

Measuring and Addressing Pain in People with Limited Communication Skills: The “I Hurt Help Me” Pain Management Project.

Taylor, Ian R. MSc, MCSP, Dip RGRT, Head of Physiotherapy, Adult Learning Disability Service, Kent Community Health NHS Trust, UK.

Conway, Val. MSc RN, BSc (hons) LicAc, Consultant Nurse and Clinical Lead for Chronic Pain, Kent Community Health NHS Trust, UK

Knight, Anneyce E. MSc, PGCE, BA (hons), RN, FRSA. Senior Lecturer in Health and Social Care, School of Health, Exercise and Social Sciences, Southampton Solent University, UK.

Abstract

There are no national standards for pain assessment and treatment for people with Learning Disabilities or those who have limited communication skills. Residential homes are usually privately run with non NHS employees and there is a lack of training on pain and its management, with many staff unaware of basic treatment options. Following an audit within a range of Learning Disability Care Homes in a district in one county in the United Kingdom (UK) looking at pain assessment and management, a small feasibility study was carried out to ascertain which of three pain measurement tools were found to be most useful. DISDAT was identified as the tool of choice. A training package entitled "*I Hurt Help Me*" was developed for managers and carers working with people with a learning disability. The training consisted of how to assess pain using the DISDAT tool and pain management. The training sessions involved 203 carers in 54 residential homes, providing care for more than 287 residents. The evaluation of these sessions is presented here and demonstrates that carers' pain assessment and management skills improved facilitating more individualised intervention. The standard of recording has improved and Health Action Plans (HAPs) are now becoming commonplace with detailed descriptors of individual residents - allowing a baseline to work from, enabling faster and more effective care for people with Learning Disabilities and the resultant reduction in challenging behaviour. The importance of training non-registered staff is highlighted and the need for further development in this area.

Key words: Pain, Pain Assessment, Learning Disabilities, Limited Communication

Corresponding Author: Ian R Taylor, Head of Physiotherapy, Adult Learning Disability Service, Kent Community Health NHS Trust; email: Ian.Taylor6@nhs.net

INTRODUCTION

Learning Disabilities services across the United Kingdom (UK) are provided by small local integrated health and social services teams. The services are community based and clients are seen in their own homes, supported living accommodation or within residential homes. The learning disability team is multi-disciplinary and may consist of nurses, physiotherapists, speech therapists, occupational therapists, care managers, sensory therapists and psychologists. Input to the person is always individualised and person-centred and is agreed in association with the person themselves. It correlates directly with their individual aims and aspirations, quality of life and socio-economic needs. The Learning Disability service will address how to improve health inequalities, health and wellbeing needs, as well as more specific Learning Disability related health issues. It also supports, not only mainstream services to make reasonable adjustments within their services, but also facilitates client access to these services with specific initiatives; for example, pain profiles.

Chronic musculo-skeletal pain is the commonest form of pain in the general population, with associated reduced mobility, muscle weakness, falls and possible reduction in

mental health and quality of life (1). In the general population it has been recognized that up to 80% of people living in residential homes may suffer from acute or chronic pain and that this is often undetected and undertreated (2,3,4). This figure is likely to be reflected in the Learning Disability client group, but at a much younger age as a result of co-pathologies (1) and will be discussed in more detail below.

There are approximately 28,000 people in Kent with a Learning Disability, many of these have co-pathologies such as reduced communication ability, decreased mobility, reduced function, contractures, weight loss, poly-pharmacy, arthritis, epilepsy and other degenerative disorders (5). People with a Learning Disability often have reduced mobility, altered muscle tone, and increased risk of falls from an early age, so premeditating early onset of symptoms (1). Pain can cause increased distress to the individual as their efforts to communicate their pain are often misinterpreted as challenging behavior, “it’s just how they are”, and therefore the symptoms are ignored (6,7,8,9). By assessing and treating pain, people with learning disabilities can be socially included as they are able to participate in meaningful activities and social interaction, with the resulting enhancement in their quality of life and reduction in costs for supporting agencies.

The belief that pain is under-reported and under-treated amongst cognitively impaired adults is prevalent (10). Cognitive impairment affects an individuals’ ability to communicate their pain, resulting in uncertainty as to how to best assess their pain (11). Evidence for the effectiveness of pain assessment tools for adults with cognitive impairment is inconsistent but suggests those with severe impairment have difficulty completing self-report pain assessments (12, 13). Untreated pain has been found to

have profound consequences upon cognitive ability and physical function. The associations found between chronic pain, cognitive impairment and physical function raises significant issues for the management of pain amongst this group.

