PAIN EXPERIENCE AND MANAGEMENT IN A FORENSIC LEARNING DISABILITY SERVICE

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INTRODUCTION

- People with intellectual disabilities generally experience pain more frequently, and to a higher degree than the general population (Defrin et al., 2004).
- This is due to the physical health conditions often associated with the disability, and the increased likelihood of experiencing painful life events, such as surgery or assault (Symons et al., 2008).
- Despite this, people with intellectual disabilities have historically been excluded from pain research, and there is a paucity of empirical research in this area (Symons et al., 2008).
- Research has identified a number of barriers with the effective identification and subsequent management of pain in this population.

INTRODUCTION

- In terms of identification, pain treatment is usually reliant on self-report from the person affected (McGuire et al., 2010).
- However, the communication impairments associated with intellectual disability often cause difficulty in verbally describing pain (Foley and McCutcheon, 2004; Findlay et al., 2013).
- Although there are tools available to assist staff with identifying pain in those with intellectual disabilities, these are not routinely used in services (Beacroft and Dodd, 2009).
- People with intellectual disabilities sometimes ignore pain, and do not seek treatment, due to concerns about bothering carers (Turk et al., 2012).
- A further problem is that people with intellectual disabilities can present with pain in atypical ways, which may be labelled as “challenging behaviour” (Kerr et al., 2006).
- It has also been noted that pain reports from people with intellectual disabilities are not always believed (Findlay et al., 2013).

INTRODUCTION

- Beacroft and Dodd (2009, 2010) carried out a large-scale audit that investigated pain management in community intellectual disability populations.
- The authors interviewed people with intellectual disability, staff and carers, and also accessed Health Action Plans (HAPs) and company policies. The authors reported that:
  - staff were reluctant to administer prescribed pain medication to their clients.
  - some staff believed those with intellectual disabilities have higher pain thresholds than the general population. Many clients did not have a HAP and if present, pain was often not considered.
  - staff had not had training in pain management for those with intellectual disabilities, and company policies often did not guide or support practice in pain management.

PAIN IN FORENSIC ID SETTINGS

- Pain in inpatient forensic intellectual disability settings is under-researched. At present, it is unclear how findings from community settings extrapolate to forensic settings, due to differences between client groups and services.
- Within forensic intellectual disability services, patients typically have mild disabilities, poor psychosocial backgrounds, offending behaviours, self-harm, significant co-morbidity, such as severe mental illness, personality disorders, pervasive developmental disorders and substance misuse histories (Alexander et al., 2011; Plant et al., 2011). It is possible that features of the forensic client group may further complicate pain management.
- Research in psychiatric/forensic populations suggests that nurse decision making about pain management is influenced by concerns about manipulation, contributing to addiction and affected by a need to establish the legitimacy of the pain (Tilley and Chambers, 2004; Lin and Mathew, 2005; Dewar et al., 2009).
- However, the hospital setting may also have protective factors, such as nurses on duty 24/7, which could support pain management. This study investigates pain management within a forensic intellectual disability service.

METHOD

Setting/participants

- A baseline audit of pain experience and management was carried out within an 85-bedded forensic intellectual disability service in the East of England.
- At the time of the audit, there were 82 patients, with 64 agreeing to be interviewed (78 per cent response rate).
- Nurses working within the service were also invited to take part in an interview about the way in which they manage pain with their patients. Twelve nurses took part.

Procedure

- The study employed a mixed methods design to investigate the experience and management of pain in the service.
- Semi-structured interviews with patients – designed to elicit patients' experiences of pain and pain management within the service.
- Semi-structured interviews with staff – designed to ascertain their pain management practices.
- HAPs – the HAPs of all patients within the service were accessed in order to determine the extent to which pain management was being considered and recorded.
- Medication files – files were accessed to assess the frequency and patterns of pain medication administration.
- Policies – company health and medication policies were accessed, to determine the quality of recommendations for pain management.

