

Pain in adults with intellectual disabilities

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Overview

Part 1: The literature review details studies investigating pain in adults with intellectual disabilities: prevalence of pain, understanding and descriptions of pain and methods to enhance these, and unreported pains. The review highlights that adults with intellectual disabilities experience pains associated with a variety of health complaints, but often these are not reported and only identified by investigative procedures. The review also highlights shortcomings in the abilities of caregivers and professionals in recognising and acting in order to relieve pain.

Part 2: The empirical paper reports on an exploratory qualitative study of the experiences and understandings of pain in adults with intellectual disabilities and their caregivers, and the meaning given to pain. Analysis highlights the difficulties adults with intellectual disabilities experience in understanding pain and having an appropriate language to communicate about pain. Analysis also revealed that caregivers possess knowledge and to recognise and manage pain and have clear perceptions of the pain experience in the people they care for. The findings are discussed with reference to prior research, scientific and professional implications and potential future directions.

Part 3: The critical appraisal discusses the research topic and how the researchers' understanding of pain in adults with intellectual disabilities changed. It then addresses conceptual and methodological issues that arose whilst conducting the research, and evaluates the limitations of the research. Finally it highlights implications for clinical practice, whilst offering suggestions for future research directions.

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Part 1: Literature review

Studies investigating pain in adults with intellectual disabilities

Abstract

Health problems and pains can go unrecognised and untreated amongst adults with intellectual disabilities. This review details studies investigating pain in adults with intellectual disabilities: prevalence of pain, understanding and descriptions of pain and methods to enhance these, and unreported pains. A systematic search from 1990 to 2011 yielded 27 studies. The research revealed that adults with intellectual disabilities experience pains associated with a variety of health complaints, but often these are not reported and only identified by investigative procedures. This is particularly so amongst those with an impaired capacity to communicate about their pain. The studies reviewed highlight shortcomings in the abilities of caregivers and professionals in recognising and acting in order to relieve pain.

1. Introduction

A number of health issues affect adults with intellectual disabilities. They are more prone to associated physical disabilities, common health risks, and certain medical conditions such as epilepsy, hypertension, and respiratory problems (Singh, 1997). Despite more healthcare needs than the general population, adults with intellectual disabilities have worse access and poorer health outcomes than the general population (Department of Health, 2008). Health problems and associated pains are not always recognised and managed effectively. It has been argued that this results in part from barriers associated with identifying ill health and with timely access to health care (Emerson, Baines, Allerton & Welch 2011). Historically, staff in institutions took responsibility for the health needs of people with intellectual disabilities, but recent Department of Health publications emphasise the need for people to take responsibility for monitoring and improving their own health. There has been a move to community care with GPs as the main point of contact.

1.1 Enquiries and policies

In the last decade, a number of reports have highlighted the low priority and focus given to healthcare for people with intellectual disabilities. *Treat me right!* (Mencap, 2004) showed that people with intellectual disabilities receive a poor quality of healthcare from professionals and questioned why little had changed given the many reports and recommendations. *A life like no other* (Healthcare Commission, 2007) found that adults with intellectual disabilities are especially vulnerable to their human rights being breached with regards to healthcare. *Equal Treatment: Closing the Gap* (DoH, 2006) highlighted failings in access to, and delivery of, appropriate treatment in primary care for people with intellectual disabilities. In response, the

Promoting Equality (DoH, 2007) action plan was published in order to help PCTs commission enhanced primary care services for people with intellectual disabilities.

Death by Indifference (Mencap, 2007) described the circumstances surrounding the deaths of six people with intellectual disabilities whom Mencap considered to have died unnecessarily due to failings in the health service to recognise and manage pain and associated illnesses. In response, an independent inquiry *Healthcare for All* (DoH, 2008) took place into healthcare access, which found that it is much harder to access assessment and treatment and that reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act (1995), were not regularly made.

The government White paper *Valuing People* (DoH, 2001) set a policy objective that “*All people with learning disabilities get the healthcare and the support they need to live healthy lives*” (DoH, 2001:58). *Valuing People Now* (DoH, 2009) encourages adults with intellectual disabilities to be more involved in their health and healthcare. However, they do not fit well into a service reliant on people requesting help (Whitfield, 1996). They can find it more difficult to identify and describe symptoms of illness and can find it hard to navigate the NHS to obtain treatment, making it more difficult for professionals to deliver treatment effectively (DoH, 2008). Health promotion strategies and screening processes can be ineffective given that resources are rarely suitable for this client group (Dodd & Brunker, 1999).

1.2 Pain

The International Association for the Study of Pain (1994) defines pain as:

“An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Note: The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Pain is always subjective”.

Pain has a biological component, a psychological component incorporating emotions and cognitions, and a social component including cultural factors and interaction with others (Jones, 2003). As there is no objective measure of pain, decisions are based on asking the person or observing them (British Pain Society, 2010). Clinicians and researchers routinely rely on self-report, but the most frequently identified barrier to adults with intellectual disabilities obtaining effective healthcare is communication (Langan, Whitfield & Perrett, 1993; Minihan, Dean & Lyons, 1993). As identification of pain is dependent on a person’s ability to communicate, researchers have developed tools to assess pain by observation in children with intellectual disabilities, older adults with dementia and intellectual disabilities, and more recently in adults with intellectual disabilities. However, these suffer observational biases and uncertainties in what signs indicate pain.

In order to formulate a diagnosis, a GP usually needs to know the site, severity, quality and duration of pain. If adults with intellectual disabilities are unable to explain their symptoms verbally, their behaviour related to pain may be interpreted as challenging or self-injurious (Lawrie, 1995; Meehan, Moore & Barr, 1995) and health conditions can go unnoticed. One study found that 92% (N=191)

of people with profound and multiple intellectual disabilities who were physically examined had a previously undetected but treatable condition (Meehan et al., 1995). Another study found that of adults attending a health check, 87% (N=53) required one or more health interventions (Martin, Philip, Bates & Warwick, 2004).

Pain is potentially experienced by adults with intellectual disabilities whose health problems have gone unnoticed, untreated, or who have pain associated with (un)recognised disease or illness. Pain does not appear to be routinely considered in care provision for adults with intellectual disabilities and an increased prevalence of conditions that cause chronic pain are not routinely identified for pain management (Symons, Shinde & Giles, 2008). It seems reasonable to infer that chronic pain may be highly prevalent in this population because of the higher frequency of associated physical disabilities (McGuire, Daly & Smyth, 2010).

The nature and experience of pain amongst children and older adults with intellectual disabilities is an area that researchers appear to be paying increasing attention to, but there is less research concerning adults with intellectual disabilities. With the exception of the area of pain assessment, I am not aware of any reviews purely of the literature on pain in adults with intellectual disabilities.

1.3 Objective

When the literature search began the following questions were proposed.

- What is the prevalence of pain amongst adults with intellectual disabilities?
- How do they understand and describe pain, and what helps this?
- Do their pains go unreported?

1.4 Definition of Terms

People with intellectual disabilities

Whilst there are many differing descriptions and definitions of the term intellectual disability, the two definitions below ensure a distinction from the broad range of learning ‘difficulties’ which may impede educational attainment in people with ‘average’ range intelligence. The ICD-10 Classification of Mental and Behavioural Disorders (World Health Organisation, 1992) defines intellectual disabilities as:

“... a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor and social abilities. ... Adaptive behaviour is always impaired ...”

The DSM-IV Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) defines intellectual disabilities as:

- “(a) Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test.*
- (b) Concurrent deficits or impairments in present adaptive functioning (i.e. the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.*
- (c) The onset is before age 18 years.”*

2. Methodology

2.1 Search strategy

The electronic databases PsychInfo, MedLine, and Health and Psychosocial Instruments (HAPI) were searched for studies on pain in adults with intellectual disabilities from the past 20 years to make sure the research was reasonably current (January 1990 to April 2011). Electronic searches were then conducted in five journals publishing relevant articles to identify any research that had not yet appeared (Pain; American Journal on Intellectual and Developmental Disabilities; British Journal of Learning Disabilities; Journal of Applied Research in Intellectual Disabilities; Journal of Intellectual Disability Research). Citation searching of papers relevant to the search terms described below was then carried out, as well as a search of the NHS Evidence Base website (www.evidence.nhs.uk). To ensure some form of quality control, only articles published in peer-reviewed journals were considered.

2.2 Search terms

The search was conducted by entering keywords listed in Table 1 in each of these databases. The term ‘developmental disabilities’ was used as the final search term, but is not included as the other search terms identified all the relevant literature. Limits were placed on the search to include studies between 1990 and April 2011, including only humans, and papers written in English. For PsychInfo further limits were placed on articles as adulthood (18+) and papers from peer-reviewed journals. For MedLine further limits were placed on articles as young adults (18+) and ages upwards (up to 80+).

2.3 Inclusion and exclusion criteria

Articles were included if they met the following criteria: empirical studies with a focus on adults with learning disabilities and the topic of pain. Particular age-groups which have already received reviews were excluded. These were children and adolescents (e.g. Breau & Burkitt, 2009) and older adults (e.g. Gabre & Sjöquist, 2002). The topic of palliative care and cancer was excluded, as this area has its own unique issues and pain is routinely considered, as was the topic of pain assessment, as reviews of the literature have already been published (e.g. Davies & Evans, 2001; Foley & McCutcheon, 2004).

Table 1. Results from search terms

Search Term	In combination with	N of studies	Relevant reading abstract removed)	after title and (duplicates	Relevant after reading full article
Learning Disabilities*/ Intellectual Disabilities*/ Learning Difficulties*/ Mental retardation	Pain	PsychInfo			
		94	25		14
		MedLine			
		262	17		11
	Carers	HAPI			
		13	0		0
	Illness	PsychInfo			
		185	0		0
	Disease	MedLine			
		146	0		0
	Communication	PsychInfo			
		402	0		2
		MedLine			
		822	0		0
		PsychInfo			
		0	0		0
		MedLine			
		46	0		0
		PsychInfo			
		921	0		0
		MedLine			
		488	0		0

Titles were perused to identify relevant articles; if this left uncertainty, then the abstracts were read; to further resolve uncertainty the methods section of the article

was read. In order to include different perspectives, and due to the relatively small number of published articles, both quantitative and qualitative studies were included.

3. Results

The search strategy and inclusion criteria revealed a total of 27 studies, which are described below. The key findings of these various strands of research are reviewed and headed in line with the questions above:

- Prevalence of pain
- Understanding and descriptions of pain and methods to enhance these
- Unreported pains

3.1 Characteristics of the sample

The studies found were a mixture of case reports (2); qualitative studies (15) and quantitative studies (10). Ages ranged from 18 to 79 years, with a mixture of males and females in quantitative studies and case reports, but a majority of females involved in qualitative studies. Overall, the studies included differing levels of intellectual disabilities and residence (family home, residential, supported living), although most participants lived in residential homes. Sample descriptions rarely indicated the ethnicity of participants. Most studies were carried out in the USA and UK. In four studies the inclusion criteria for age of participants was relaxed to include studies with children and adults. These are highlighted in the footnotes section of the Tables 2-4. Five sampled caregivers and 22 sampled adults with intellectual disabilities with varying degrees of impairment and ability to communicate (non)verbally.

Five studies sampled caregivers, but in only two studies was it clear that nurses they were talking about experiences with people with severe intellectual disabilities who did not communicate verbally or those with ‘limited verbal communication’. In three studies it was unclear whether the people with intellectual disabilities being cared for communicated verbally or not, although levels of intellectual disabilities were indicated.

Twenty two studies sampled adults with intellectual disabilities. Fifteen studies indicated that the participants were able to communicate verbally, one included verbal and non verbal communicators, and one case report involved a person who did not communicate verbally. Three studies indicated the level of intellectual disabilities but they did not describe participant’s ability to communicate (non)verbally. In one study it was unclear whether participants communicated verbally but they were able to communicate answers to simple questions.

Table 2. Studies investigating prevalence of pain

Author(s) & date	Population	Informant	Methodology	Conclusions	Footnotes
Chou et al., 2008	55 women, mild to severe ID, verbal communicators (21-65) living in institutions	Adults with ID	Interviews	76.2% mentioned abdominal pain or swelling; problems with their breasts swelling and dizziness	
Cumella et al., 2000	60 adults with ID (25-44) not in contact with community dental service, 33 males 27 females, verbal communicators or could communicate with support from caregiver	Adults with ID	Focus groups & dental examination	9% reported pain, 5% mouth ulcers and 5% gum problems. 23% in need of dental treatment.. uptake of dental examination 43%	
Farman et al., 2003	72 inpatients, severe to profound ID	Medical examination	Digital x-rays mini-panel examinations	30% had condition possibly causing pain	
Jancar & Speller, 1994	32 adults with ID (2-74) 18 female, 14 male	Medical records	Retrospective study	2.4% of deaths accounted for by intestinal obstruction 9 had pain/distress recorded	Age 2-74
McGuire et al., 2010	157 adults with moderate to severe ID (16-70)	Formal caregivers	Questionnaire	13.4% had chronic pain. Average duration 6.5 years Complained of pain (3 never/rarely, 7 sometimes, 3 quite a bit, 4 frequently)	Caregiver estimates only. Age 16-70
McCarthy, 2002	15 women with mild to moderate ID aged 43-65, verbal communicators	Adults with ID	Interviews	Menopausal symptoms included pain for some women	
Meuwese-Jongejeudd et., al 2007	16 mild to moderate ID, recent diagnoses of hearing impairment	Adults with ID	Pilot study	3 reported pain with hearing aids, 2 reported discomfort. One had pain persistently for 6 months	
Reid et al.,	9620 Special Olympics	Adults with ID	Convenience	13.5% oral pain	

