training knowledge questions

The median score to the 24 knowledge questions increased from 15/24 points (range 6-22, 62.5%) in the pretest to 21/24 points (range 11-24, 87.5%) in the post-test: t (-17.597) = 122, p=0.001 (Figure 4). Nurses improved the median score of right answers from 69% in the pretest to 88% in the post-test, rehabilitation therapist from 67% to 89%, SHW from 62% to 84% and educators from 59% to 87% (Figure 5). Absolute score numbers are reported in Table 1.

In the pre-test there were more than 75% correct answers to the multiple-choice questions related to: Italian law 38/2010 on palliative care and pain therapy (MC1), definition of pain (MC3), most common causes of pain in PWID (MC5), pain-related behavioral changes (MC7, MC12) and preferential use of observational scales to evaluate pain in PWID unable to self-report (MC13). Among the true and false question, more than 75% correct answers were about the chance that the same behavior could have been be related to pain or psychiatric/behavioral disorders (TF5), the occurrence of atypical pain responses (TF6), occurrence of pain or spontaneous change of vital parameters due to CNS lesions (TF9, TF10) and the importance to know the baseline behavior of the person with ID to evaluate episodes of pain (TF11).

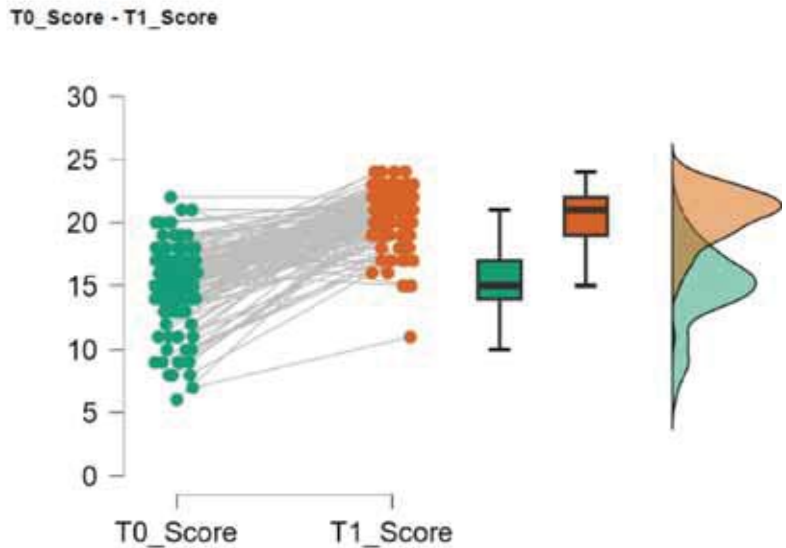


Figure 4. Median scores at knowledge questions in pre (T0) and post (T1) test

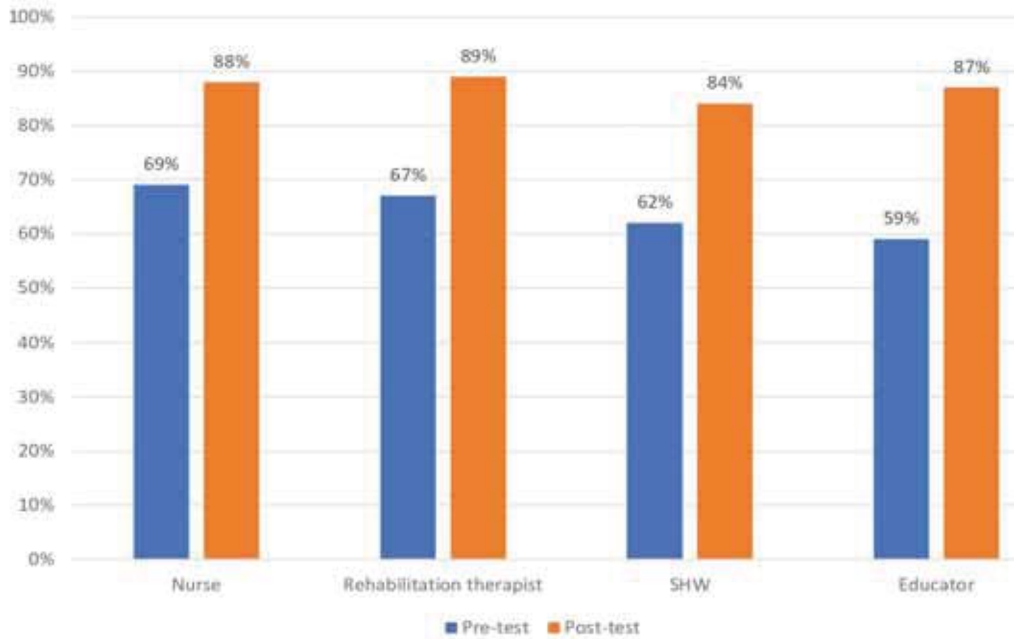


Figure 5. Percentages of correct answers by professional category

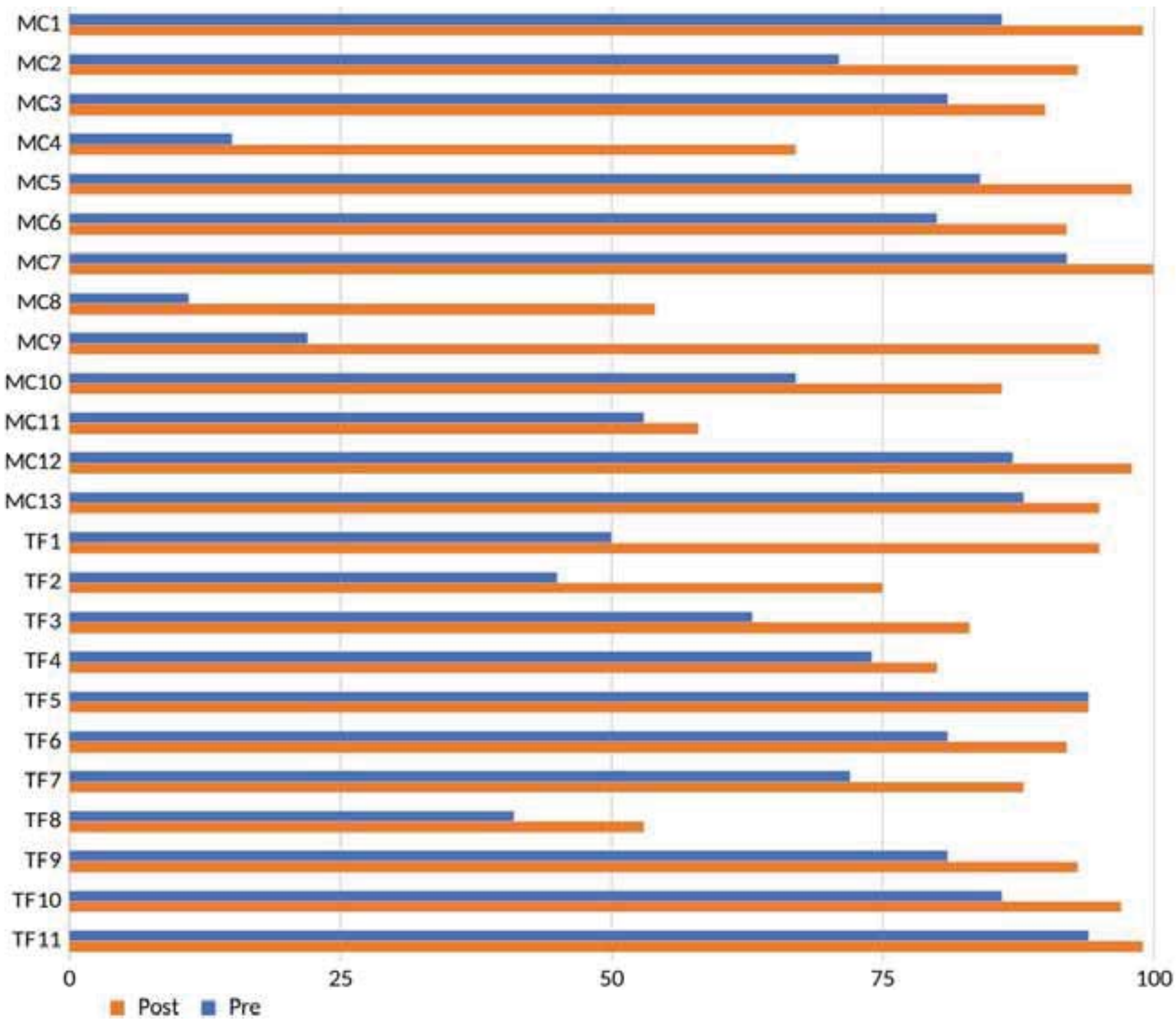


Figure 6. Score of individual choice and true/false questions pre and post training

The questions with less than 50% correct answers were about the possibility of self-evaluation in people with mild-moderate ID (TF1, TF8) and the erroneous assumption that PWID have a higher pain threshold compared to people without disabilities (TF2). The most frequently failed questions (<25%) were about the concept of nociceptive pain (MC4), the knowledge of different pain scales (MC8) and which pain scale to use in case of mild ID and blindness (MC9).