At present there are no guidelines on how to best assess and manage pain amongst people with a learning disability and there are no standardised tools for assessing pain for this group (12,14). So, there is a need for a standardised and formalised process for recognition, assessment and management of pain for people with a learning disability involving recognition, assessment, planning of intervention, multi- professional involvement and carer support (14,15,16). There is also a need to develop training materials to support health professionals working with people with a learning disability .

The aim of the "*I Hurt Help Me*" Pain Management Project, was to review what pain assessment and management guidelines were available and utilized to support equal access to appropriate pain management in the residential home setting for people with a Learning Disability. Following on from this a training package was developed for managers and carers working with people with learning disabilities.

Methodology

In 2011, Taylor carried out an audit of pain management in one district of East Kent (UK) with 69 Learning Disability residential services providing accommodation for three to fifteen residents in each home and managed by both small and large private providers. The initial phase of the audit was to conduct face to face interviews with home managers and carers from twelve homes randomly selected to ascertain a base

line of pain awareness and identify what management was taking place, to ascertain the most useful pain assessment tool and to identify strategies to develop pain assessment and management practice.

There are no specific tools for pain/distress assessment for people with a Learning Disability so within this project, the author reviewed seven of the most commonly used pain/distress assessment tools. DISDAT (Disability Distress Assessment Tool) (17), Abbey Pain Scale (18). PACSLAC (Pain Assessment for Seniors with Limited Ability to Communicate) (19), PAINAD (Pain Assessment in Advanced Dementia) (20), Wong Baker faces (21), VAS (Visual Analogue Scale) (22). VDS (Verbal Descriptor Scale) (23), Pain Thermometer (22). The Wong Baker faces, VAS and VDS were discarded from the study as they require a certain level of communication by the client/patient, an understanding of their own body image and the ability to grade their own pain themselves in order for them to be a reliable tool (24,25). As the client group in this study had limited communication skills and were classed as either having a moderate or profound Learning Disability with associated limited communication ability, Abbey, PACSLAC and DISDAT were trialed in this study.

Seven of the original twelve randomly selected residential homes across the chosen district agreed to take part in the pilot study and use these three pain assessment tools for a month at a time over three months on the same residents. Occupancy of these homes varied from 6 - 25 residents per service and all aged over 18. The three chosen pain assessment tools had any identifying references and titles removed to limit bias

from the client group which comprised of staff without professional qualifications in health. Verbal and written instructions and guidance were provided to each home on how to use the tools. Each tool was used in turn for one month, over a three month period, on clients to record a base line measure and any possible pain indicators and limit bias.

In total, seventy eight residents and eighty managers and carers took part in the month study. From the face-to-face interviews, seven homes found it a positive experience for themselves and their clients, though at times each home missed recording data due to staff shortages or bank staff covering for annual/sick leave and had not been shown how to complete the forms, thus impacting on the results of the study; nevertheless valuable feedback was obtained.

The Abbey Pain Scale was found to be quick to fill in but did not record sufficient data in the detail needed (for example, nuances of facial expression) and it was therefore difficult to use to provide a base line. This also meant that then it impacted on the continuity of information and the assessment of pain by co-workers or other professionals. PACSLAC was seen to be a satisfactory tool but it was not popular with the residential services as they reported it did not give a base line assessment that was easy to use. The breaking down of facial nuances was difficult to fit into the boxes by the care staff and verbal descriptors were seen to be more helpful. It was the preferred tool of choice for only one of the seven homes.

DISDAT was the preferred tool for six of the seven homes. It was seen to provide a reliable baseline, with nuances easily identifiable in the residents facial expression, behaviours, mobility and posture.

It was perceived to be a useful tool to pass on information about a client to colleagues and other professionals especially when visiting the General Practitioner. This was seen to facilitate continuity in pain assessment, pain management and going monitoring. Subsequently, DISDAT was incorporated into the clients communication passport by three separate homes to enhance interprofessional communication as DISDAT provides daily monitoring sheets. Location of the pain was deemed by most to be problematic as the people they looked after couldn't communicate this and staff considered felt this was a "job for the doctor". Staff thought they may be able to support both the client and the doctor by attending appointments and using the DISDAT tool for a few days prior to attendance as this would help the doctor make his diagnosis.

***"I Hurt Help Me"* Pain Management training**

Following analysis of the feedback from this audit it was decided to produce the training package, "*I Hurt Help Me*", for managers and carers working with people with a learning disability. "*I Hurt Help Me*" training needed to address several key areas:

- Understand and recognise the various ways people demonstrate that they are in pain or discomfort.
- Learn different ways to manage pain for people with a Learning Disability.
- Have an understanding of and complete a DISDAT tool.