2003	athletes at 40 sites across USA, 54.1% male, 42.0% female, 3.9% missing data		sample survey	30.4% untreated caries
Rodgers et al., 2006	452 women aged 14-55 mild to profound ID, verbal and non-verbal communicators	Caregivers	Postal questionnaire	Pain frequently reported as a problem during menstruation.
Walsh et al., 2011	7544 adults with mild to profound ID, 18-79	Formal caregivers	Postal questionnaire	15.4% reported to experience chronic pain for average 6.3 years
Willis, 2008	15 women with mild to moderate ID, verbal communicators	Adults with ID	Interviews	Pains reported by 10 women incl. headaches, 'tummy' pain and calf pain.
Willis et al., 2011	45 women with mild to severe ID (35-65), verbal communicators	Adults with ID	Interviews	6 women mentioned pain, 21 when asked directly. Referred to headaches, stomach/breast pain

Key:

ID = intellectual disabilities

Table 3. Studies investigating understanding and descriptions of pain and methods to enhance these

Author(s) & date	Population	Informant	Methodology	Conclusions	Footnotes
Beacroft & Dodd, 2010a	40 adults with mild to moderate ID (25-79) 17 female, 23 male, “good verbal abilities”, excluded people with autism or challenging behaviours	Adults with ID	Questionnaire	Used emotive language If in pain 25% feel sad, 13% angry. 35% would tell someone if in pain. 3/40 wouldn't tell anyone	Retrospective questions rely on memory, not necessarily a reflection of behaviour.
Broughton & Thomson, 2000	52 women with ID (20-64) in CLDT, verbal communicators, severe ID excluded	Adults with ID	Interviews	One theme: those who had the test were more likely to make reference to pain experienced	
Bromley, Emerson & Caine, 1998	20 adults with ID (19-71) 12 male, 8 female, verbal communicators 20 controls: 10 male, 10 female (23-72)	Adults with ID	Tasks body map, pain ruler & photographs Adaptive Behaviour Scale, Medical questionnaire	Location and intensity of pain ratings stable over time, except in one picture, 3 rated as significantly more intense	
Brown & Gill, 2009	84 women with ID (33-71), verbal communicators	Adults with ID	Focus groups	2 relevant themes to pain were ‘general aging’ and ‘women’s health’	
Chou et al., 2008	55 women with ID (21-65), verbal communicators	Adults with ID	Interviews	One theme ‘I feel pain but I am not affected by it’. 76.2% mentioned abdominal pain or swelling; problems with breasts swelling	

Defrin et al., 2006	159 adults with mild-severe ID – 66 males, 57 females (39-43). Controls: 38 (22 male, 16 female, mean age 43) in institutions with physical disabilities and no ID	Trained raters	Observer ratings	Facial ‘freezing’ response occurred in 47-50% of those with severe-profound ID compared to 8-13% mild to moderate ID and 5% controls	
Dodd & Bruner, 1998	10 adults with ID (31-46) 5 male, 5 female, verbal communicators	Adults with ID	Teaching package	Increased knowledge of bodies/ bodily problems and what to do when ill. A ‘majority’ retained at 6 month follow up	No statistical analysis. Only 3/10 follow up cards returned.
Donovan, 2002	8 nurses of non-verbal adults with severe ID	Nurses	Interviews	Most common pain sign was crying	
Lewis, Bell & Gillanders 2007	32 year old female with mild-moderate ID, verbal communicator	Adult with ID	Case study	Glasgow Anxiety Scale – Learning Disability (GAS-LD) showed consistent reduction. Glasgow Depression Scale – Learning Disabilities (GDS-LD) higher at month 2 but decreased at month 4. Fear-Avoidance of Pain Scale (FAPS) showed less fear and avoidance of activities. Activity and walking increased, improved sleep, reduced use of ice pack	No follow up. Clinically significant, but is it statistically significant?
Ruddick & Oliver 2005	21 adults with ID (33-57) 13 female, 8 male, “verbal or partly verbal” communicators	Adults with ID	Interviews, development & trial of Health Status Measure	Found internal consistency for parts looking at Physical Function, Bodily Pain, General Health and Vitality (≥ 0.60)	Could not look at construct validity using factor analysis.
Rodgers, 2001	21 women with mild to moderate ID, verbal communicators	Adults with ID	Interviews	Pain related to menstruation experienced by some women	

Webb & Stanton , 2008	11 adults with LD, verbal communicators	Adults with ID	Group programme	Learned what to do when in pain, how to make doctor's appointment, how to make needs clear at doctors	No explanation for those who got worse. No follow up evaluation.
Willis et al., 2011	45 women with mild to severe ID (35-65)	Adults with ID	Interviews	6 women mentioned pain, 21 when asked directly. Referred to headaches, stomach/breast pain	

Key:
 ID = Intellectual Disabilities
 CLDT = Community Learning Disability Team

Table 4. Studies investigating unreported pains

Author(s) & date	Population	Informant	Methodology	Conclusions	Footnotes
Beacroft & Dodd, 2010b	58 staff from residential/supported living	Staff	Interview	Staff do not use pain recognition tool/communication aids. Some believe pain thresholds are higher, effects how they manage pain	
Clarke & Thompson, 2007	8 parents (44-84), 6 mothers: 2 fathers of 6 daughters: 2 sons (20-48)	Parents of adults with ID	Interviews	Master themes: not seeing son or daughter in much pain; felt they were generally healthy, would know if in bad pain, doesn't feel pain same as others, is tolerant of pain	
Defrin et al., 2006	159 adults with mild-severe ID – 66 males, 57 females (39-43). Controls: 38 (22 male, 16 female, mean age 43) in institutions with physical disabilities and no ID	Trained raters	Observer ratings	Facial 'freezing' response occurred in 47-50% of those with severe-profound ID compared to 8-13% mild to moderate ID and 5% controls	

Donovan, 2002	8 nurses of non-verbal adults with severe ID	Nurses	Interviews	ID nurses believed that someone with verbal skills is not necessarily a guarantee that the person can communicate pain	
Hinder & Perry, 2000	19-year old non-verbal man with profound ID	Case notes	Case report	Symptoms of pancreatitis such as pain were absent	No quantitative measure of episodes of SIB
Jancar & Speller, 1994	32 adults with ID (2-74) 18 female, 14 male	Medical records	Retrospective study	2.4% deaths accounted for by intestinal obstruction. Pain only recorded in 9 patients	Age range at death 2-74
Turk et al., 2010	187 adults with ID (18-83) 61% male, verbal communicators	Adults with ID	Questionnaire	23% said they did not consult GP in past year, 21% did not tell anyone when in pain	
Willis, 2008	15 women with mild to moderate ID, verbal communicators	Adults with ID	Interviews	Pains reported by 10 women incl. headaches, 'tummy' pain and calf	

Key:

ID = Intellectual Disabilities

SIB = self-injurious behaviour

3.2 Prevalence of pain

Twelve studies described the prevalence of certain pains in adults with intellectual disabilities. Prevalence of pain was often not the primary focus of the study but was referred to as part of the study's findings. Prevalence has been noted or estimated regarding dental pain, chronic pain, pain associated with hearing aids, menstruation, menopause, and intestinal obstruction. Research in these areas is reviewed in the following sections by type of pain.

3.21 Dental pain

Three studies suggest a level of unmet clinical need for dentistry and consequent dental pain amongst adults with intellectual disabilities. In a study examining the extent of unmet clinical need in 60 adults with intellectual disabilities not in contact with UK community dental service (Cumella, Ransford, Lyons & Burnham, 2000), rates of dental problems were higher than in the general population. Although the results should be interpreted with caution due to a response rate of 52%. Caregivers were also interviewed about the dental services used by the person they cared for, and reported difficulty in identifying dental problems, only able to pinpoint the cause of observed discomfort through a process of elimination.

In a convenience sample survey of 9,620 adult athletes with intellectual disabilities investigating prevalence and predictors of untreated caries and oral pain (Reid, Chenette & Macek, 2003), 14% reported current oral pain. Predictors of oral pain were found to be untreated caries (30% of population), being female, gingivitis, and frequency of cleaning. These were a sample of comparatively high functioning

and relatively well-supported adults, who possibly have better dental health than the larger population of adults with intellectual disabilities.

Prevalence of pain might be expected to be higher amongst non-verbal adults, unable to report it. In a clinical trial to evaluate the impact of x-ray mini panels on dental treatment planning, all 72 adults with severe and profound intellectual disabilities and unable to verbally communicate their symptoms had radiological dental findings that were unsuspected on clinical evaluation (Farman, Horsley, Warr, Ianke & Hood, 2003). In over 30% of participants the dental problem possibly caused pain and suffering. In 61% the findings influenced treatment plans.

The studies consistently report unmet clinical oral care needs for adults with intellectual disabilities. Oral pain is likely for many, and where adults with intellectual disabilities could not articulate their dental pain they were reliant on caregivers who had difficulty recognising pain. This emphasises the role of caregivers as gatekeepers to health services and raises questions about caregivers' knowledge, attitudes and dental care practices (Cumella et al., 2000).

A methodological concern when asking adults with intellectual disabilities about dental pains is the possibility of over/under reporting by participants in an attempt to please the examiner, or not wishing to disclose pain for fear of dental investigations and treatment. It is important to ask why those who can communicate verbally do not report oral pain. In the study by Cumella et al., 57% of participants refused an oral examination but agreed to participate in an interview, suggesting fears of dental examinations or past experience of pain during dental treatment.

Further research is needed to explore this issue, as the views of adults with intellectual disabilities are unknown.

3.22 Chronic pain

Chronic pain (pain present most days for a minimum of six months) amongst adults with intellectual disabilities has been investigated in two studies. In one study chronic pain in adults with intellectual disabilities in the UK was estimated by 157 caregiver reports through a postal questionnaire (63% response rate) as 13.4% (McGuire, Daly & Smyth, 2010). This prevalence is low compared to rates in the general population of 47% found in one study (Elliott, Smith, Penny, Smith & Chambers, 1999), although McGuire et al. did not use the IASP definition of pain and was diluted to include the term ‘discomfort’, which may account for this result.

In McGuire et al.’s study there was a higher prevalence of chronic pain in group homes versus family homes, not explained by the age of participants. The average duration of chronic pain was 6.5 years, but longer on average for those in family homes (22 years) versus group homes (13 years). These findings were possibly due to the higher proportion of people with severe and profound intellectual disabilities with associated complex health problems living in residential homes. Also it is possible that family caregivers were more attuned to signs of pain, whereas in residential homes it may be harder to get to know individuals’ pain signs. Chronic pain appeared more prevalent in adults with mild intellectual disabilities (28%) than severe intellectual disabilities (14%), but cross-tabulations showed that those with mild to moderate intellectual disabilities were more likely to complain compared to those with severe and profound intellectual disabilities. The latter group were more

likely to experience multiple and complex health problems and the authors infer that they therefore may experience more pain. Prevalence figures therefore reflect prevalence of pain report or detection using nonverbal behaviour, rather than prevalence per se. There may have been an underestimation of chronic pain estimates by caregivers but it is unclear. It is possible that caregivers are not attuned or aware of chronic pain amongst the people they care for (McGuire et al., 2010). In particular, all participants with cerebral palsy were estimated as experiencing no pain, a striking contrast with the 82% of people with cerebral palsy who self-reported experiencing pain in another study (Jahnse, Villier Aamedlr, Stanghelle & Holm, 2004).

Another study in Ireland (Walsh, Morrison & McGuire, 2011) found the prevalence of chronic pain to be slightly higher at 15.4%, again as estimated by 753 caregiver reports through questionnaires (31.6% response rate), for an average of 6.3 years. This study found that females had significantly more pain (20.1%) than males (13.4%). In contrast to McGuire et al.'s study no statistically significant association was found between level of intellectual disability or place of residence and having chronic pain, although those living in independent housing were more likely to experience chronic pain. There was no association between service users' ability to verbally report pain and caregiver reports of pain severity. There was an association between having a physical disability, paralysis or mobility problems and having chronic pain, with chronic pain present in 34% of service users with cerebral palsy, in contrast to McGuire et al.'s study. When caregivers were asked how they knew the service user was in pain, 64.4% said because they verbally reported it, 32% used facial expressions or grimacing as an indicator, as well as irritability (26%) and low

mood (23%). The study should be interpreted with caution due to the lower response rate relative to McGuire et al.'s (2010) study.

The validity of caregiver proxy reports was complicated in both studies by caregivers possibly not being aware or attuned to chronic pain amongst their clients. Almost all behaviour associated with pain can be attributed to other causes by observers. It is unclear why differences were found in the two studies regarding associations between the presence of chronic pain and level of intellectual disability and place of residence. There may have been biases related to the accuracy of caregiver's interpretation of pain cues or preconceived beliefs about pain in adults with intellectual disabilities (Walsh et al., 2011), such as those who responded feeling more confident in detecting pain.

3.23 Menstrual pain

Three studies provide data on the proportion of women who experience menstrual pain. One study asked 452 caregivers via a postal questionnaire (64% response rate) of women with intellectual disabilities about the extent of problems experienced during menstruation in the last six months (Rodgers, Lipscombe & Santer, 2006). Caregivers reported that pain featured strongly as one of the worst and most frequently reported problems during menstruation. Overall 54% were said to have experienced menstrual pains as a problem in the last six months and 16% cited pains as the most bothersome problem during menstruation. Three respondents talked about their clients experiencing headaches. This survey shows that caregivers are aware of menstrual pains amongst their clients; however it is unclear if proxy respondents provide an accurate representation.

One qualitative study exploring menopausal experiences of women with intellectual disabilities in the UK reported 32% of the 45 women interviewed mentioning abdominal pain or swelling (Willis, Wishart & Muir, 2011). In another similar study, 76.2% of 55 women living in institutions in Taiwan interviewed mentioned this (Chou, Lu, Wang, Lan & Lin, 2008). The differences in pain prevalence may be explained by Willis asking about pain only whereas Chou et al. asked about pain and swelling. Willis found that women tended not to mention pain spontaneously, but responded positively when asked directly (Willis et al., 2011). Studies relying on spontaneous report therefore are likely to underestimate pain substantially.