In the post-test there was an improvement in the rate of correct answers to each question. A remarkable improvement, one standard deviation higher (M = 67.41, SD = 24.93), was about the concept of nociceptive pain (MC4), the knowledge of different pain scales used in PWID (MC8), the possibility to use a numeric scale in case of mild ID and blindness (MC9), the knowledge of self-report as gold standard (TF1) and the erroneous assumption that PWID have a higher pain threshold compared to people without disabilities (TF2). Little improvement was about the parameters utilized in the observational pain scale (MC11) and the possibility of self-evaluation in people with mild-moderate ID (TF8) (Figure 6).

Pre- and post-training confidence questions

Before the training most of the participants (64; 52%) felt "not much confident" about evaluating pain in PWID, while 34 (28%) felt "quite confident", 10 (8%) "not at all confident", and only 1 (1%) "very much confident". The great majority considered "very difficult" (7; 6%), "difficult" (28; 23%) or "not always easy" (71, 58%) differentiating behavioral changes due to physical pain from those of psychiatric-behavioral origin. After the training the majority of participants (90; 73%) felt "quite confident" in assessing pain in PWID, while 26 (21%) felt still "not much confident" (Figure 7). Most participants found it "quite easy" to use the self-evaluation pain scale (NRS and WBPS) (96; 78%) and the r-FLACC scale (104; 85%). All participants were able to correctly utilize the pain scales (NRS, WBPS, r- FLACC) in the role-play practical session.

Table 1. Professional categories' scores at knowledge questions in pre- and post-test

Occupation	Pre-test			Post-test		
	Range	Mean	%	Range	Mean	%
Nurses	9-20	17	69	17-23	21	88
Educators	9-22	14	59	15-24	21	87
SHW	6-21	15	62	11-24	20	84
Rehabilitation therapists	8-21	16	67	18-24	22	89