AUDIT STANDARDS

Table I Audit standards

Effective pain management	1. All patients are written up for PRN pain relief
	2. Pain relief (or other appropriate treatment) is offered if pain is suspected/ reported
	3. Patients followed-up if pain has been reported. Pain relief or other treatment offered as appropriate
	4. Referral to GP or other services as required
Health Action Plans	5. Health Action Plan in place for all patients
	6. Health Action Plan should document the patient's health conditions which could, or are known to cause pain
	7. Health Action Plan to document patients' individual presentations of pain and preferences for pain management
Staff training and information	8. Training courses in pain management in intellectual disability are available to members of the nursing team
	9. Wards should hold resources regarding pain management, including communication aids
Policy	10. Services should have appropriate physical healthcare policy in place
	11. The policy should mention pain management

RESULTS

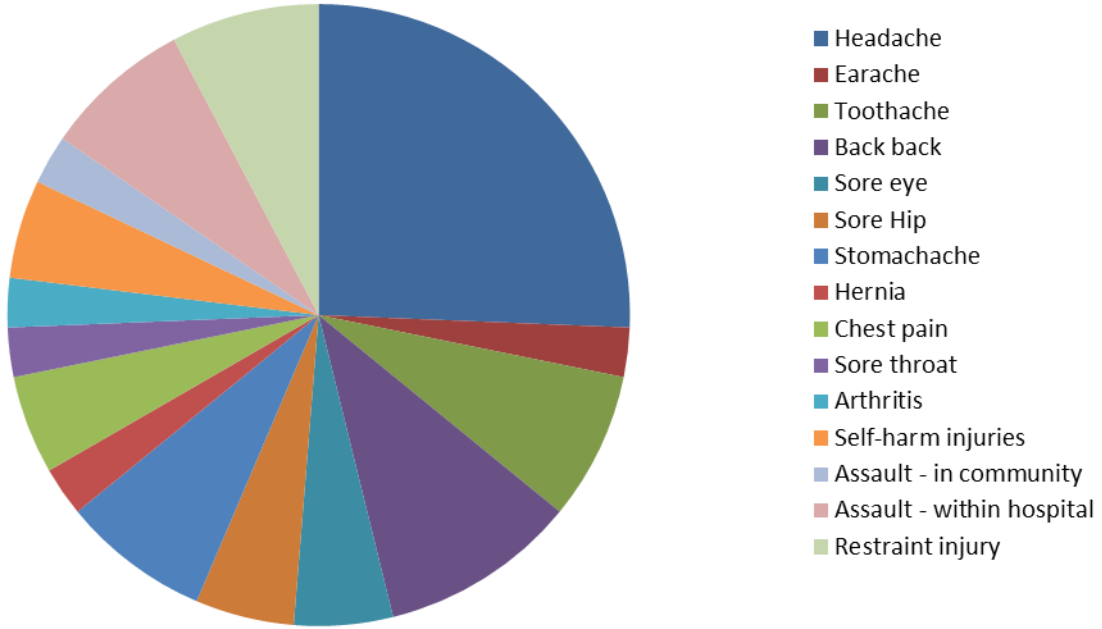
1. Pain Experience
2. Pain Management (Audit)

PAIN EXPERIENCE

PAIN PREVALENCE

Patients were asked if they had experienced any pain in the last month.

- Of those interviewed, 48 (75%) stated that they had experienced pain in the last month.