3.24 Menopausal pain

Three studies investigated experiences of menopause amongst women with intellectual disabilities. Pain experienced during menopause varied from two out of 15 women interviewed (McCarthy, 2002) to 10 out of 15 women interviewed (Willis, 2008). Willis (2008) found that pains reported during menopause included headaches, 'tummy' pain and calf pain. Willis et al. (2011) found that whilst some women reported aches and pains, very few women responded fully to the questions; in both studies, further probing by the authors revealed that pains reported tended to be related to current health problems and not menopause. Reasons for the differences found in pain prevalence amongst the two samples are unclear, but it is possible that differing interview techniques elicited different information.

3.25 Hearing aid associated pain

As part of a study interviewing 16 adults with mild to moderate intellectual disabilities in the Netherlands about expectations and satisfaction with hearing aids, three out of 16 adults reported pain, one of whom still had pain six months after fitting, and two reported discomfort (Meuwese-Jongejeugd, Verschure & Evenhuls, 2007). Although only a small sample size it seems pain associated with hearing aids is present in this population.

3.26 Summary

On the basis of the limited research conducted to date, adults with intellectual disabilities experience chronic pain, and pain associated with untreated dental conditions, menstruation and menopause and hearing aids. Some pains may be under-recognised and under-treated, particularly in those with severe and profound intellectual disabilities and impaired capacity to communicate. It is difficult to obtain reliable information about pain prevalence due to the complexities of direct assessment of some adults with intellectual disabilities. Firstly, their pains are not always apparent to others. Secondly, people behave differently with pain, and behaviours which could indicate pain are by no means unique to pain. So even where the behaviour is observed, it may not be accurately interpreted. This highlights a problematic dependence on others to interpret behavioural responses, recognise pain and act in order to relieve pain.

Prevalence rates for pain have been reported for a variety of health-related issues; but this was not generally the focus of the studies and consequently the methods used were not always clearly reported or reliable. As most studies did not

report the method of obtaining information about pain, or used unreliable methods, at this point it is difficult to estimate the prevalence of different types of pain in adults with intellectual disabilities. Further research including larger samples needs to be carried out. Many different types of pain have not yet been investigated, including musculoskeletal pain, joint pain, cardiac pain, and pain associated with injury (including postsurgical pain).

3.3 Understanding and descriptions of pain, and methods to enhance these

In total thirteen studies describe different aspects of the descriptions that adults with intellectual disabilities gave of their experiences of being in pain, investigating understandings of pain, and methods to enhance self-report of pain. One study reported helping a woman with chronic pain.

3.31 Understandings of pain

One audit has been carried out of communication skills and understanding of pain and health needs with 40 adults with intellectual disabilities, using a structured questionnaire in an interview format (Beacroft & Dodd, 2010a). When asked “what is pain?” researchers found various depths of responses, but typically respondents used language which conveyed the feeling or emotion that resulted from the pain (‘painful’, 38%; ‘hurt’; 25%; ‘horrible’, 15%) while the function of pain was not described. When asked to say how they would feel if they were in pain, 25% said they would feel sad and 13% said angry (other response percentages not reported). This supports the notion that challenging behaviour may be attributed to pain and highlights the importance of assessing pain. Only 22% said that staff/caregivers use pictures to help them talk about pain, and 15% said that their doctor used them.

There is a need for communication aids and education for adults with intellectual disabilities to enable effective communication about pain, and a need to include the perspectives of adults who cannot communicate verbally in an interview.

3.32 Descriptions of pain

Five studies have included adult women with intellectual disabilities in research about their experiences of pain. Pain was not the focus of the interviews but was discussed in the context of conversations around menstruation, smear tests and ageing.

Three studies have explored experiences of menstruation amongst women with intellectual disabilities in interviews. Women described menstruation in a variety of ways. For example, in one study where 45 women were interviewed about their experiences of menopause (Willis et al., 2011) four women with Down's Syndrome described their menstrual periods as painful, one saying "*it was like a nightmare...it's like having a baby*" (despite never having experienced childbirth). Willis et al. found that women with more severe intellectual disabilities tended to respond with a cluster of easily-describable symptoms, such as rubbing their stomach and saying "*sore*". In another study interviewing 55 women with intellectual disabilities in Taiwan (Chou et al., 2008) one woman commented "*Red is coming a lot, I bleed a lot...abdomen is very painful, I am very tired*". In Rodger's (2001) study interviewing 21 women with mild to moderate intellectual disabilities, some respondents described pain in terms of the feeling itself, such as "*stabbing*", "*struck*" and "*pinched*" but women often referred simply to 'pain'.

Interviews with 52 women with intellectual disabilities about their views and experiences of cervical smear tests showed that the women typically experienced the cervical smear test as painful (Broughton & Thomson, 2000). The women described pain associated with smear tests although in little detail. The authors note that fear of pain was discussed by some, and women who had the test were more likely to make reference to pain experienced, as opposed to any anxiety. They talked about difficulties experienced as a result of feeling tense during the test and were aware that this anxiety caused the procedure to be painful or terminated. One woman attributed the pain to the large size of the instrument used. This highlights the issue of attendance at smear tests as it is possible that some women are too fearful to attend appointments. Women with intellectual disabilities need to be well informed about the procedure and possibility of pain and discomfort during it.

Six focus groups with 34 women regarding perceptions of health issues generated two themes relevant to pain: 'general aging' and 'women's health' (Brown & Gill, 2009). One woman's description of ageing included pain: "*You get a cold or a sore throat [and] get it quicker and as you grow old, you be hurting a lot*". Almost all the women associated pelvic examinations and mammograms with pain and anxiety, and several said they would not have the exams because of these. It is possible that some women with intellectual disabilities do not understand the concept of short-term discomfort in a smear test for longer-term reassurance that precancerous cells could be detected. Therefore sensitivity to verbal and non-verbal signs is needed by caregivers to notice pain particularly when women are undergoing procedures which they previously feared would be painful. It seems women do not

always communicate pain in these settings and the authors suggest that caregivers need to be more aware of potential feelings of intimidation.

The findings suggest that some women with intellectual disabilities experience and report pain during menstruation and smear tests. Only those with adequate verbal communication skills took part and their views and experiences cannot be assumed to represent those without. The research is limited by focusing on women's issues; men have not been asked about their pains.

3.33 Enhancing understanding and self-report

The use of body maps and analogue colour scales to assess the location and intensity of pain in photographs of people depicting pain scenes amongst adults with intellectual disabilities has been investigated (Bromley, Emerson & Caine, 1998). Compared to 20 controls, the answers of 20 adults with intellectual disabilities regarding assessing the location and intensity of pain were stable over the course of two sessions. They could judge the location of pain as well as the controls in 93% of photographs, with the exception of a 'severe leg injury' photograph. They were able to discriminate differing levels of pain for five out of six photographs, compared to six for the controls. They rated three photographs of people's faces as significantly ($P < 0.05$) more intense than controls, and all 'mild' pain scenes and 36% of 'severe' pain scenes as significantly ($P < 0.05$) more intense than controls. This indicates that they were less accurate in their judgements of pain intensity.

These findings demonstrate that some adults with intellectual disabilities can make use of analogue scales and body maps, but anecdotally the authors note that

participants seemed reluctant to use the lower end of the scale. No significant correlation was found between indicators of cognitive ability and task performance, so cognitive ability within the range of the respondents is a poor predictor of ability to use such scales. However, being able to recognise pain in others does not necessarily translate to being able to identify and describe pain in oneself. No published research has investigated what proportion of adults with intellectual disabilities could use these tools to indicate the location and intensity of their own pains. Donovan (2002) described one nurse who used a simple pain faces scale with a patient, which they used to indicate the degree of pain in area of their body.

Ruddick and Oliver (2005) adapted a Health Status Measure (SF-36 revised by Ware & Sherbourne, 1992) used in the general population, which contains two questions about bodily pain intensity, duration and frequency and limitations in usual activities because of the pain. When 21 verbal or partly verbal participants with moderate intellectual disabilities were asked these two questions they provided reasonably consistent responses across two presentations (70% agreement; 0.66 correlation between responses). There are no other established reliable/valid health status measures for people with intellectual disabilities for comparison, but this illustrates that self-report may achieve insights not necessarily accessible from third parties. The study highlights the skills a person needs to observe one's own physical sensations and bodily states and recognise that one is in pain, and translate these into words or relate them to pictorial representations. Self-report was provided by adults with moderate intellectual disabilities, so the findings may not represent those with severe and profound intellectual disabilities.

Other researchers used a faces pain scale depicting five faces during an influenza vaccination with 129 adults with intellectual disabilities and 38 control participants (Defrin, Lotan & Pick, 2006), and although they did not report any further details or exact numbers, they found that many participants chose smiling faces at baseline and immediately after vaccination. Others chose the face at the middle of the scale (which has no particular expression). The authors felt the participants could not use the face scale because they did not comprehend the meaning of ranks and could not transpose their pain experience onto faces. Or they saw the task as choosing the one they liked, which will usually be the smiling one. Below is an example of pain faces scales used in this type of research.

3.34 Group teaching programmes

A teaching package was developed to help 10 adults with intellectual disabilities understand and communicate about physical illness using pictures and communication aid cards to describe symptoms (most commonly pain) and severity and duration of pain (Dodd & Brunner, 1999). Teaching these skills can help develop awareness of the need to communicate when feeling pain, and encourage the person in pain to inform another person of illness/pain using communication cards.

GPs reported that the communication packs could be useful particularly in diagnosing type, intensity and exact location of abdominal pain. There was some reduction in knowledge at six month follow up, but it shows the potential for using aids more widely. Unfortunately, in Beacroft and Dodds's (2010b) study with residential staff, they found that no staff were using the 'Feeling Poorly' pack Dodd and Brunker (1999) developed.

A 12-week programme was developed to enable 11 adults with intellectual disabilities to better access primary healthcare (Webb & Stanton, 2008). Qualitative analysis revealed that participants improved their awareness of symptomatology, with the commonest symptom being pain. Participants were able to discuss their pain and most showed a good understanding of its presentation and the appropriate action to take, according to the severity and type of pain. The authors felt this indicated that they learned to distinguish between mild pain appropriate for self-management, and severe pain which indicates a need for professional help. This study showed that improvements in skills and knowledge about pain can be made amongst adults with intellectual disabilities, but there was no follow up to see if these were retained and acted upon.

3.35 Cognitive Behavioural Therapy

One case study reported a 32-year old woman with mild-moderate intellectual disabilities with chronic pain (Lewis, Bell & Gillanders, 2007). The authors describe trying to use pain measures designed for the general population that were difficult for her to understand. By adapting chronic pain management strategies for use in the general population she could take part in cognitive behavioural therapy for chronic

pain. The results suggests ‘considerable’ change for her as she showed less fear and avoidance of activities, and verbally reported experiencing lower levels of pain, and feeling able to carry out a range of activities. This shows the need for clinicians to consider the possible role of pain in an individual’s presentation, and shows that chronic pain management can potentially be adapted for adults with intellectual disabilities.

3.36 Summary

There are currently no in depth descriptions of pain experiences amongst adults with intellectual disabilities and only one study has asked them about their understanding of pain. The research reviewed suggests that they can convey the emotion associated with pain and can self-report their own pains reasonably consistently with structured questions. They can assess the location of pain in others accurately and the intensity of pain in others well to some extent. Whilst research has examined the use of pictures and analogue scales to detect pain in others, to date researchers have not examined their use in self-reporting pains. It is possible to teach adults with intellectual disabilities to communicate more effectively about their pains along with communication aids to describe symptoms of pain, but regrettably little use is made of communication aids.

Research has only investigated verbally communicating adults with mild-moderate intellectual disabilities, which does not necessarily extrapolate to those who experience communication difficulties or are unaware of the need to communicate pain to their caregivers (such as adults with intellectual disabilities and autism).

3.4 Unreported pains

Four studies discuss diagnostic difficulties related to pain not appearing to be present in conditions where pain would be expected, amongst adults with severe to profound intellectual disabilities. In addition to self-report discussed previously, there are five descriptions of the lack of self-report amongst adults with intellectual disabilities.

3.41 Pain not observed/diagnosed

A retrospective study of hospital records provides data about recordings of pain observed in 32 people with intellectual disabilities who died from intestinal obstruction (Jancar & Speller, 1994). The study found that pain and distress were recorded in nine patients (28%) and five (16%) displayed signs of tenderness and guarding. The authors noted that this group appeared at greater risk of pain going unrecognised and unrecorded by staff. On the basis of the findings the authors suggested that pain was less clearly communicated by those with more severe intellectual disabilities, or it is possible that staff did not perceive the episodes as serious because signs of illness were less apparent than expected.

One case study reported a 19-year-old male with profound intellectual disabilities who presented with no obvious clinical signs of pancreatitis despite typical early symptoms including abdominal pain (Hinder & Perry, 2000). Blood tests revealed he was indeed suffering from pancreatitis. The authors note that the recognition of pain requires high standards of observation and recording as well as the development of relationships with caregivers. These two studies, although using small sample sizes, demonstrate difficulty in diagnosing painful conditions in people

with severe and profound intellectual disabilities, and the importance of understanding clinical presentations in this group.

One qualitative study asked eight parents of adults with intellectual disabilities about their experience of caring for their son/daughter who had a diagnosed health condition (Clarke & Thompson, 2007). They found that a majority did not perceive their son or daughter in much pain, which was generally attributed to their being healthy or receiving suitable treatment. It is possible that due to the age range of adults with intellectual disabilities (20-48 years) they may have been less likely to experience the sort of chronic musculoskeletal pain usually associated with older people. Breau, MacLauren, McGrath, Camfield and Finley (2003) suggest that parents may be underestimating the presence of pain in their children with intellectual disabilities, which serves as an unconscious defence mechanism, potentially against feelings of guilt or distress.

Another qualitative study asked intellectual disabilities nurses about being with adults with severe intellectual disabilities in pain (Donovan, 2002). The nurses reported that they used their knowledge of the client's personality to interpret the significance of body postures and vocalisations such as crying. A difficulty identified by several nurses was that they believed crying to often be the only indicator of pain.