- Learn how DISDAT can be applied to benefit a persons' health.
- Recognize and have an awareness of pain relief medication and related policies.
- Deliver a “best practice pain pathway” when a person with Learning Disabilities is in pain or discomfort.

A hotel was chosen for the training venue that was central, with easy access and the space to accommodate up to 25 carers for each session. Flyers were sent out to all care homes in the district that provided services for people with a Learning Disability, followed up by telephone calls and visits to encourage attendance. A charge of £20.00 was made to cover the cost of the venue and refreshments. The training was delivered over ten half day sessions and was delivered to 203 carers, working in 54 residential homes, providing care for 287 residents.

Each half day was delivered by a Consultant Nurse in Pain and a Clinical Specialist Physiotherapist in Pain and Learning Disabilities. The content of each half day included:

- Pain awareness checklist.
- How people express pain.
- How to manage pain.
- The use of the DISDAT tool.
- Pain medication and pathway.
- Evaluation questionnaire

The Teaching sessions were interactive encouraging individual, group participation and feedback using self-reflective questionnaires on current knowledge of pain recognition and management and small group work. Participants were encouraged to share

knowledge and their experience of both effective and poor practice. At the end of each session handouts were provided on the subject covered.

Teaching strategies

On arrival, the participants were provided with a training pack which included the agenda, timings and subjects to be covered. The teaching sessions were as interactive as possible encouraging individual, group participation and feedback. The teaching sessions were broken down into self-reflective questionnaires on current knowledge of pain recognition and management and facilitated small group work. Overall group interaction was encouraged during the feedback from the questionnaires and group work. Participants were encouraged to their share knowledge and experience of both good and poor practice within an environment that ensured confidentiality. At the end of each session, handouts were provided and there was the opportunity for “any other questions”.

Changes being initiated as to ensure that, as the facilitated interactive group work was the most popular with all the participants, the trainers will seek to embed this teaching and learning style throughout the session. The trainers will also provide more time for feedback and “any other questions”, as this opportunity to share and question was seen by the participants to be very useful and often had to be cut short due to timing constraints.

Results

Following statistical analysis on 116 completed evaluations of attendees from 26 September 2012 to 17 January 2013, the results are as follows. Table 1 presents an overview of the participants' responses. 82.8% of people completing the training session found the training useful with 71.1% perceiving that they had gained new insights into pain assessment and management (Figures 1 and 2). 89 respondents felt that the training was 'highly relevant to their current job responsibilities (see Figure 2) with 82.1% scoring their understanding of the topic as excellent. The most useful elements of the training were seen to be the information on pain management and assessment, in particular medication and assessment tools (see Figure 3). Teaching and learning strategies utilized during the training sessions were also included in the evaluation and discussions rated very highly. 64.7% felt that no improvement was needed to the training as they thought that their expectations were 'somewhat met' or 'mostly met' as opposed to fully met' compared to other suggested improvements (see Figure 4). However, a greater proportion of people thought more information would have improved the training (7.8%) as opposed to other suggested improvements which included venue and refreshments (2.6%), more time (3.9%), more cases studies (3.9%) and more activities (3.9%). 100% of participants stated that they would recommend the training to others.

A Pearson Chi Squared Test was performed between some of the variables to find any associations; the number of these with a count of less than 5 is well above 20% so in terms of reliability and validity, the results may be questionable. Nevertheless, the results do demonstrate that the participants perceived they had benefitted from this type of training.

Analysis

Overall, it would seem that this training package was beneficial to the participants. As the interactive group work was the most popular with all participants the trainers are exploring ways of altering other aspects of the training to this format to facilitate learning. More time will be provided to answer participants questions.

It would be beneficial in a future evaluation to include demographical data on the evaluation form, as it may be that sessions varied depending on variables such as occupation, qualifications and experience and who was leading the session as this may have impacted on how useful and relevant the participants found the sessions.

Further research is needed into how this training package has enhanced pain assessment and pain management for people with learning disabilities in the district, in particular those with limited communication skills.

Conclusion and Recommendations

This was a small scale study. However, it does suggest that DISDAT can be a successful measuring tool for people with a Learning Disability, cared for in residential homes by people with a range of skills, abilities, qualifications, training and experience.

The interactive "*I Hurt Help Me*", training package allowed carers to discuss and identify their own strengths and weaknesses. Initially the DISDAT tool was sometimes difficult to implement in the care homes as carers needed some extra support to get started. It would have been beneficial to this study to include demographic information and to note if there were any differences between sessions on different dates such as the occupations/level of people attending or who was running the session that impact the usefulness and relevancy.