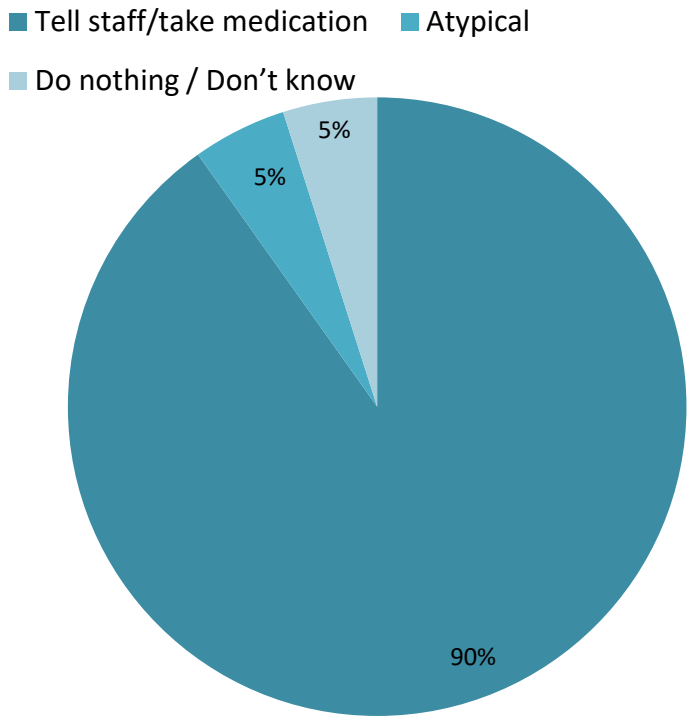


EFFECTS OF PAIN

- Many expressed the impact that pain had upon their daily living and activities, e.g., “it affects sessions”.

- Patients often discussed the impact of pain upon their moods, emotions and mental state, e.g., “depressed” and “agitated”.

PAIN REPORTING



The majority of the patients (n = 55, 90%) said that if in pain, they reported this pain to staff.

- A further 11% (n = 7) did not appear to have strategies for reporting their pain.
- Three patients (3%) said that they either did not know what to do, or did nothing when in pain. One patient said that she would "sleep and not eat".
- A number of the male patients (n = 3) gave atypical responses such as "I enjoy it", or, "Just let it get to me – no pain no gain".

Patients' decision as to whether to report pain and take medication was affected by a number of factors and health myths:

- "I'm already on meds for my mental state, I'm on painkillers, I'm on PRN painkillers, I'm on Ibuprofen."
- "Sometimes I feel worried about telling nurses."
- "Don't take it as it damages your body"
- "Paracetamol is a waste of time."
- "I don't think Paracetamol helps. They are like smarties aren't they?"
- "Stronger painkillers than paracetamol e.g. tramadol or codeine"

PATIENT COMMENTS

They try their hardest to help me

Nurses help quickly to sort things out and give paracetamol

Sometimes when I ask for painkillers they don't let me have them

They can't do any more for me than they already do

Sometimes I say to them that I am in pain and they say 'its nothing, just a little pain'

PAIN MANAGEMENT

1. EFFECTIVE PAIN MANAGEMENT - PATIENTS SHOULD HAVE THEIR PAIN MANAGED EFFECTIVELY, ACCORDING TO THEIR CHOICE AND PREFERENCES.

1. All patients are written up for PRN analgesia.
   - 100% of patients (n = 82) were written up for PRN paracetamol or another analgesic.
   - A number were also written up for a regular administration of analgesic (n = 12, 15%).
   - Medication files rarely showed four-six hourly administration patterns, with many one-off, or two doses.