One study investigated the affect of level of intellectual disabilities on pain behaviour during an influenza vaccination (Defrin, Lotan & Pick, 2006). Given that levels of intellectual disabilities are highly and positively correlated with motor and functional limitations (AAMR, 2002), this may affect the measurement of pain. This

study compared 129 adults with intellectual disabilities to 38 controls with physical disabilities and normal levels of cognition living in institutions. Raters observed flu vaccinations using two checklists of facial and bodily pain behaviours. The Facial Action Coding System (Ekman & Friesen, 1978 cited in Defrin et al., 2006) is validated for use with older adults and intellectual disabilities and those with dementia and intellectual disabilities. The Non-Communicating Children's Pain Checklist-Revised (McGrath, Rosmus, Canfield, Campbell & Hennigar, 1998 cited in Defrin et al., 2006) is validated for use with children with intellectual disabilities.

Defrin et al. found that the level of intellectual disabilities significantly affected pain behaviours as during pre-vaccination those with more severe and profound intellectual disabilities showed an elevated baseline of facial and bodily pain expression, compared to mild to moderate intellectual disabilities and controls. During vaccinations they only showed an increase in bodily pain scores whereas those with mild to moderate intellectual disabilities increased on both ratings. As bodily pain scores increased, this indicated that pain was present, but it appeared that a facial 'freezing' response occurred in 47-50% of those with severe and profound intellectual disabilities compared to 8-13% of adults with mild to moderate intellectual disabilities and 5% of controls. The authors suggest that this 'freezing' gives a false impression of not being affected by pain, which previous studies may have taken as evidence of pain insensitivity. The presentation of pain in those with severe and profound intellectual disabilities may hinder pain detection.

Length of stay in institutions affected pain behaviour, as longer time periods resulted in a higher frequency of pain behaviours during vaccination, whereas the

opposite was true for controls. It is possible that feedback from caregivers in institutions may serve as negative feedback, inducing reduced bodily reactions if communication skills are intact. Therefore it is possible that there was a need to display increased pain behaviour as a survival skill (Lotan et al., 2006). There are methodological issues including the use of checklists not validated for use amongst adults with intellectual disabilities, and the possibility of observer bias. Caregiver and independent rater scores appeared to correspond, providing evidence for inter-rater reliability. However, all observers are subject to biases related to age, sex, attractiveness, and beliefs about people with intellectual disabilities. Finally, the behaviours observed may have resulted from emotional distress caused by pain (fear, anxiety, anger, surprise, attention) (Defrin et al., 2006) or potentially even helplessness.

3.42 Pain not self-reported

An interview study with 19 adults with intellectual disabilities about experiences of GP consultations (Turk, Kerry, Corney, Rowlands & Khattran, 2010) found that four of the 19 adults with intellectual disabilities said they did not tell anyone when they experienced pain, and had not consulted their GP over the previous year. Reporting pain was not significantly associated with number of GP consultations ($p=0.55$). The reason that these individuals were not self-reporting their pains are unclear.

A study in which 56 residential staff were asked about pain thresholds and strategies to recognise and manage pain in adults with intellectual disabilities (Beacroft & Dodd, 2010b) found that only half thought that their clients would tell them if they were feeling unwell; 45% of staff thought that someone with mild-

moderate intellectual disabilities would not say so. This conflicts with the expectation that pain will be spontaneously verbally reported. Some staff said they would have to ask the person first.

Donovan (2002) found that intellectual disabilities nurses believed that someone with verbal skills is not necessarily a guarantee that the person can communicate pain. One nurse described a very bright and verbal patient who told the nurse he had had a pain in his foot for the past few days. Upon examination a large piece of glass was found embedded in his foot. Another patient with limited vocabulary used the word “arm” to describe pain in any part of the body; yet another spontaneously started saying “medicine” when she wanted pain relief in hospital.

In interviews with 15 women with intellectual disabilities regarding menopause few women reported noticing any symptoms until prompted by the authors (Willis, 2008), raising concerns regarding whether women’s menopausal pain relief needs are being met if they are not spontaneously reporting these. This is of concern given that 80% of women in the UK general population experience symptoms including pain leading up to menopause (NHS, 2010). There is no evidence that women with intellectual disabilities experience less symptoms and pain, but it is possible that they do not report their pains as much as women in the general population. It is unclear if researchers asked specifically about common symptoms experienced during menopause. It appears that the women were expected to remember which pains they had, which is problematic in terms both of attribution and of memory.

3.43 Summary

Researchers have reported instances amongst adults with severe to profound intellectual disabilities of pain not appearing to be present in conditions where pain would be expected. Also amongst those with mild to moderate intellectual disabilities, pain is sometimes not reported, although the reasons for this remain unexplored.

4. Discussion

4.1 Conclusions

Several conclusions can be drawn from the studies reviewed. Some pains may be under-recognised and under-treated, particularly amongst those with severe and profound intellectual disabilities. However, in some research is complicated by asking for proxy responses from caregivers, which are not necessarily an accurate interpretation of the pain experienced by the people they are caring for. There appears a reliance on others to recognise and respond to pain. Earlier studies suggested that adults with intellectual disabilities have a higher pain threshold than is typical, but one recent study with better methodology found lower heat-pain thresholds amongst adults with intellectual disabilities.

Self-report of pain has only focused on women's pains and so far men have not been asked about their pains, and these self-reports were in the context of discussions about health issues and were not the focus of the research. Adults with intellectual disabilities can self-report their pains reasonably consistently with structured questions, but the research is limited to people with adequate verbal

communication skills. It is possible to achieve more effective ways to communicate pains with tools but these are used little in everyday settings.

The understanding of a person's pain is dependent on their ability to communicate their experience to other people (Gabre & Sjöquist, 2002). Literature reviews of research investigating pain assessment for children with intellectual disabilities have noted that self report is the gold standard, playing a central role in the literature for other populations, and because clinicians often prefer self report as a first line assessment technique (Breau & Burkitt, 2009). It is important to consider self-report as a possibility when assessing pain in children with intellectual disabilities, but further evidence is needed before it can be recommended as a first line assessment technique. However previous studies have shown that as the degree of intellectual disability increases in children, verbal reports of pain decrease (LaChapelle, Hadjistavropoulos & Craig, 1999). Similarly, research with older adults shows that the more serious the cognitive impairment, less pain is self-reported (Cohen-Mansfield & Marx, 1993; Parmelee, Smith & Katz, 1993). It is unclear if the pain experience is in fact altered in these populations or if an inability to describe pain is the cause. One literature review concluded that the low frequency of reported pain in adults and older adults with intellectual disabilities is influenced by a limited ability to report pain, as well as caregivers' interpretations of pain (Gabre & Sjöquist, 2002).

The current literature review included many more reports of unreported pains in adults with intellectual disabilities who could not communicate verbally, compared to those who could. There are different methods useful with individuals

who have a limited ability to verbally report pain, and methods with individuals who have no ability to report pain (Gabre & Sqöuist, 2002). In the latter situation pain registration must be done by an observer, and currently more research is needed into the effectiveness of methods to enhance abilities to detect and report pain amongst people with more severe intellectual disabilities. Research suggests that pain can be expressed in different ways in adults with severe and profound intellectual disabilities where a facial ‘freezing’ response has been observed (Defrin et al., 2006). Challenging behaviour and self-injurious behaviour can exist alongside undetected pain (e.g. Bosch, Van Dyke, Smith & Poulton, 1997), and a thorough health assessment is important whenever challenging or self-injurious behaviour are significant causes for concern. Self-injurious behaviour can be reduced with medication acting on pain receptors (e.g. Symons et al., 2001), but the role of pain in self-injurious behaviour is not well understood.

However, there are not many definitive strong conclusions that can be drawn from the literature review as many of the studies have methodological limitations or biases, such as relying on volunteer/referrals with consequent sampling biases, often using no objective outcome measures or measures inappropriate for adults with intellectual disabilities. When little was known about the issues surrounding pain in adults with intellectual disabilities, more exploratory methods such as case studies were appropriate, but as our knowledge increases more scientific rigour is necessary. The type of questions asked also needs to be considered, as some are very appropriate and clinically useful, others less so. Studies investigating barriers to recognising pain and staff beliefs which make them attribute behavioural disturbance

to reasons other than, could prove very valuable. Further intervention studies are also needed.

4.2 Clinical implications

There are several clinical implications to be taken from the research. There needs to be more awareness that adults with intellectual disabilities experience a variety of pains which they may not communicate; from undiagnosed medical conditions, regular pains from chronic conditions, but also from common pains experienced by people on a frequent basis (e.g. migraines, menstruation, dental pain). A continued appreciation is needed that pain is often underestimated and undertreated. Clinicians and caregivers need up-to-date knowledge about pain conditions, sources of pain, and the increased risk factors present in adults with intellectual disabilities that may increase the prevalence of pain (Charlton, 2005).

When adults with intellectual disabilities present at health services, a thorough assessment for possible pain and underlying medical problems should take place. If the person can communicate verbally, communication aids such as body maps and pain scales can be used to help ascertain the location, intensity and duration of the pain experienced. This is challenging as there are currently no validated measures that adults with intellectual disabilities can complete regarding their pains.

For those who cannot communicate verbally there are many obstacles to recognising pain. Caregivers are in a position to notice and respond to pain, and need to be encouraged to use their knowledge of the person and their behaviours to

be vigilant for pain. Caregivers and healthcare professionals need to be aware of their own beliefs regarding pain in adults with intellectual disabilities, including views about pain thresholds and what behaviour they consider to represent pain.

Pain amongst adults with intellectual disabilities is certainly more visible in clinical settings recently as evident in the recent publication of a manual for staff/professionals to help teach service users to manage their own chronic pains (McManus & McGuire, 2010). At times professionals have been found to link self-injurious behaviour as a possible response to physical pain or being unwell (Heslop & Macaulay, 2009). Literature investigating children with intellectual disabilities has concluded that other aspects of children's behaviour should also be addressed, including self-injurious behaviour, which may be a cue that pain is present and may assist in localising pain (Breau et al., 2003).

4.3 Further research

There are still huge gaps in our knowledge regarding pain in adults with intellectual disabilities, particularly related to prevalence of pain and self-reported experiences of pains, as currently we really do not know the extent of pains experienced by adults with intellectual disabilities. Researchers have not yet asked about experiences of everyday pains such as headache, backache and joint pain. Future research efforts also need to include the experiences of males with intellectual disabilities. Adults with intellectual disabilities who do not communicate verbally were not well represented in the research reviewed. The difference in prevalence of pain across differing levels of intellectual disabilities should be investigated in order to find out

if people with more profound intellectual disabilities are experiencing different pains due to more complex health problems going unrecognised.

There are currently no in-depth focused studies asking adults with intellectual disabilities about their past individual experiences of acute or chronic pain, so researchers could start to look at this by conducting interviews or focus groups. Another area where research is needed is to look at the impact of pain. For example, does fear of pain at the dentist or during a cervical smear screening reduce attendance? And how does chronic pain impact upon people's social lives and emotional wellbeing? Feelings associated with being in pain need to be researched, such as anxiety and helplessness. Further research could investigate why adults with intellectual disabilities who can communicate verbally are not reporting pains. Further studies are needed to investigate the use of pictures and analogue scales to enhance the capacity of adults with intellectual disabilities to detect the location of pain, report it, and use new skills to seek help.

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Part 2: Empirical paper

Experience and meaning of physical pain in adults with intellectual disabilities

Abstract

Physical pain is an important and often neglected aspect of health care for adults with intellectual disabilities. This study explored experiences and understandings of pain, and the meaning given to pain, in 15 adults with intellectual disabilities and 10 caregivers. Content analysis of semi-structured interviews with adults with intellectual disabilities highlights the difficulties they experience in understanding pain and having an appropriate language to communicate about pain. Interpretative phenomenological analysis of semi-structured interviews with caregivers identified superordinate themes of suffering in silence; searching for meaning to explain the complaint; knowledge and skills needed to recognise and manage pain; perceptions of the pain experience; acting to try and reduce pain; and the emotional impact of pain. The findings indicate that caregivers possess knowledge and skills that are often not drawn on enough during interactions with health care professionals, resulting in inadequate pain management and dissatisfaction.

1. Introduction

The Department of Health and other organisations have continuously emphasised that NHS trusts must play a central role in meeting with health needs of people with intellectual disabilities (Emerson & Baines, 2010). NHS trusts in England have a legal responsibility to provide ‘reasonable adjustments’ for people with intellectual disabilities, such as making information more accessible and offering longer appointment times. Despite the guidance and policy available, the physical health needs of people with intellectual disabilities are often poorly met (DoH, 2001, 2006, 2007, 2008 & 2009; Carnaby, 2004; Healthcare Commission, 2007; Mencap, 2007) and consequently the assessment and management of their pain is still poorly understood. A brief overview is provided of why it is important to conduct research about pain in people with intellectual disabilities, differences in how they may communicate their pain, and research to date investigating their experiences of pain.

1.1 The importance of pain in people with intellectual disabilities

Pain is one of the most common of all human experiences, a highly subjective and individualised experience. It is present in many illnesses and injuries and is often what prompts people to seek medical attention (Bowsher, 1993). Pain is defined as:

*“An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. **Note:** The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment.”* (IASP, 1994).

Misconceptions persist about pain in people with intellectual disabilities, not least because they were historically excluded from pain research and early studies

suggested that they had higher pain thresholds than the general population (Biersdroff, 1994; Hennequin, Morin & Feine, 2000). However, one recent study that addressed methodological problems of previous studies found that adults with intellectual disabilities were in fact more sensitive to heat-pain than the general population, but that the expression of pain is sometimes different (Defrin, Pick, Peretz & Carmeli, 2004). Incidences of insensitivity or indifference to pain are no more than in the general population, and at most are anecdotal and only occurring among certain individuals. Individual differences in pain experience and behaviour in people with intellectual disabilities are as diverse as in the general population, with damage to the central nervous system and psychosocial conditions such as speech disorders affecting the perception of pain, the elaborated experience of pain, and the manner in which pain is expressed (Hadjistavropoulos, von Baeyer & Craig, 2001).