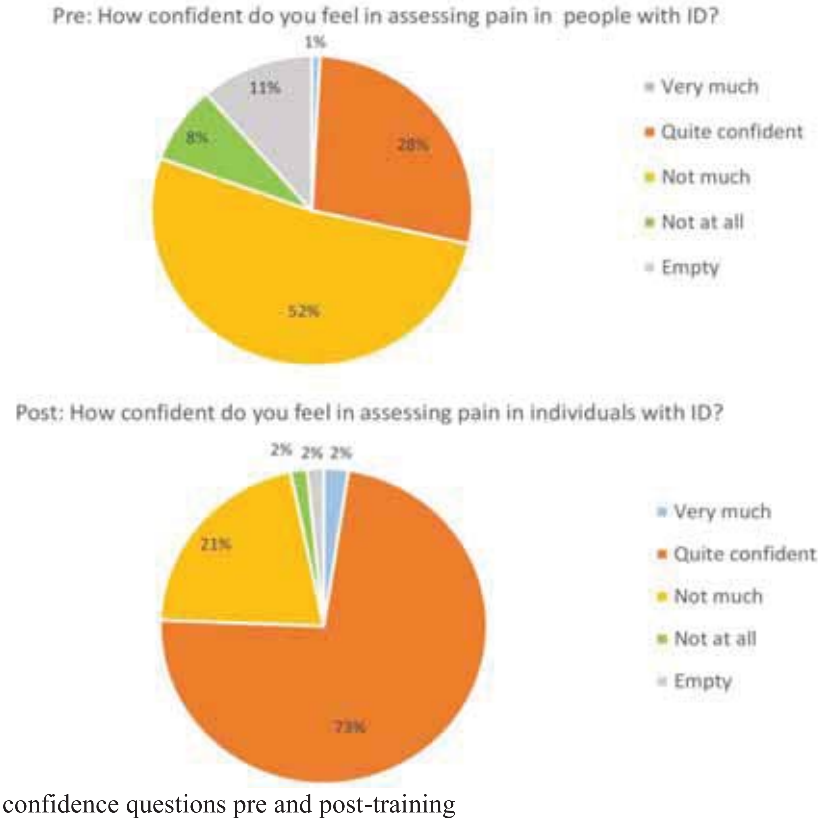


Figure 7. Answers to confidence questions pre and post-training

DISCUSSION

The results of our study highlight the great need of training programs on pain assessment for health and educational personnel working with people with disabilities, particularly in children and adults with cognitive and communication impairments. The fact that 83% of the employees who participated in the study declared that they had not received a specific training on the evaluation of pain is worthy of further reflection. The Italian law 38/2010 at Article 8 provides for updates to the educational curricula of specific academic pathways in palliative care and pain therapy. The law stipulated that within six months of the effective date of the same law, the Minister of Education, Universities and Research, in consultation with the Minister of Health, would identify the general criteria for the regulation of the educational systems of specific educational pathways in palliative care and pain therapy. Given the complexity of the education system and the time requested for implementation of the above matter, detailed criteria for the activation of specific training paths on palliative care and pain therapy were identified only in 2018, to update the degree programs in Medicine and Surgery, Nursing, Physiotherapy and Occupational Therapy, Psychology, and Social Work (Ministero della Salute 2020). Finally, the document "Program for teaching/learning palliative care and pain therapy" in undergraduate courses in Medicine and Surgery, Nursing, Psychology and Social Work was published in 2020. In Italy the Curriculum of the SHW, who represented the majority (63%) of the participants in our training, includes only a few notions on pain but does not include specific lessons on this topic. Academic courses in education do not cover the topic on evaluation of pain. Among the 17 participants to our training who graduated between 2020 and 2022 (1 nurse, 1 rehabilitation therapist, 13 SWH, 2 educators), only the nurse and a SHW declared to have received a specific formation on pain during their academic courses. Three out of 5 nurses who reported to have received some formation on pain assessment, declared to have also received some training on evaluation of pain in PWID, while three SHW said to have received it only in PWID. In an additional interview, we found out that only nurses had received formation on pain within academic or on job training, while SHW reported that they received some general notions within the diploma course or in other educational courses. A limitation on the interpretation of these results is that the answers about the previously received formation may have been different, based on self-perception or understanding of the meaning of “specific” formation on pain, both in general population and PWID. It is in fact noteworthy that none of the rehabilitation therapists declared to have received a specific formation on pain. It is not surprising that the educational staff stated that they had not received any previous training on pain, as this topic is not included in the diploma/degree program on Education. We may argue that it would be appropriate to include at least some basic knowledge in pain assessment in PWID in the academic course of educators, particularly those in special education, as they spend much more time with children and adults with ID in schools and rehabilitation centers than nurses or doctors do. The fact that they often know the children and adults with ID entrusted to their care better than the health staff, place them in the best position to observe changes in behavior that may be indicative of pain. If educators fail to recognize pain in PWID in the resident setting or during different rehabilitation activities, they cannot refer them to nurses and doctors for prompt assessment and management (Quinn & Serna 2019). The choice to involve both the healthcare and educational personnel in the training was to assure that all professionals caring for PWID at Serafico could acquire the knowledge and tools for assessing pain and to facilitate the collaboration between educational and health care professionals in pain assessment and management, according to specific competences and skills.

The need for education and training of health personnel on assessing pain in PWID has been advocated in the international scientific literature (Barney et al. 2020, Genik et al. 2017, 2018, Quinn et al. 2020, Quinn & Smolinski 2018). A study conducted in Finland to evaluate pain assessment among non-communicating PWID by nursing staff, revealed that only 8% of the nurses had undergone any additional education for pain management (Kankkunen et al. 2013). The poor confidence and difficulties in pain assessment in PWID, reported by the majority of the participants in this study and the positive impact of the training in increasing both pain related knowledge and confidence, are in line with what was reported in other studies (Barney et al. 2020, Crosta et al. 2014, Kerr & Wilkinson 2006, Tosato et al. 2012, Wilkinson et al. 2005). Genik et al. found that a 3 to 3,5-hour training pain workshop significantly increased respite workers' pain-related knowledge as well as their confidence and skill in pain assessment and management in children with ID (Genik et al. 2018, 2021). A 3 hours educational program to increase school nurses’ knowledge and skills, piloted on 14 nurses by B. Quinn and M. Smolinsk (2018) regarding pain and assessment for schoolchildren with ID, showed a statistically significant decrease ($p<0.0001$) in pain assessment difficulty. The authors concluded that educational programs can help increase school nurses’ pain assessment knowledge and skills (Quinn & Smolinski 2018).