2. PAIN RELIEF (OR OTHER TREATMENT AS APPROPRIATE) IS OFFERED IF PAIN IS REPORTED.

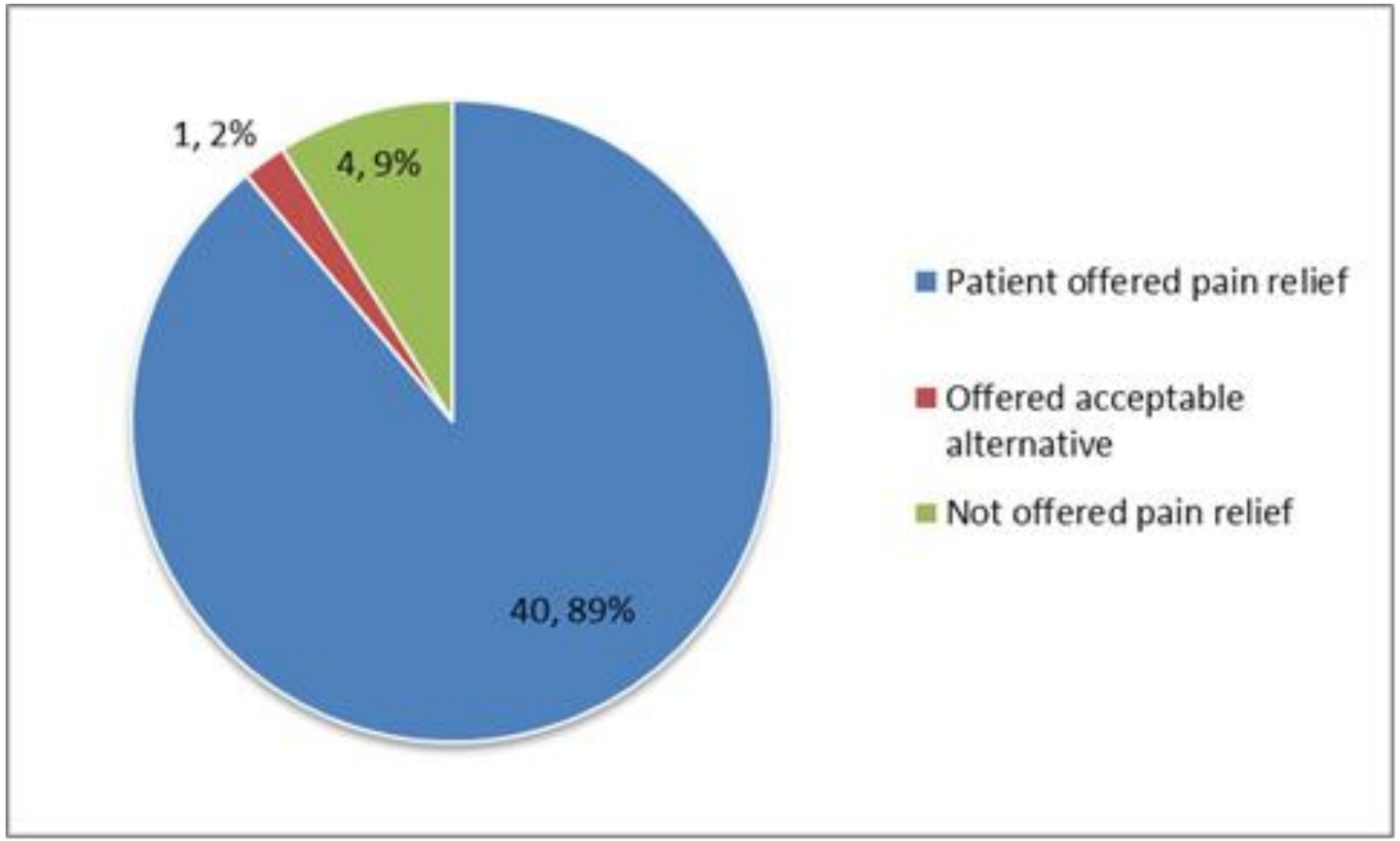
- Nurses were asked what they do if a patient reports pain to them, or if they suspected a patient was in pain.
  - Pain location and duration.
  - Non-verbal indicators of pain.
  - Medication offer - in accordance with the prescription in the patient's medication file.

- Reliance on self-report - "We don't have any of those patients [patients with communication difficulties]. Most patients are quite capable".

- Personal beliefs affecting practice - "Don't like giving paracetamol.", "There are patients I will not give painkillers to" & "See whether they can do without it first, then give medication".

- Need to establish legitimacy - "It can be a habit for some patients to ask for tablets. It can be difficult to assess if complaints are true or not".

All the patients who had reported experiencing pain in the past month (n = 48) were asked about the way in which their pain had been handled after they had reported it to staff.



3. PATIENTS FOLLOWED-UP IF PAIN HAS BEEN REPORTED. PAIN RELIEF OR OTHER TREATMENT OFFERED AGAIN AS APPROPRIATE.

Most nurses (n = 10, 83%) said that they would follow up the patient after a pain report.

- A number (n = 5, 42%) stated that they would give a follow-up dose only as the patient asked for it, rather than offer at regular 4-6 hourly intervals.
- Proactively offering a repeat dose of analgesic was deemed unnecessary with some or all of the patients, "Patients who are more able come and ask, more moderate you follow up" and "They are all able to say".

- Patients that received pain medication for their pain (n = 39) were asked if the pain medication had worked. 17 (44%) reported that it had.

- However, 22 (56%) said that it had not worked. Many felt that the medication was not working, or that it was not strong enough.