Pain is particularly relevant to people with intellectual disabilities as they have poorer health (NHS Health Scotland, 2004; Nocon, 2006), and more injuries, falls and accidents than their non-disabled peers (Finlayson, Morrison, Jackson, Mantry & Cooper, 2010). In particular, people with profound and multiple disabilities have substantial, sustained, complex health care needs which often involve pain (Mansell, 2010). However, pain does not appear to be routinely considered in care provision for people with intellectual disabilities (Symons, Shinde & Gilles, 2008). A stark example is Mencap's (2007) report of six adults with severe intellectual disabilities who died from undiagnosed and untreated health problems. They included descriptions of inadequate care, doctors failing to recognise symptoms and signals of pain, and failure to offer pain relief where

needed. Despite enquiries such as this and the policy reviews which often follow, pain is still not always readily acknowledged in this group and is often poorly assessed, inappropriately managed, or left untreated (Oberlander, Symons, van Dongen & Abu-Saad, 2003).

1.2 Pain communication in people with intellectual disabilities

One of the primary factors in pain assessment is the reliance on self-report as the gold standard (Jones, 2003). Without communication of pain, and since there is no objective measure of pain, accurate identification of pain is compromised. However, amongst people with intellectual disabilities, self-report may be uncommon due to cognitive and communication impairments (Hadjistavropoulos et al., 2001; Bottos & Chambers, 2006) and having fewer words in their vocabulary to describe pain (Beacroft & Dodd, 2010a). Cognitive impairments include difficulties in understanding the meaning of events, remembering related experiences, and anticipating what is likely to happen, or engaging in problem solving and coping (Hadjistavropoulos et al., 2001). They may also give rise to problems relating an illness to a dysfunction in the body (March, 1991), describing symptoms and feelings (Howells, 1995; Lindsay, Howells & Pitcaithly, 1993; Simpson, 1995), and recognising symptoms as a sign of illness and report and answering questions about them, or knowing that help can be obtained through a doctor (Simpson, 1995).

Therefore there is a reliance on those in regular contact with people with intellectual disabilities to recognise pain-related behaviours and report them on their behalf. Several behavioural pain assessment methods have been developed, typically consisting of checklists of possible changes in facial expression, body posture and

behaviour that may suggest pain and/or distress (see Symons et al. 2008 for overview). Many of these tools have not been tested for reliability and validity in adults with intellectual disabilities, although they may be clinically useful (Balridge & Andrasik, 2010). Tools such as these require the observer to infer the cause of distress, which may or may not include pain, and require observational and attributional skills, rather than the ability of the person in pain to consciously communicate his or her experience (Astor, 2001). This is complicated by some adults with intellectual disabilities displaying pain in other ways, such as behavioural changes, which are not interpreted as pain signals (e.g. Chivell, 2001; Cheetam, 2001). Research shows that tools based on facial reactions alone may give the false impression that people with severe and profound intellectual disabilities are insensitive to pain (Defrin, Lotan & Pick, 2006).

1.3 Pain research in adults with intellectual disabilities

1.3.1 Experiences of pain in adults with intellectual disabilities

Our understanding of pain experiences in this population to date is limited to a focus on pains specific to women such as menstrual pain (Chou, Lu, Wang, Lan & Lin, 2008; Rodgers, 2001; Willis, Wishart & Muir, 2011), menopause (McCarthy, 2002; Willis, 2008) cervical smear tests (Broughton & Thompson, 2000) and pelvic examinations, mammograms and ageing (Brown & Gill, 2009). In these studies pain was not the focus of the interviews or focus groups, but pain was discussed in the context of conversations around these particular experiences. Thus far only one study has considered both men and women when asking about pain associated with hearing-aids (Meuwese-Jongejeud, Vershuure & Evenhuis, 2007).

Only those with adequate verbal communication skills took part in these studies, and their views and experiences cannot be assumed to generalise to all adults with intellectual disabilities. No research has investigated the meaning that pain holds for adults with intellectual disabilities and there are currently no in depth descriptions of pain experiences in adults with intellectual disabilities.

1.32 Understandings of pain amongst adults with intellectual disabilities

Research investigating understandings of pain is very limited and highlights difficulties adults with intellectual disabilities experience in understanding the concepts related to pain and having sufficient language to describe their pains. When adults with intellectual disabilities were asked to describe pain they could not describe the ‘function’ of pain in the body and instead responded with language which described pain in emotional terms (‘painful’, 38%; ‘hurt’; 25%; ‘horrible’, 15%) (Beacroft & Dodd, 2010b). When asked how they would feel if they were in pain, 25% said they would feel sad and 13% said angry (remaining percentages were not reported).

In an unpublished study where adults with intellectual disabilities were asked to describe pain their responses varied from not recognising the word to understanding the word in the context of being unwell (Stone Pearn, 2002). Participants were more likely to give strong negative descriptions when describing the severity of their pains (e.g. “*terrible*”). Verbal inquiry was found to be the most helpful to elicit information about pain, followed by pictures to illustrate aspects of pain. So far research investigating understandings of pain has only involved verbally communicating adults with mild to moderate intellectual disabilities, which does not

necessarily extrapolate to those who experience significant language/communication difficulties or are potentially generally less likely to communicate with others (such as individuals with autism spectrum disorders).

Recent attempts to increase understandings of pain and support self-report of pain in adults with intellectual disabilities have been encouraging. These include:

1) A pilot study to increase understanding and communication regarding the symptoms of illness (Dodd & Brunner, 1999) which showed it was possible to teach service users to understand how the body functions, understand the process of going to the doctors, and using pictures to support discussions about pain. However, participants had difficulties in identifying and describing abstract concepts of pain that help doctors to make an accurate diagnosis.

2) An adaptation of a Health Status Measure (SF-36 revised by Ware & Sherbourne, 1992), normally used in the general population, containing two questions about bodily pain intensity, duration and frequency, and limitations in usual activities because of pain (Ruddick & Oliver, 2005). Participants with moderate intellectual disabilities provided reasonably consistent responses across two separate presentations of the Health Status Measure (70% agreement; 0.66 correlation between responses).

3) Using pain scales depicting five faces of varying pain intensity to express the intensity of pain experienced during a vaccination (Defrin et al., 2006). In this study many participants chose smiling faces at baseline and immediately after vaccination, and others chose the face at the middle of the scale (which has a neutral expression). The authors felt the participants could not use the scale as they did not comprehend the meaning of ranks and could not transpose their pain experience onto

the faces. Alternatively they may have understood the task as choosing the face they liked, usually the smiling one.

4) A group programme to increase knowledge and skills in primary health care settings (Webb & Stanton, 2008) which resulted in increased awareness of symptoms of illness, and improved language to describe experiences and symptoms including those of pain.

1.33 Experiences of caring for adults with intellectual disabilities in pain

Typical roles for caregivers include monitoring symptoms of illness and reactions to medication, acting as gatekeepers to health services, and being advocates during encounters with health professionals (Langan, Whitfield & Russell, 1994). Because of their intimate knowledge of the individual, caregivers are an important source of information on the experience of pain (Bottos & Chambers 2006). GPs may rely on caregivers attending consultations to provide information to assist in assessing and diagnosing pain, but this can be difficult if new temporary staff lack long-term knowledge of the individual's health conditions and characteristic behaviours (Martin, 2003). Often caregivers do not identify health needs (Hogg, 2001; Wilson & Haire, 1990), and have little knowledge of specific health needs of people with intellectual disabilities (Carnaby & Cambridge, 2006). Alborz, McNally and Glendinning (2005) found that caregivers were reluctant to seek healthcare for adults with intellectual disabilities if they thought the complaint was 'trivial' or the person would not benefit from the intervention. Such findings are not surprising as observations of others are affected by individual factors such as the observer's background or prior experience with pain (Hadjistavropoulos et al., 2001). Therefore

it is of great importance to consider caregivers' perceptions, views and understanding of clients' pain.

Nurses working with non-verbal adults with intellectual disabilities described the importance of a caring relationship with the person, recognising changes in verbal and nonverbal behaviour, searching for meaning in the person's behaviour, negotiating with other health professionals, and sharing in the person's feelings (Donovan, 2002). The nurses reported observing both conventional and 'nonconventional' methods of communication used by service users to express pain, including aggressive and self-harming behaviours.

In contrast parents of adults with intellectual disabilities and associated health problems did not often perceive them to be in pain (Clarke, Thompson, Buchan & Combes, 2007). In order to recognise pain they looked for visible signs indicating possible pain and used a process, described by one parent as 'trial and error', to determine causes of pain. Strategies for dealing with pain included making the person more comfortable, administering pain medication, contacting professionals, and seeking medical interventions. Parents reported psychological effects on themselves including distress, empathy, worry, guilt, and using a strategy of 'bearing it'. The authors suggested that three factors might result in pain not being detected by parents: 1) overreliance on self-report even amongst adults with intellectual disabilities; 2) a lack of awareness of pain and training in this area (as suggested by DoH 2001 and MENCAP 1997); and 3) underestimating the health needs of adults with intellectual disabilities in relation to other problems they face – a factor supported by Rodgers (1994).

A recent study found that one third of staff working with adults with intellectual disabilities believed that service users had a higher pain threshold than people in the general population (Beacroft & Dodd, 2009), despite there being no evidence to support this. This belief will likely impact on how they respond to pain in the people they care for. Recently two attempts have been made to improve recognition and management of pain by caregivers. Firstly, a pain training pack has been created for staff in how to recognise and manage pain (Beacroft & Dodd, 2010a) which helped staff to change their attitudes towards pain and to recognise pain and manage pain more effectively (Mackey & Dodd, 2010). Secondly, a manual of practical guidance for caregivers has been produced to help them teach service users to manage their chronic pain more effectively (McManus & McGuire, 2010). These attempts are encouraging as they are trying to impart knowledge and change attitudes amongst caregivers, as well as offer guidance for everyday practice.

1.4 Rationale

To date our knowledge about how people with intellectual disabilities understand and experience pain is very limited. Little qualitative research has been conducted amongst adults with intellectual disabilities asking about their experiences of pain, and men's experiences have been largely ignored. Most research has been conducted with adults with relatively mild intellectual disabilities. Therefore we do not know how people with intellectual disabilities understand pain and what their experiences of pain are. In order to address these shortcomings, the present study used a qualitative approach to explore in-depth adults with intellectual disabilities' experiences of being in pain, and the experiences of caring for adults with intellectual disabilities who may have been in pain.

1.5 Research questions

1. What are the phenomenological experiences of adults with intellectual disabilities regarding pain? In particular:
 - What are their experiences of being in pain?
 - What meaning do they give to pain?
 - How do they understand pain?
2. How do caregivers respond to possible or actual pain in adults with intellectual disabilities? In particular:
 - Do they recognise pain?
 - What is the emotional impact of these processes and events?

2. Method

2.1 Procedure

2.11 Ethical approval

Ethical approval was obtained from the Trust's Ethics Committee, which provided an opportunity to consider relevant ethical issues (Appendix A). Guidance on informed consent amongst people with intellectual disabilities was adhered to (Arscott, Dagnan & Stenfort Kroese, 1998; Bray, 1998). Informed consent was sought by providing information at an appropriate level (verbally, in writing and pictorially) regarding the content and purpose of the study and what to expect if taking part (Appendix B2). The person's free choice to take part and participants' right to not answer questions and/or to withdraw at any time for any reason was emphasised, as was anonymity of participants and responses. A discussion took place with each participant regarding the advantages and disadvantages of taking part, including the potential to become upset whilst talking about pain. Adequate

time was given for the process of obtaining consent with a 20 minute initial meeting and then a minimum period of 24 hours before the interview took place. Consent was recorded by the participant writing their name or signing/marketing the consent form (Appendix B3 & C3).

2.12 Pilot study

Four pilot interviews took place with two adults with intellectual disabilities and two caregivers. This provided a test of the interview schedule and generated valuable feedback which highlighted questions requiring alteration. As the interview schedules only underwent very minor revisions following these, the pilot data for the two adults with intellectual disabilities were included in the analysis.

2.13 Recruitment

Adults with intellectual disabilities

Participants were invited to participate by professionals working in a Community Team for People with Learning Disabilities in the London area. In mid 2010, staff were asked to hand out 135 invitations (Appendix B1) and information sheets to clients they were working with, but it was not possible to track how many were actually given to service users. These invitations and information sheets were based on relevant guidance about accessible writing (Mencap, 2000). No specific strategy was employed to recruit people more likely to be in chronic pain as there was equal interest in more 'everyday' pains. Reminder emails were sent to staff and a presentation was given to generate interest. Potential participants indicated their interest to staff (n=18) or contacted the researcher directly by telephone (n=2). Four were excluded due to 1) having a medical condition which meant they could not feel

pain; 2) declined to take part via telephone; 3) declined to take part during the initial meeting as they were uncomfortable with the tape recorder; and 4) were not contactable after initial meeting.

An introductory meeting lasting 20 minutes took place at participants' homes, to talk through the information sheet and consent sheet and reinforce the purpose of the meeting (Appendix B). The information sheets provided details of the study using clear language and images which explained about the researcher and study. The researcher asked a set of five questions which helped to determine the person's understanding and ability to consent (as suggested by Arscott et al., 1998).

Caregivers

Informal caregivers (parents) of service users with intellectual disabilities in the same part of London were given an invitation (Appendix C1) and information sheet (Appendix C2) approached through a local carers group. Anyone who expressed an interest in taking part was initially contacted by telephone. Six provided contact details and five were interviewed, as one was not at home during the arranged interview time. Formal caregivers (paid staff) were approached and given an invitation and information sheet whilst the researcher visited homes to conduct interviews with adults with intellectual disabilities. Five of the six who were approached agreed to be interviewed.