Standard of recording has improved and HAPs are now becoming common place with detailed descriptors of individual residents – allowing a baseline to work from, enabling faster and more effective care for people with Learning Disabilities. The interactive nature of the training has recently won praise from Jane Cummings, England's Chief Nursing Officer, as an example of excellent practice which should be provided across the UK. However, it is evident that more research is required in this area, firstly in the light of the limited literature available in this area as discussed earlier and, more specifically, to focus on the most effective pain assessment tools and pain management to meet the need of people with learning disabilities or those who have limited communication skills to enhance their quality of life and physical and mental wellbeing.

References

1. Emerson E, Baines S, Allerton A, Welch, V. *Health inequalities & people with learning disabilities in the UK*. Learning Disabilities Observatory 2011.
2. McGuire BE, Daly P, Smyth F. Chronic pain in people with an intellectual disability: Under-recognised and under-treated? *Journal of Intellectual Disability Research*, 2010; 54:240-45.
3. Elliott A. Prevalence of pain in older adults. In: Schofield P, ed. *Guidelines for the Management of Pain in Older Adults*. Age & Ageing, March 2013.
4. Lotan M, Schofield P, Merrick J. Pain and individuals with intellectual disability: A wake up call. *Journal of Pain Management*, 2009; 2:1-2.
5. Breau LM, Camfield C S, McGrath PJ, and Finley GA. Pain's impact on adaptive functioning. *Journal of Intellectual Disability Research*, 2007; 51(Pt2):125-34.
6. Cooper SA, Smiley E, Allan L, Jackson A, Finlayson J, Mantry D. Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour and related factors. *Journal of Intellectual Disability Research*, 2009;53:200-16.
7. Arron K, Oliver C, Moss J, Berg K, Burbidge C. The prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*, 2011;55:109-20.
8. Mencap *Death by Indifference*. London: Mencap, 2007.
9. Emerson E, Heslop P. *A Working Definition of Learning Disabilities*. Durham: *Improving Health & Lives*. Durham: Learning Disabilities Observatory, 2010.

10. Shega JW., Hougham GW, Stocking CB, Cox-Hadley D, Sachs GA. Management of noncancer pain in community-dwelling persons with dementia. *Journal of the American Geriatrics Society*, 2006; 54:1892-1897.
11. Mackey E, Dodd K. Evaluation and effectiveness of pain recognition and management training for staff working in learning disability services. *British Journal of Learning Disabilities*, 2011; 39:243-251.
12. Beacroft M, Dodd K. Pain in people with learning disabilities in residential settings – The need for change. *British Journal of Learning Disabilities*, 2010; 38:201-209.
13. Bromley J, Emerson E, Caine A. The development of a self-report measure to assess the location and intensity of pain in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 1998; 42(1):72-80.
14. Kingston K, Bailey C. Assessing the pain of people with a learning disability. *British Journal of Nursing*, 2009; 18:420-423.
15. Jones D. Pain management and people with learning disabilities: A complex challenge. *Journal of Learning Disabilities*, 2003; 7:291-295.
16. Zwakhalen SM, Van Dongen KA, Hamers JP, Abu-Saad HH. Pain assessment in intellectually disabled people: non-verbal indicators. *Journal of Advanced Nursing*, 2004; 45:236-45.
17. Regnard C, Mathews D, Gibson L, Clarke C. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 2003; 9:173-176.
18. Abbey J, Piller N, Debellis A, Esterman A, Parker D. The Abbey Pain Scale: A 1-minute numerical indicator for people with late-stage dementia. *International Journal of Palliative Nursing*, 2004; 10:6-13.

19. Fuchs-Lacelle S, Hadjistavropoulos T. Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing*, 2004; 5:37-49.
20. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association*, 2003; 4:9-15.
21. Wong DL, Baker C. Pain in children: Comparison of assessment scales. *Pediatric Nursing*, 1988; 14:9-17.
22. Price DD, McGrath P A, Rafii A, Buckingham B. The validation of visual analogue scales as ratio scale measures for chronic and experimental pain. *Pain*, 1983; 17:45-56.
23. Herr KA, Spratt K, Mobily PR, Richardson G. Pain intensity assessment in older adults: use of experimental pain to compare psychometric properties and usability of selected pain scales with younger adults. *Clinical Journal of Pain*, 2004; 20:207-19.
24. March P. How do people with a mild/moderate mental handicap conceptualise physical illness and its cause? *British Journal of Mental Subnormality*, 1991; 37:80-91.
25. Symons FJ, Shinde SK, Gilles E. Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research*, 2008; 52:275-286.