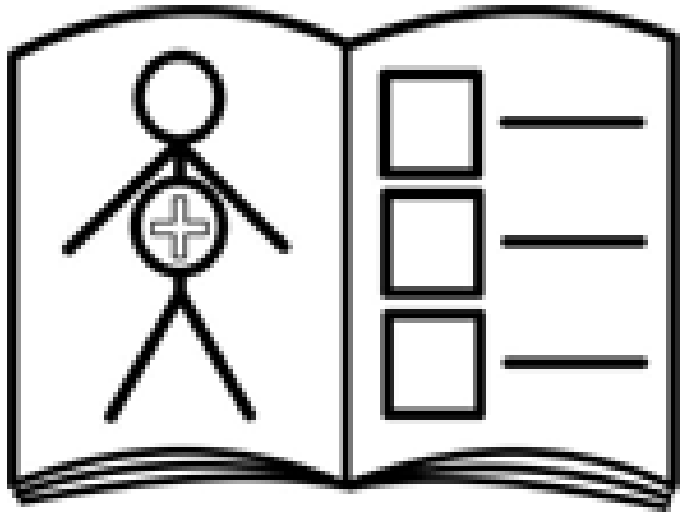
4. REFERRAL TO GP OR OTHER SERVICES AS REQUIRED.

Of the 48 who had reported experiencing pain in the past month, 20 (42%) had been to see their GP. 18 had requested to see the GP themselves and two had been referred to see the GP by their nurses. 28 (58%) had not been to see the GP. Of this group, five patients had asked to see the GP but had not at the time of the interview.

5. HEALTH ACTION PLANS - PAIN AND ITS MANAGEMENT SHOULD BE ROUTINELY CONSIDERED AND RECORDED IN HEALTH ACTION PLANS, IN A PERSONALISED MANNER.

Health Action Plan is in place for all patients.

- Health Action Plans were available for 95% of patients (n = 78). All patients who did not have a HAP (n = 4) were admitted very recently to the service.

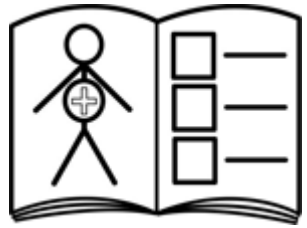


6. HEALTH ACTION PLAN SHOULD DOCUMENT THE PATIENT'S HEALTH CONDITIONS WHICH CAUSE PAIN, OR COULD POTENTIALLY CAUSE PAIN.

The HAP templates in use did not have a section regarding pain.

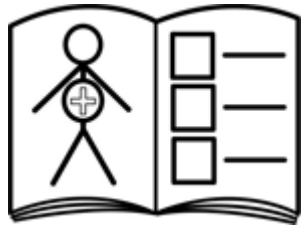
Of the 78 HAP's, 22 (28%) mentioned pain.

- However, the level of detail and depth was quite variable.
- Three HAP's had a specific care plan for the patient regarding their pain.



7. PATIENTS' PERSONAL PREFERENCES RE: PAIN MANAGEMENT ARE DOCUMENTED WITHIN THE HAP.

None of the HAP's held this type of information.



8. TRAINING COURSES ARE AVAILABLE TO MEMBERS OF THE NURSING TEAM.

- None of the nurses interviewed had received any specific training in pain identification and management with people with learning disabilities within the present service.
- Some had received training in a previous place of work or within their nursing training.
- “I'm not an LD nurse”.
- Nurses commented that they would find this type of training beneficial to their practice.

9. WARDS SHOULD HOLD RESOURCES REGARDING PAIN MANAGEMENT THAT THE NURSING TEAM CAN ACCESS, INCLUDING COMMUNICATION AIDS FOR USE WITH PATIENTS WITH COMMUNICATION DIFFICULTIES.

- None of the wards held resources on this topic.
- None of those interviewed had access to pain identification or assessment tools for use with patients.
- There was also some debate as to whether or not it was needed with the client group.

POLICY - SERVICES SHOULD HAVE POLICY AND PROCEDURES IN PLACE WHICH SUPPORT EFFECTIVE PAIN MANAGEMENT.