2.14 Data collection

Interviews took place at participants' home/place of work/day centre dependent on their preference. All adults with intellectual disabilities and informal caregivers

asked to be interviewed at home and all formal caregivers at their workplace. One adult with intellectual disabilities had a member of staff support him in the interview. Written informed consent was gained before the interview started. Each interview began with some general chat to relax participants and to informally gather demographic data. The interview was conducted using a semi-structured interview schedule (Appendix D & E) and was tape recorded. The interviews varied in length from 20 to 70 minutes and were guided by how much participants had to say. Pictorial resources were used to initiate and facilitate the interviews with participants with intellectual disabilities to support them in answering questions as fully as possible (Appendix D3). During interviews participants were monitored for signs that they might want to stop, were uncomfortable or losing concentration. Participants with intellectual disabilities were given £10 as a thank you for participating.

2.2 Instruments

Two semi-structured interview schedules were designed by the researcher, one for adults with intellectual disabilities and one for caregivers (Appendix D & E). The schedules were developed in line with guidance on constructing semi-structured interview schedules (Smith et al., 2009; Smith & Osborn, 2003). They were refined with input from the research supervisors in response to the pilot interviews.

Adults with intellectual disabilities

The schedules for adults with intellectual disabilities also reflected guidance on conducting interviews with this population (Baxter, 2005). The researcher was mindful of potential acquiescence in this population (e.g. Gudjonsson, Murphy &

Clare, 2000; Finlay & Lyons, 2002) which was addressed by questions being asked in simple language and phrased in an open ended manner, with responses reflected back to ensure that the meaning intended by the participant had been captured. The three line drawings presented to participants were obtained from the internet (Appendix D1). These represented three types of 'everyday' pain that the researcher felt participants would be likely to be familiar with (headache, stomach ache, backache) to familiarise them with the topic of pain. These were also a way of starting by talking about someone else's pain before asking more personal questions about participants' own experiences of pain. A Speech and Language Therapist from the Community Team and the researcher's supervisors were consulted to ensure the appropriateness of pictures and visual aids.

Caregivers

Caregivers were first invited to recall and reflect in detail on two particular episodes they had experienced of pains that were easily recognised and not so easily recognised. Caregivers were also asked questions related to their experiences of caring for people in pain, using a semi-structured interview schedule (see Appendix E).

2.3 Analysis

Interviews were audiotaped and transcribed. A qualitative method was believed to be most appropriate as little is known about the experiences of pain amongst adults with intellectual disabilities and their caregivers. Qualitative research also can access the perspectives and experiences of groups who lack the power to make their voices

heard through traditional academic discourse, such as people with intellectual disabilities (Booth, 1996).

2.31 Rationale for analytic approach taken with adults with intellectual disabilities

Data from adults with intellectual disabilities was analysed using content analysis, guided by literature on content analysis (Graneheim & Lundman, 2004; Elo & Kyngäs, 2008). An open mind was maintained with regards to how to analyse the data. Such an approach contravenes the advice given by Willig (2001) that *“researchers should never collect data without having decided how to analyse it”* (pp.21), but there was a desire to strike a balance between generating a piece of research that was ‘fit for purpose’ and would contribute to the literature, and the researcher’s learning process of trying to access participants’ experiences by whatever method was appropriate. In response to the data collected and in careful discussion with supervisors it was decided that content analysis was appropriate given the limited length of detail in participants’ responses.

Content analysis can be used to analyse verbal communication, and is concerned with meanings, intentions, consequences and context (Downe-Wamboldt, 1992). It is a systematic and objective means of describing and quantifying phenomena (Krippendorff, 1980). It is assumed that when classified into the same categories, words, phrases and the like share the same meaning (Cavanagh, 1997). Usually the purpose of those categories is to build up a model, conceptual map or categories.

2.32 Rationale for approach taken with caregivers

Data from caregivers was analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). IPA is popular and widely used in health psychology. Its aim is to capture and explore how participants make sense of their personal and social worlds, emphasising the meanings assigned to experiences (Smith & Osborn, 2003). IPA was deemed particularly suitable because it offers a detailed first person account of participants' experiences. Access to the participant's world is mediated via the researcher who brings his/her own ideas, understandings, preconceptions and background (Smith & Osborn, 2003).

2.33 Process for adults with intellectual disabilities

The process of content analysis is presented in Table 1 and based on available literature (Graneheim & Lundman, 2004; Elo & Kyngäs, 2007). The focus was on both manifest and latent content. An accessible version of the results was sent to all participants with intellectual disabilities who took part.

Table 1

Process of content analysis performed

Phase	Stage	Description of the process
<i>Preparation</i>		Select units of analysis and read through interviews several times to make sense of the data and obtain a sense of the whole.
<i>Organising</i>	Open coding	Write notes and headings in the text to describe all aspects of the content.
	Coding sheets	Collect headings from margins and transfer onto coding sheets.
	Grouping	Group list of categories under higher order headings.
	Categories Abstraction	Formulate categories through interpretation. Name each category using content-characteristic words. Group subcategories with similar events and incidents together. Group categories together as main categories. Continue as far as is reasonably possible.
<i>Reporting</i>		Report the analysing process and results. Develop a model, conceptual map or categories.

2.34 Process for caregivers

Table 2 describes the process of IPA analysis based on available literature (Smith & Osborn, 2003; Willig, 2007; Biggerstaff & Thompson, 2008). Analysis is a cyclical process with new themes tested against earlier data (Biggerstaff & Thompson, 2008). A summary of the results was sent to all caregivers who took part.

Table 2

Process of IPA performed

No	Phase	Description of the process
1	Coding	Read transcript for first time and make notes in left hand margin which include statements/phrases/words that are concerned with the phenomenon. Read for second time and make notes in right hand margin of which include the researcher's reflections/questions.
2	Cluster	Group statements into the themes they invoke and write one general statement to capture the essence of the theme.
3	Organise	Write list of themes, with extracts, for each transcript, Repeat for each transcript. Check fit with supervisors.
4	Integrate/cluster	Identify themes shared by all participants, themes shared by some but not all participants, and themes which disconfirm/contrast shared themes – tabulate.
5	Superordinate themes	Group themes under shared headings and count how many participants contributed to each – tabulate. Identify/list unique themes to acknowledge those invoked by only one participant
6	Summary statement	Produce final statement describing the phenomenon

2.35 Criteria for evaluating quality

Guidelines were employed in the analysis to ensure the quality of the data collected and interpretations made (Barker & Pistrang, 2005). During interviews, efforts were made to reflect responses back to ensure that the meaning intended by the participant had been captured; a research diary was kept of thoughts and reflections on each interview; and memos were kept which reflected the development of categories. Quality control took the form of following guidance for publishing qualitative research studies (Elliot, Fischer and Pennie, 1999). Two clinical psychologists with experience of qualitative research with adults with intellectual disabilities and IPA and content analyses carried out credibility checks by reviewing the themes

generated from a selection of transcripts and the master themes for the content analysis and IPA, to ensure that different researchers interpreted the texts in a similar way.

2.4 Researcher's perspective

My perspective is based on working with adults with intellectual disabilities as inpatients and in community settings, prior to and during training in clinical psychology. My initial beliefs about adults with intellectual disabilities and pain were based on observations whilst at work that pain is often overlooked in this group, particularly in those with challenging behaviours, those who self-injure and those who cannot communicate verbally. Despite the communication difficulties and challenges that were expected during interviews, I felt strongly that adults with intellectual disabilities have something worthwhile to say and their experiences of pain are important to listen to and understand.

2.5 Participants

Adults with intellectual disabilities

Inclusion criteria were: over 18 years; can communicate verbally; needs support from other people to access healthcare; can give informed consent to taking part in the study. The fifteen participants consisted of eight men and seven women (age range 21-61, mean 44.93, SD 12.96), as noted, two of these took part in pilot interviews. Ten were White British; two spoke English as a second language. Details of the participants are set out in Table 3 (ages have been broadened so that participants are less identifiable).

Caregivers

Inclusion criteria were: over 18 years; a paid, voluntary or family caregiver of a person/people with intellectual disabilities. The eleven participants consisted of four men and seven women (age range 29-67, mean 46.64, SD 15.31). A further two participants took part in pilots but their data was not used for analysis as they were no longer working with people with intellectual disabilities. Details of the participants are set out in Table 4.

Table 3
Participant characteristics – Adults with intellectual disabilities

Name	Gender	Age	Ethnicity	Accommodation	Current health problems/treatments*
SU1	Male	Mid 50s	White British	Residential	Diabetes, catheter for water retention, retinal dysfunctional degenerative disorder, asthma, high blood pressure & cholesterol
SU2	Male	Early 20s	White British	Family home	Migraines
SU3	Female	Late 30s	White British	Supported living	Arthritis, menstrual pains
SU4	Female	Late 50s	White British	Residential	Epilepsy, bunions, chronic back pain
SU5	Male	Early 60s	White British	Residential	Rheumatism, asthma, aortic aneurysm, high blood pressure, high cholesterol, prostate problems, Menière's Disease
SU6	Female	Mid 40s	White British	Supported living	Arthritis, diabetes, epilepsy
SU7	Male	Late 40s	White British	Residential	Obesity, gout, hernia, foot ulcers, migraines, two heart attacks
SU8	Female	Early 60s	White British	Nursing home	Arthritis, osteoporosis, renal failure, diabetes, peripheral neuropathy, hypertension, aortic stenosis
SU9	Female	Late 40s	White British	Supported living	Menstrual pains
SU10	Male	Early 20s	Black British	Family home	Migraines
SU11	Male	Late 40s	Black African/ Caribbean	Residential	Leg cramps
SU12	Male	Early 30s	White British	Supported living	Diabetes, obesity
SU13	Female	Mid 50s	White British	Supported living	Self-catheter, bunions
SU14	Female	Early 50s	Asian	Supported living	Arthritis, eczema, epilepsy, menstrual pains
SU15	Female	Early 30s	Asian	Family home	Menstrual pains, earache and sore throat

*Health conditions disclosed by interviewees. Where appropriate, and with the participant's permission, the technical terminology was gained by asking their caregiver.

Table 4
Participant characteristics – Caregivers

Name	Gender	Age	Ethnicity	Role
FC1*	Male	34	White European	Paid staff working with verbal adults, 1 year
FC2*	Female	32	White European	Paid staff working with verbal adults, 2 years
FC3*	Male	31	White British	Paid staff working with verbal and non-verbal adults, 18 months
FC4*	Male	29	Black African/Caribbean	Paid staff working with verbal adults, 8 years
FC5*	Female	33	White European	Paid staff working with verbal adults, 5.4 years
IC6 & 7	Male & Female	61 & 67	White British	Parent of daughter with ID who communicates non-verbally
IC8	Female	53	South Asian	Parent of sons with ID who communicate verbally
IC9	Female	67	Black African/Caribbean	Parent of daughter with ID who communicates non-verbally
IC10	Female	47	Black African/Caribbean	Parent of daughter with ID who communicates non-verbally
IC11	Female	59	Black African/Caribbean	Parent of daughter with ID who communicates non-verbally

Key

* Caregivers of participants with intellectual disabilities (ID) who were interviewed

3. Results

This study aimed to increase our understanding of pain in adults with intellectual disabilities by investigating their experiences and understanding of pain, and caregivers' responses. The results are presented in two parts to reflect this dual focus. In the extracts presented (Q) represents clarifying questions asked by the interviewer. Participants are denoted as (SU) service user; (FC) formal caregiver; and (IC) informal caregiver, together with the participant number. The number of times a word was used by participants is denoted as 'n' within the text.

3.1 What are the phenomenological experiences of adults with intellectual disabilities regarding pain?

The particular experiences of pain that were recalled by participants, and who expressed being in pain at the time of the interview, are listed in Appendix G1.

3.1.1 What are adults with intellectual disabilities' experiences of being in pain?

This section provides descriptions of the pain experienced by participants, as well as how others responded to their pains. Table 5 shows the categories and subcategories identified along with the number of participants who discussed these.

Descriptions of pain

A variety of words were used to express experiences of pain, including traditional language (e.g. "painful", "hurting", n=84), colloquial language ("gyp", "trouble", n=4), words indicating the sensation experienced (e.g. "ache", "sharp", n=54), visible signs (e.g. "swollen", n=7) and general words related to illness (e.g. "not well", n=4).

Table 5

Categories, subcategories and number of participants who referred to them (N=15)

Categories	Subcategories	n
Descriptions of pain	Descriptive words for pain	15
	Location	15
	Negative connotations	11
	Severity	11
	Imagery	6
Responses to pain	Medical investigations/treatments	15
	Emotional impact	14
	Tell/do not tell others	13
	Impaired mobility/activities	10
	Alternative pain management	10
	Response of others	10
	Hiding pain	4
	Questioning genuineness	3

Eleven participants used strong words to convey their very negative experiences (e.g. “*agony*”, “*unbearable*”, n=96).

“My leg pain’s murder. It doesn’t go away. It’s non-stop hurting me.” (SU8)

Rich imagery was used by six participants to describe their pains, including images of the pain as hot (“*like molten ash*”, “*a furnace*”, “*a fire*”); and the type of damage inflicted (“*sharp like an electric shock*”, “*a knife sticking in*”); and violent imagery of pain (e.g. “*like an assault*”, “*like being kicked by a horse*”). Other imagery included “*having your head pinched in*” and “*my brain starting to burst*”.

Participants remembered pain experienced in a variety of locations including their head/face (n=50), limbs (n=45), and torso (n=82), as well as internal structures (spine, arteries, bowels, heart, n=4) and other less clearly defined areas (e.g. “*on the side*”, n=3). When asked to rate the severity of specific instances of pain on a

pictorial and numerical pain scale (see Appendix D3), 11 participants rated their pains. Four participants were not asked as the researcher felt that the scale would have been difficult to use given their limited verbal communication skills. Participants tended to use the upper half of the scale, with 32 ratings between 6 and 10 and only four ratings between 0 and 5.