In our study there was a significant improvement ($p \leq 0.0001$) in the median score in the pre- and post-training knowledge questions across all categories of trainees. The trainees showed a basic knowledge on general topics related to Italian pain legislation, definition of pain, pain associated behavioral and vital parameters changes and preferential use of observational scales to evaluate pain in PWID, unable to self-report. The most frequently failed questions (>75%) in the pretest were about nociceptive pain, the knowledge of different pain scales and the possibility to use a self-evaluation scale in individuals with mild ID. Regarding this last topic, studies are inconsistent about the ability of individuals with ID to provide adequate pain self-reports using scales; most authors agree that the degree of ID plays an important role in the ability of individuals in using them. Considering that pain is by its own nature a subjective experience and self-reporting is considered the gold standard of pain assessment, patients with mild to moderate ID who are able to communicate should be given the chance to use self-report pain scales (like the numeric pain scale or other visual analogue pain scale), once their ability to understand and use them correctly has been established (Dillane & Doody 2019). During our training the participants learned how to test people with mild to moderate ID, explaining to them each time before administration, in plain language, how the self-report pain scale works and to select the most appropriate and easy to use scale for each subject.

Most of the responders (>50%) to the pretest thought that PWID had a higher pain threshold than people without ID. The assumption that children and adults with cognitive impairment are insensitive or indifferent to pain is a widespread idea even among health practitioners and caregivers (Bambi et al. 2021, Tosato et al. 2012). Kankkunen et al. found that two thirds of interviewed nurses working with PWID living in long-term care, considered their pain threshold to be high (Kankkunen et al. 2013). Irritability, crying, sleep disorders, feeding difficulties, aggressive or self-harm behaviors in children with severe neurological impairments are often interpreted as psychiatric manifestations, without an in-depth evaluation of possible causes of pain. In the past, parents have often been reassured that their child with severe central nervous system damage was not experiencing pain, likely reflecting the lack of studies on pain behaviors (Berger & Baria 2022). While it is true that some conditions associated with ID could have a specific profile of decreased pain experience, resulting from unique neuropathology, and that PWID may not show the expected responses to pain related to trauma and accidents, there are also studies showing that individuals with ID may be hypersensitive to pain as reflected by their lower pain thresholds (Bembich et al. 2021, Benromano et al. 2017, Defrin et al. 2021, McGuire & Defrin 2015, Riquelme et al. 2021).

In the post-training test all the questions were answered correctly by the majority (>50%) of study participants, with a significant improvement of the median score as compared to the pre-training test. The improvement concerning the question on pain threshold in PWID is particularly noteworthy, given the importance in overcoming a diffuse bias regarding the ability of PWID to perceive pain.

The practical session of the training was focused on the use of two self-reporting pain scales (NRS and WBPS) and the r-FLACC. Most of the trainees found it quite easy to use the self-evaluation scales and the r-FLACC. The fact that the majority of participants felt “quite confident”, but not “very confident”, in assessing pain in PWID was considered a correct perception of the difficulties in evaluating pain in people with complex disabilities and intellectual, behavioral and communication impairment. Ongoing training was carried out weekly by the research team to ensure that the scales were used correctly in day-to-day practice and to fill possible training gaps.

A difficulty experienced in conducting this training was the heterogeneity in knowledge and experience of the trainees; some concepts could have been proposed more efficiently if it would have been possible to train the different professional groups separately. On the other hand, this modality, chosen for continuity of care reasons, offered the possibility of a fruitful interaction and exchange of competences between all participants, reflecting the day to day working environment at Serafico.

CONCLUSIONS

This study highlights the great need of educational programs on pain assessment for health and educational personnel caring for PWID. The results of the training on pain assessment, which is part of an ongoing study on evaluation of pain in PWID through the systematic use of validated pain scales, resulted in a significant improvement in confidence and knowledge among participants. Despite the well-recognized challenges in pain evaluation in people with cognitive and communication impairments, a greater awareness of pain incidence, causes, clinical manifestations, and the consequences of untreated pain, could improve patient care, quality of life and the attainment of rehabilitation goals.

Conflict of interest: *None to declare.*

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Conflict of interest: *None to declare.*

Contribution of individual authors:

All the authors have given substantial contribution to the study conception and design.

Ornella Ciccone, Alessandro Lepri & Olga Zaffini to acquisition, analysis and interpretation of the data.

Ornella Ciccone & Olga Zaffini have drafted the manuscript.

All authors read and approved the final version of the manuscript.

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