Figures

Figure 1: Perceptions of new insights into pain assessment and management

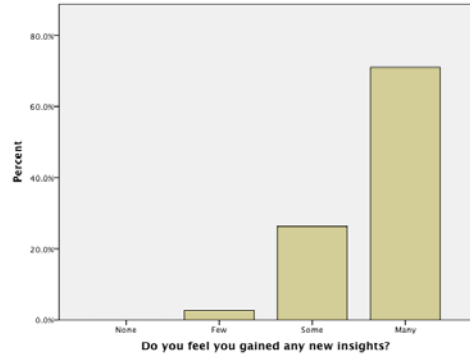


Figure 2: Usefulness and relevancy of training to current job responsibilities.

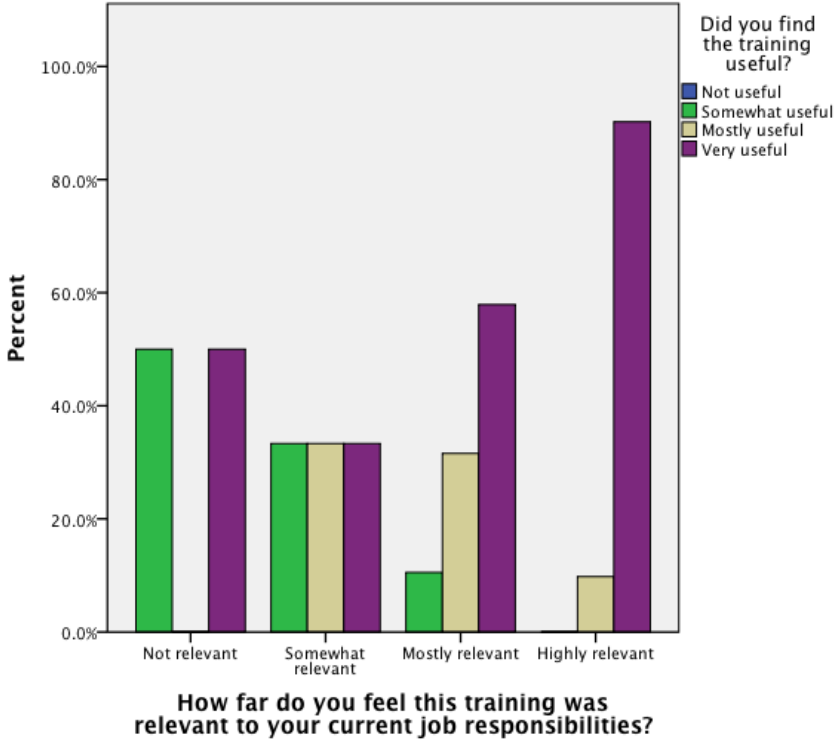


Figure 3: Most useful elements of the training

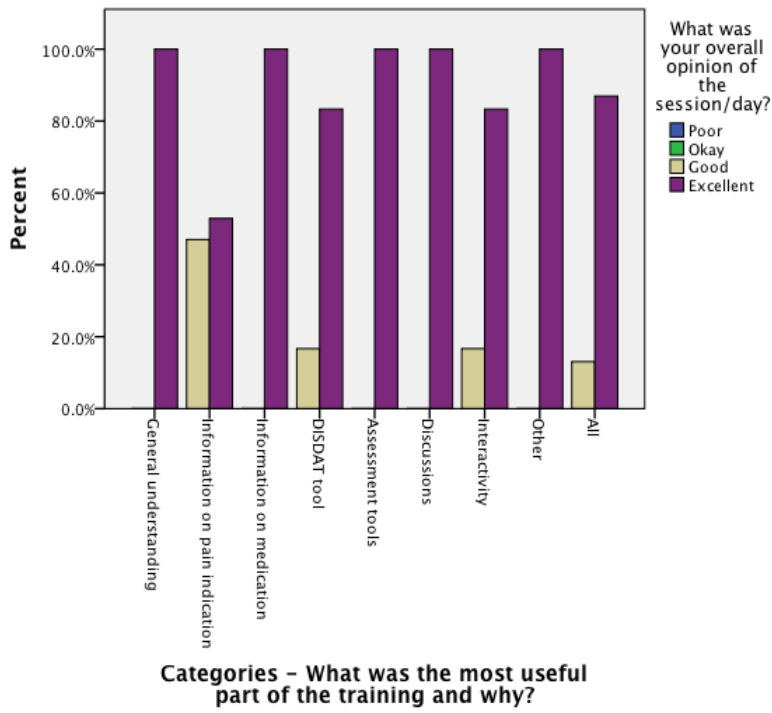


Figure 4: Expectations of Training Sessions