Responses to pain

Responses to pain included a range of investigations and treatments, most commonly painkillers or other medication (n=34), visits to health services (n=18), investigations (n=7), and treatment for injury (n=4). Pain self-management strategies described included relaxation/rest/sleep and trying to take one's mind off the pain (n=23), and strategies applied to the body such as gargling salt water, and hot baths (n=17). There were a few descriptions of trying to "*let it (the pain) go*", and "*going around as usual*" (n=3). While some strategies were described as helpful (n=8) or sometimes helpful (n=15) in alleviating pain, most were judged as of little or no help, most commonly medication (n=24).

Other responses were telling people when in pain (n=19), most commonly staff and less so family members, a friend, boss or just "*someone*", not telling others (n=4) or only sometimes (n=3). Some participants described keeping their pain to themselves for a variety of reasons, including feeling frightened of how others would react, not wanting to waste others' time, and not feeling that it is worth letting others know (n=6).

"No 'cos what's the point if you don't get nowhere." (SU8)

Four participants described actively “*hiding*” their pain from other people.

“I try not to show my pain so my manager won’t know I’m injured.” (SU10)

When discussing pain, participants mostly described the emotional impact of pain as feeling “*low*” (e.g. “*sad*”, “*miserable*”, n=54) and “*angry*” (e.g. “*irritable*”, “*annoyed*”, n=40). There was also an awareness of the impact of pain on quality of life, including reduced mobility (e.g. “*could not get up*”, n=23) and physical restrictions to daily activities (e.g. “*could not bathe*”, n=19), with sleep difficulties the most common negative effect of pain.

Participants described a wide range of responses by others when they were in pain including thinking that others were upset, worried, and angry. One woman described how others appeared to find it funny and laugh, and several disbelieved her complaints of pain, which made her feel “*terrible*” (SU4). One man worried about hurting others when he was in pain as he sometimes shouted (SU1). Other responses included people asking questions (e.g. “*why are you limping?*” n=4), offering advice (e.g. “*take it easy*”, n=11) and taking action (e.g. got nurse/doctor, n=6).

Some described others as taking no notice (n=7) or refusing their requests for help (e.g. “*for painkillers*”, n=5). One woman complained that support staff had their favourites whom they helped with their pains, but that she was left to “*sit and suffer*” (SU8). One man described having injured both his arms in a fall and not receiving a prompt diagnosis.

“I went up the doctors and they didn’t think there was nothing wrong with it. I think it took, yeah err, about two or three weeks until, my mum only realised ‘cos my arm started going blue. And they weren’t gonna give me one of them scans. Actually had to pester them to get my scan. (Q) I think it took about a week and a half, two weeks for me to get someone to actually say I’ve broken my arms.” (SU2)

Three participants questioned the genuineness of pain in the pictures, and had an awareness that others may question the genuineness of their pains, or even disbelieve them.

“They think it’s all in my head. They think I’m making it up.” (SU8)

One woman questioned if the people in the pictures were *“putting it on”* (SU4). This woman later described how she perceived staff not to believe her pains. One man mentioned many times what he perceived to be the level of ‘genuineness’ of the people in the pictures, describing one as *“no fake”*, another as *“real genuine”* and another as *“not convincing”* (SU1). He observed that others cannot tell what genuine pain is and what is not. There seemed a link between those particular participants who described that other people could/did do nothing for pain, and deciding not to tell others or hide their own pains.

Summary

When describing pain some participants used negative meanings and strong imagery, but there was generally little detail in descriptions. When using a pain scale to indicate severity of pain experienced, participants tended to use the upper half of the scale indicating more severe pain. Participants typically described the impact of pain as an emotional one and causing reduced mobility and activity. Participants varied

in whether they would report their pains to others, which may have related to past responses, including receiving help and feeling ignored or disbelieved.

3.12 What meanings do adults with intellectual disabilities give to pain?

This section describes the wide range of perceived causes of pain and how participants said they coped with pain. Table 6 shows the categories and subcategories developed along with the number of participants who discussed these.

Table 6

Categories, subcategories and number of participants who referred to them

Categories	Subcategories	n
Cause of pain	Health problem	11
	Injury	9
	Bodily function	9
	Physical environment/miscellaneous	8
	Damage to body	6
	Movement	6
	Weather	4
	Emotions	4
	Unknown	3
	Just happens	2
Coping with pain	Control	4
	Helplessness	4
	Not bothered	2

Cause of pain

Participants were aware of a wide range of potential causes for pain, and cited health problems (n=123) and injuries (n=82) as the most likely cause of their pain. They also cited pain resulting from everyday bodily functions such as menstruation (n=23), movement (n=15), the weather (n=13), the physical environment (n=7), and

general ‘damage/hurt’ or the body not mending (n=12). Only one man described what pain was to him.

“Your mind telling your body that you’re hurt.” (SU10)

In general participants portrayed a mixture of reasons for different pains, so after providing a cause of their pain such as illness, some would then go on to attribute the same pain to something else like the weather. Some of these causes bore little relation to established causes of pain.

When asked about the causes of pain, a few participants spoke of life events and their emotional impact in a manner similar to talking about physical pain. These included stories of bereavement and *“having the mickey taken”* which resulted in pain (n=14). Emotions were cited as possible causes of physical pain by some, including worry, stress and anger (n=23). Two participants were unable to state any causes of pain, saying *“it just happens.”*

Coping with pain

Three participants alluded to feeling helpless when experiencing pain.

“I just have to sit and wait until it’s time for my painkillers.” (SU8)

This participant said *“learning to live”* with pain was what she had been told to do, although she felt that no one should have to live with pain. In contrast to this, four

participants alluded to trying to control their pain; something they could do themselves.

“Just chuck it in the bin. I have to do myself.” (SU7)

One man described the person depicted as having a headache as *“losing control”* whilst in pain, which needed help from others.

“Help him have things controlled.” (SU11)

The idea that one can get rid of pain was mentioned by only two participants. Two participants said they were not *“bothered”* by their pains, for example one man explained how his love of playing football meant that he had to play in pain.

“Pain is not a big deal.” (SU10)

Summary

Participants provided a variety of reasons why pain occurs but sometimes multiple causes were given for one pain or they bore no relation to established causes of pain. Two participants could not state any causes of pain. Whilst participants said little about how they coped to pain, some alluded to feeling helpless, losing control and not feeling bothered by pain.

3.13 How do adults with intellectual disabilities understand pain?

This section details participants' discussion of concepts regarding pain and their beliefs about pain observed in other people. Table 7 shows the categories and subcategories developed along with the number of participants who discussed these.

Table 7
Categories, subcategories and number of participants referring to them

Categories	Subcategories	n
Concepts regarding pain	Reduction	15
	Induction	7
	The urgency of pain	5
	Prevention	3
	Wait and see	2
Pain in other people	Signs	15
	Recognisable by others	12
	Recognition of similar pain	7

Concepts regarding pain

The concepts surrounding pain were discussed by few participants. Methods to prevent injury and pain were volunteered by three participants.

“If you go on the cooker keep away from the gas. (Q) You’ll get burnt otherwise.” (SU1)

“Just look around where you’re going.” (SU7)

Several participants described activities or circumstances that can make pain worse (n=17) including physical movement/exercise (n=10), and hot temperatures (n=2).

Methods of pain reduction were discussed by all participants, with a variety of strategies provided. Letting medical professionals know, or other people such as

family members, was the commonest response (n=135). This was followed by obtaining medical treatment such as painkillers (n=78), visiting a medical setting (n=54), and having an investigation or operation (n=44). Alternative strategies for pain relief were also suggested including relaxing and sleep (n=30), doing something directly to the body (e.g. applying a cold pack, n=15) and changing one's diet or drinking more water (n=8).

Five participants believed that one should seek urgent treatment for *any* pain.

"I'd demand to be seen straight away, 'cos the longer you leave it, the worse it can get." (SU1)

Only two participants suggested waiting and going to the doctor or hospital if the pain got worse.

"Take it easy or if it's worse go and see a doctor." (SU10)

Pain in other people

When discussing pain in others, as depicted in the pictures shown during interviews, some recognised the pain in the pictures as being the same pain they had experienced (n=13). Seven participants indicated that the pains represented in the people in the pictures were the same as pain they had experienced and/or expressed empathy for the person.

"I know exactly what he's going through." (SU1)

All participants described a variety of signs that to them indicated pain in other people. These included facial signs (e.g. clenched teeth, n=53), position of limbs (e.g. feet up, n=15), and actions (e.g. “*holding*” various body parts, n=40). Also taken as signs indicating pain were vocalisations (e.g. “*screaming*”, n=10) and symptoms that participants inferred were present in pictures of people in pain (e.g. “*looking pale*”, “*dizzy*”, n=7).

Twelve participants felt others would also be able to see that the people in the pictures were in pain, most commonly family members, but also medical staff, support staff and whoever is around. Two participants thought that others would not know the person in the picture was in pain.

Summary

Few participants discussed the concepts surrounding pain and five participants overestimated the need to seek urgent treatment for *any* pain. Participants were able to relate to pictures of others in pain, and could recognise a wide range of pain signs present. There seemed a general belief that others can tell when someone is in pain, which may have implications for the efforts they go to in reporting pain to others.

3.2 How do caregivers respond to possible or actual pain in adults with intellectual disabilities?

Do they recognise pain?

What is the emotional impact of these processes and events?

A total of 24 themes and six superordinate themes were identified for the caregiver data. Table 8 details the themes and superordinate themes and which participants contributed to these themes. The themes provide the focus for the analytic commentary that follows.

Table 8

A list of themes and superordinate themes

Super-ordinate themes	Themes	Number of participants who endorsed theme
Suffering in silence	Not recognising pain	9
	Not voicing pain	9
	Hiding pain	4
Trying to understand	Verbal complaints of pain	7
	Communicating pain non-verbally	6
	Communicating with the person about pain	10
	Monitoring changes	9
	Noticing signs of pain	9
	Being a detective	6
	The individuality of pain expression	6
Knowledge and skills needed to recognise and manage pain	Staff support, knowledge and consistency	3
	Awareness of risks of missing pain	2
	Training and education	2
	Confidence in recognising pain	8
Perceptions of the pain experience	Questioning the genuineness of pain	3
	Coping, pain threshold and tolerance	10
Trying to reduce pain	Understandings of pain	6
	Mediating with healthcare professionals	10
	Involving parents	3
	Thinking/talking for the person	4
	Trying medical and alternative solutions	10
Emotional impact of pain	Comfort	3
	Impact on the 'sufferer'	3
	Impact on the caregiver	7

Super-ordinate theme 1: Suffering in silence

This super-ordinate theme contains three themes describing experiences of pain being invisible due to caregivers not recognising when the person with an intellectual disability was in pain, the persons not having voiced or complained about pain that they were in, and stories of caregivers perceiving the person hiding their pain.

Theme 1: Not recognising pain

Nine caregivers described incidents when the person they were caring for had a health problem which likely caused significant pain, but the caregiver had not recognised this. They also described general difficulties in recognising pain in people with intellectual disabilities.

“He had a hernia. And you couldn’t tell whether he was in pain or not...you never knew quite how much pain he was in.” (FC3)

“You can’t see that they are in pain, you know what I mean. Everything is alright.” (FC4)

Theme 2: Not voicing pain

Nine caregivers reported numerous occasions when the person they cared for had not complained when in pain. They often talked about this in a way that suggested they expected that people should complain about pain and found it surprising when they did not.

“In fact he actually his shoulder was dislocated or whatever it was and he wouldn’t complain about it.” (FC1)

“Because people think that he’s able to express himself, that he can come and tell us. And that’s what I get, well what he should tell us. But he doesn’t.” (IC8)

Some caregivers discussed reasons why pain may not be voiced, including being afraid of doctors, not knowing how to explain the pain, and not having learnt appropriate language to describe pain.

“He won’t go to the doctor and describe that to them. Because they’ll ask him more questions and he can’t answer them. I think that’s the issue.” (IC8)

“With X he registers pains, but I’m not quite sure he knows how to explain it.” (FC3)

Theme 3: Hiding pain

Incidents when the person had tried to deliberately hide their pain from other people were described by three caregivers.

“If she’s feeling rough she will still carry on eating. She wants to eat the food and she wants to have everything as normal....And she hates being sick. She will swallow it as such... She doesn’t like to show any form of pain.” (IC6)

“They can hide pain. X can hide pain. Even when they have pain they don’t want you to know... (Q) Yeah she can hide, because as I said, I mentioned the other day when you were there that she had this boil in her armpit, and she hide it so long and I didn’t even know...(Q) Coz she didn’t want me to see.” (IC10)

One informal caregiver talked about how pains are not hidden but that the person has difficulty expressing their feelings, and other people misinterpret this as ‘hiding pain’.

“I don’t think they are hiding pains. They are misjudging the person. And I think that hiding pain is just to say that they are in pain, but this is something

different that is happening to them, and they cannot express their feelings to tell their parents.” (IC9)

Super-ordinate theme 2: Trying to understand the complaint

This super-ordinate theme contains seven themes which illustrate the process on the part of both the caregiver and the person with an intellectual disability of figuring out what the complaint was about, and seemed to be the product of a caring relationship and close knowledge of the person. The process led to a shared understanding that something was not right.

Theme 1: Verbal complaints of pain

Verbal complaints of pain by the person with an intellectual disability were described by seven caregivers, which some alluded to as a positive thing.

“I think this is the main point, actually, because she can explain, she can...so it’s good because she can explain.” (FC2)

Theme 2: Communicating pain non-verbally

There were descriptions of the person with intellectual disabilities trying to communicate or indicate through non-verbal means that they were in pain by six caregivers. These communications included gesture and touch:

“When the foot is hurting her probably she will feel discomfort with the shoes, she’ll remove the shoes and maybe want another pair. ... So these are all signs telling me “I am not comfortable in that shoe, I don’t want it, and that means it’s hurting me”.” (IC9)

“Sometimes what I find is that when I touch her somewhere that is painful then she pushes me up. She takes my hands off from her.” (IC10)

They also described people as behaving in challenging ways when in pain, such as being uncooperative and confrontational, screaming, and using aggressive language and behaviour. Alternative descriptions of becoming withdrawn and quiet were also provided as a communication of pain. Some caregivers described self-injurious behaviours as a way to communicate pain or distress:

“And the other one bites himself so if he’s stressed that’s how he’ll communicate it, his hand.” (FC1)

Theme 3: Communicating with the person about pain

All but one caregiver described how they would communicate verbally with the person about possible pain, typically asking them directly if they were in pain, including individuals who did not communicate verbally. The reciprocal nature of communicating about possible pain in whatever way possible was emphasised by many, resulting in a shared understanding of the problem.