11. Services should have appropriate physical healthcare policy in place.
- There was a physical health policy

12. The policy should mention pain management.
- The policy did not mention pain.

AUDIT STANDARD COMPLIANCE

	Audit Standards	Compliance
Effective Pain Management	All patients are written up for PRN Pain relief.	Met
	Pain relief (or other treatment as appropriate) is offered if pain is reported.	Partially Met
	Patients followed-up if pain has been reported. Pain relief or other treatment offered again as appropriate.	Partially Met
	Referral to GP or other services as required.	Met
Health Action Plans	Health Action Plan should document the patient's health conditions which could, or do cause pain.	Partially Met
	Patients personal preferences re: pain management be documented within the HAP.	Not Met
Staff Training and Information	Training courses are available to members of the nursing team.	Not Met
	Wards should hold resources regarding pain management that the nursing team can access, including communication aids for use with patients with communication difficulties.	Not Met
Policy	Services should have appropriate physical healthcare policy in place.	Met
	The policy should mention pain management.	Not Met

CONCLUSIONS

- 75% of patients reported experiencing some pain in the last month.
- Experiencing pain could be an important factor regarding mental health, and engagement in therapeutic treatment / occupational activity.
- The majority of patients had coping strategies which were sufficient for them to receive treatment for their pain. However, a minority of patients were identified to need additional support in this area. A minority of patients appeared less able to communicate their needs and obtain subsequent treatment. Further support is required for these patients.

CONCLUSIONS

- 85% reported receiving appropriate treatment for their pain. Medication for pain was given routinely. However, factors other than the pain report itself affected the nurses decision as to whether to offer analgesia.

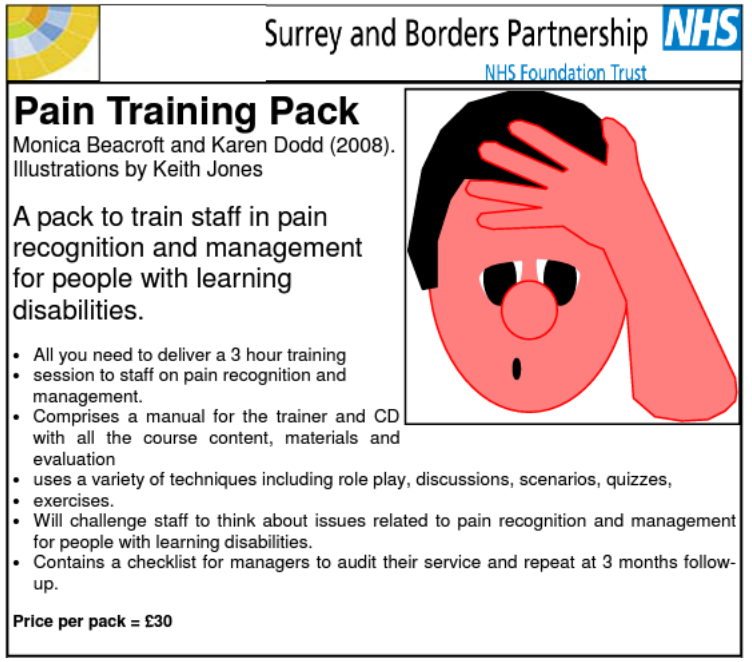
- Pain was not routinely discussed within Health Action Plans.

- Patients' likelihood to seek, and engage with treatment for pain was affected by health myths and other factors.

- A number of patients felt that the medication had not worked. This could be improved by following 4-6 hourly administration patterns, in order to maximise optimal levels of the analgesic.

WAY FORWARD

- A standardised approach to pain management is needed within services. This would have benefits for both patients and staff.
- The approach should incorporate policy, guidelines and training.
  - Pain training for staff.
  - Pain communication tools available in services.
  - Pain included as a topic within patients' Health Promotion psycho education sessions.



Surrey and Borders Partnership NHS
NHS Foundation Trust

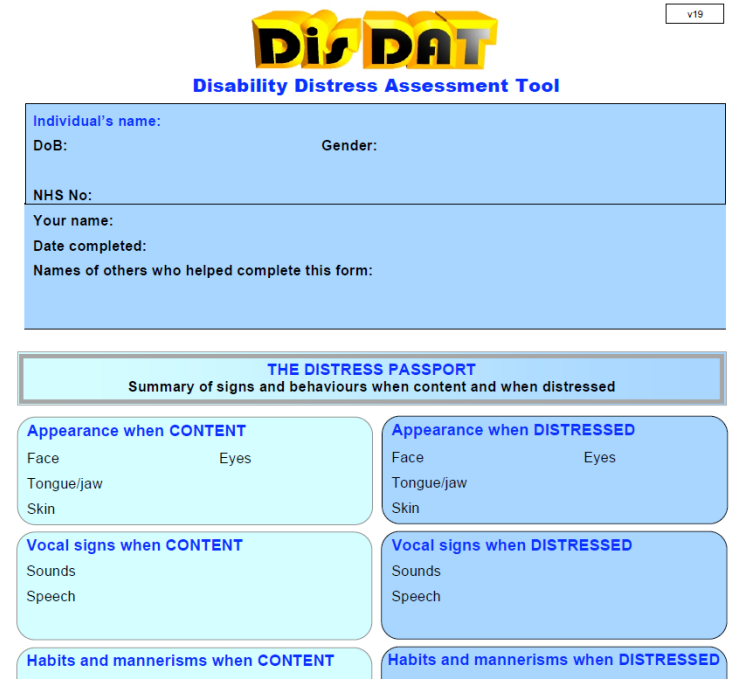
Pain Training Pack

Monica Beacroft and Karen Dodd (2008).
Illustrations by Keith Jones

A pack to train staff in pain recognition and management for people with learning disabilities.

- All you need to deliver a 3 hour training
- session to staff on pain recognition and management.
- Comprises a manual for the trainer and CD with all the course content, materials and evaluation
- uses a variety of techniques including role play, discussions, scenarios, quizzes,
- exercises.
- Will challenge staff to think about issues related to pain recognition and management for people with learning disabilities.
- Contains a checklist for managers to audit their service and repeat at 3 months follow-up.

Price per pack = £30



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DisDAT

Disability Distress Assessment Tool

Individual's name:
DoB: Gender:
NHS No:

Your name:
Date completed:
Names of others who helped complete this form:

THE DISTRESS PASSPORT
Summary of signs and behaviours when content and when distressed

Appearance when CONTENT	Appearance when DISTRESSED
Face Eyes	Face Eyes
Tongue/jaw	Tongue/jaw
Skin	Skin
Vocal signs when CONTENT	**Vocal signs when DISTRESSED**
Sounds	Sounds
Speech	Speech
Habits and mannerisms when CONTENT	**Habits and mannerisms when DISTRESSED**

THANK YOU FOR LISTENING

Any Questions?

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Pain experience and management in a forensic intellectual disability service

Verity Chester and Marie Henriksen

Verity Chester is a Research Assistant and Marie Henriksen is a Practice Nurse, both are based at Partnerships in Care Learning Disability Services, Norfolk, UK.

Abstract

Purpose – *Research investigating the experience and management of pain in people with intellectual disabilities has mainly been carried out in community services. The purpose of this baseline audit aims to examine this area in a forensic intellectual disability setting.*

Design/methodology/approach – *A baseline audit of pain management was carried out. Audit standards were derived from recent research, and the performance on each measured. Patients and nurses were interviewed. The audit included 82 patients, of which 64 were interviewed. Twelve nurses were interviewed. Health Action Plans and medication files were accessed for information.*

Findings – *There were interesting differences and similarities in the experience and management of pain between community and forensic intellectual disability patients. Within this sample, most patients were able to communicate their pain, and access appropriate treatment. However, a minority required further support. Nurse decision making about providing pain treatment was affected by fears of manipulation, contributing to addition and disbelieving the patient. Additionally, a number of patients appeared to have insufficient knowledge about how to best manage pain.*

Practical implications – *Results suggested that a standardised approach to pain management, incorporating policy, staff training, and health promotion and psycho-education for patients, would have benefits for both patients and staff within secure intellectual disability services.*

Originality/value – *At present, there is little research focusing on pain experience and management in forensic intellectual disability settings.*

Keywords *Intellectual disability, Learning disability, Forensic, Mental disorder, Pain, Secure*

Paper type *Research paper*