“And when anyone asks her, she can communicate very well and she’d understand, you know. And she will answer “Are you okay?” and say “Yeah I’m alright.” “What’s wrong?” You know there is a problem so usually give them their space for a little bit and then go later on and say”... He ends up saying things what we both know.” (FC4)

“But then you have to ask her, is that a big toe, small toe? Or whatever. Then with (this) time, she said it’s the small toe. If you ask her, she’ll say.” (IC11)

Only one caregiver described how asking people whether they were in pain was not something he really thought about, and felt it was not acceptable in a social setting to do so.

“Maybe ask him, but then again because people are just not in the habit of asking people...I guess you’re not really focussed on people having pain. And just simply you could ask people “Are you feeling ok, do you have any pain in your body?” It’s just not socially acceptable. Maybe in this environment you should, but we don’t.” (FC1)

Theme 4: Monitoring changes

Nine caregivers described monitoring the person for signs of pain or illness, particularly in terms of observing changes in the person’s usual behaviour, mood, body posture, eating and drinking. This seemed a fundamental tool to notice when something was not right with the individual, where pain could be considered as an option.

“If it’s someone whose normally happy sometimes their mood can change. They can either become completely ecstatic or they can be quiet, and they can be a bit more confrontational, not want to do things.” (FC3)

“I think for anybody on shift in this business, to be honest, you’ve got to be vigilant at all time, you know... 'Cos little behaviours--you’ll miss something out, you know...(Q) Yeah. As I said, behaviour. The meals, especially, the meals – are they eating their meals well? Drinking? Their urine and faeces?...You just have to look out.....” (FC4)

“It’s for us really, to watch.. to take note of any change within her character. That’s when we know that we’ve got to do something...It’s monitoring all the time.” (IC7)

Theme 5: Noticing signs of pain

Nine caregivers discussed signs indicating pain, including obvious signs such as bruising and limping, to signs which could indicate different things such as crying. Some also described more subtle signs that required knowledge of the person’s usual facial expressions to detect differences. The theme implies that vigilance was needed to notice signs of possible pain.

“In some cases you know the way they would sit down or touch a particular part of their body, or hold it.” (FC1)

“When she’s crying then I know that she’s very, very in pain.” (IC10)

Theme 6: Being a detective

Six caregivers portrayed a process of guesswork in order to figure out if the person they were caring for was in pain or not, and sometimes the location and cause of the pain. In this process a lot of effort and careful thought was clearly involved. Two caregivers used the word ‘detective’ to describe the process.

“So then I become like the detective and you find out.” (IC8)

“You just have to guess and guess. Sometimes it will take a few days then you will just get it, “oooooh maybe it was this”. You don’t get it all, it’s very very difficult. It’s very very very difficult. You don’t... It’s not easy. It’s not easy at all.” (IC10)

Theme 7: The individuality of pain expression

Six caregivers talked about how pain expression was quite different amongst different people, suggesting that knowing the person was the key to recognising their individual ways of expressing pain.

“So you’ve got to know him very very well to know all that kind of screaming... So you’ve got to know if he’s in pain, or he’s just in himself, you know. So you’ve got to know. And I think that’s the key to be honest. Working with them for a while, getting to know them, you know. As individuals. That’s the key.” (FC4)

Super-ordinate theme 3: Knowledge and skills needed to recognise and manage pain

This super-ordinate theme contains five themes describing what appeared to help caregivers in identifying and managing pain amongst those they cared for. It also included attitudes some held surrounding the genuineness of pain and their confidence in accurately identifying pain.

Theme 1: Staff support, knowledge and consistency

Three formal caregivers described support and sharing of knowledge as helpful, as well as consistency amongst the staff team so that important changes in people could be observed.

“So I think the key word on that is consistency within staff. You need to keep the staff. If you have new people coming in and out, they will miss things.”
(FC4)

“Bring the manager also for advice and guidance and discuss with colleagues as well on the floor that day and just see everyone's opinion and then we agree on one thing.” (FC4)

Theme 2: Awareness of risks of missing pain

Two formal caregivers highlighted the risk of not spotting pain present in people they cared for.

“It's too much of a risk, especially with someone who can't talk, who can't communicate, you know.” (FC4)

Theme 3: Training and education

One formal caregiver thought that training about pain would be helpful, but had not received this. Another formal caregiver said training had helped them to better understand signs of pain in someone she cared for.

“They give us some training about X, you know, your colleagues, because they knew X better than I was.” (FC5)

Theme 4: Confidence in recognising pain

There were expressions of confidence and certainty in being able to recognise pain in the people they cared for, or expressions of lacking confidence and certainty from eight caregivers.

“Because you can, you can tell, when she’s really in pain. Yes, you can tell when she’s really in pain but when she’s not.” (FC2)

“It’s difficult in a way because you’ve if you don’t know someone’s in pain you tend to almost ignore it. Not intentionally but you don’t know.” (FC3)

Theme 5: Questioning the genuineness of pain

Three formal caregivers described questioning whether the person was in genuinely in pain or was only complaining of pain in order to achieve a particular goal, such as avoiding an activity, or gaining attention. They described trying to distinguish between what they perceived as genuine and exaggerated or even made up pain.

“She would build it up to a situation where she would want to get her objective, which is staying at the hospital, and exaggerating, not exaggerating, but actually acting out in front of the doctor which she would

not otherwise in front of the carers, because she would want to convey that she is in extreme agonising pain.” (FC1)

“X, she complains all the time. Because, one reason, because she like attention... When she need attention, she want someone to care about her.” (FC2)

Super-ordinate theme 4: Perceptions of the pain experience

This super-ordinate theme contains two themes describing caregivers appearing to put themselves in the position of the person in pain. This included thinking about how they themselves might cope with pain, their tolerance to pain and their general understanding of the pain experience.

Theme 1: Coping, pain threshold and tolerance

There was a general feeling among caregivers that the people they cared for seemed to be able to tolerate more pain than other people and that their pain thresholds were higher.

“He just doesn’t seem to be bothered about it, because it’s probably something he’s already become tolerant of or has mentally adapted to it.” (FC1)

“He’s got quite high threshold, I’ll be honest with you, very, like me. Again, that’s something we’ve built up, because if we didn’t, we wouldn’t have been able to live our life the way we have. So, you know, he’s got very high pain threshold.” (IC8)

Theme 2: Understandings of pain

Six caregivers considered how the people they cared for may understand pain. Caregivers had mixed views about whether people had an understanding of the concept of the causes of pain and pain relief.

“Some of them would not understand the concept of cause and effect, and some of them would, not, might be impaired to understand how one thing leads to another.” (FC1)

“I don't know if it's because we are more conscious, you know, of pain than them. Oh, and you thinking about, ‘oh what happens after?’ I think there are a lot of things, you consider a lot of things where it's probably, but they don't.” (FC4)

Super-ordinate theme 5: Trying to reduce pain

This super-ordinate theme contains five themes describing what solutions caregivers recruited to attempt to alleviate the persons' pain. These included practical strategies such as mediating with healthcare professionals and trying medical and alternative solutions. This also included methods to search for a solution by involving the persons' parents and thinking/talking for the individual.

Theme 1: Mediating with healthcare professionals

All caregivers talked about involving health care professionals and mediating during interactions in order to try and obtain appropriate pain treatment. Some described this as a positive experience.

“See as long as you know you can get on that phone to somebody and they will listen. This happens, we, we are very fortunate c'cos you hear of people that..they phone up and they like..don't really wanna know. That is when we'd have a problem.” (IC6)

“He's the, the surgeries that we go to really is very good indeed, you know. Just no problem at all with them. Anything that you do want they will sort it out.” (IC7)

The majority of caregivers expressed dissatisfaction with health care provided, including due to poor communication with people with intellectual disabilities, not asking about pain, and not looking holistically at the individual.

“You know what’s the problem with doctors and consultants, is they just deal with one item. They don’t look at them as a whole person. And especially for people with learning disabilities, because they only want to go to that one appointment, and get it over with. Because that’s hard enough for them. But it’s like people don’t see that, they want them to go to this one, to that one, and they can’t handle it. And they don’t understand that.” (IC8).

“But if the doctor never asks if you are in pain, and you cannot tell – you can tell the doctor you are in pain, but if somebody’s not talking, and the doctor is doing his professional work, he probably should say ‘are you in pain?’. But that was never asked of her, or me to say - ‘Yes I think she’s in pain’, or ‘no I don’t think she’s in pain.’” (IC9)

Caregivers talked about being reliant on health care professionals to judge and recognise pain.

“But generally you’re reliant on the fact that you’ve hopefully got a good GP who can spot things.” (FC3)

“Usually we don’t leave; we don’t leave it to us to make the judgement. We leave it to the professionals, the doctors, so we just ring up the doctors, if the surgery is open; if not, we ring NHS Direct for advice and guidance.” (FC4)

Theme 2: Involving parents

Three caregivers talked about involving the individual’s parents to help identify pain and mediate with health care professionals.

“But then with X his family come as well, one of his family members comes as well so they can help express it for him as well.” (FC3)

“His mum is really involved in his day-to-day life. So we give her a ring, just tell her the situation, you know, she'll help us as well. 'Cos she knows him better than any of us.” (FC4)

Theme 3: Thinking/talking for the person

Four caregivers described trying to think and/or talk for the person in order to identify pain or consider treatment options. Talking for the person was seen as sometimes useful, but sometimes unhelpful when mediating with health care professionals as the caregiver did not feel able to speak accurately on behalf of the individual.

“They (doctors) can't rely on my answer, can they?” (IC6)

“I know she's not like me who'll be able to talk, and I have to talk for her. So her voice is my voice. And my voice is her voice. That's how I look at me and her, we are married together.” (IC9)

Theme 4: Trying medical and alternative solutions

All caregivers talked about repeatedly searching for and trialling pain relief solutions, including over-the-counter painkillers, strategies such as hot water bottles and alternative therapies.

“Maybe it's just something really easy and simple, just give the paracetamol or something. Sometimes, I think, for X, if you give even, a sweet or something, and you tell her it's a help, she, I think, her pain will stop.” (FC2)

“But if it's not very bad I just give her little hot drinks, rub her with Vicks or I've got some oil, and rub her feet and keep her warm and if I see the sign of a cold coming before I give her two paracetamol and the cold disappear.” (IC9)

Theme 5: Comfort

Three caregivers explained how they cared for the person when in pain by providing comfort, verbal reassurance and/or trying to be supportive.

“Just sit down, comfort her... Give her comfort. Make her feel assured and I’m there for her.” (IC9)

Super-ordinate theme 6: Emotional impact of pain

This super-ordinate theme contains two themes describing the emotional impact on the caregiver of seeing someone in pain as well as on the person in pain.

Theme 1: Impact on the ‘sufferer’

Three caregivers perceived the impact on the ‘sufferer’ as limiting what the person can do in different ways, and causing emotional distress:

“He gets a bit claustrophobic.” (FC3)

“When he’s having an asthma attack, and he’s in pain and everything, because it all plays up.... He says that to me, he said, “Mum, I wish, you know, that I was dead”.” (IC8)

Theme 2: Impact on the caregiver

Seven caregivers described a variety of emotions when discussing the emotional impact of dealing with pain. These were most commonly worry/concern about the person and distress as a result of seeing the person in pain:

“That’s when I get really, really down when I see her tears.” (IC10)

Caregivers described feeling sympathy, experiencing vicarious pains, or that it was painful to see the person/people in pain. These feelings often seemed accompanied by statements indicating feeling helpless to stop the pain:

“When she’s in pain, I am in pain... And the same way when she has pain, if she’s having the pain, I’m having the pain too...My pain is not the abdominal pain she have, but it’s another kind of pain which I am feeling that ‘what can I do for her, what can I do to release her from the pain she’s in? Is there anything more I can do?’” (IC9)

Caregivers also talked about feeling stressed and frightened when someone they care for may be or is in pain:

“At first it was a bit of a shock ‘cos obviously never seen her like that before.” (FC3)

One caregiver described feeling frustration when dealing with health care professionals who she felt did not understand the pain her son was in. Another caregiver described feeling angry that she had not discovered earlier that her daughter was in pain.

“And I was so so very very angry that I couldn’t find out.” (IC10)

Finally two formal caregivers said they felt no emotional impact of seeing the person in pain.

“I’m sort of used to dealing with it, so you pretty much react by taking action, taking the person to GP or the A&E, whatever the case. Was it distressful? Was it? No just probably my job I guess, I’m used to.” (FC1)

“I’m not really worried... But, because I know them, so it’s not really for, it’s not really bothering.” (FC2)

Summary

Caregivers talked about pain not being recognised in the people they cared for, partly due to them not perceiving it but also due to the person with an intellectual disability not communicating or actively ‘hiding’ pains. Caregivers described actively working with the individual to try to understand the complaint, which was potentially pain, although it was often unclear at first. A detailed knowledge of the person helped this process of recognising and managing pain. Caregivers had clear ideas about how they felt adults with intellectual disabilities coped with pain, and in general believed that their tolerance for pain was high. Caregivers acted in a number of ways to try and reduce pain. Some described the negative emotional impact that seeing the person in pain had on them.

4. Discussion

The study aimed to explore the phenomenological experiences of pain in adults with intellectual disabilities, and their caregivers’ responses to possible or actual pain. Overall, the findings highlight the difficulties of people with intellectual disabilities in understanding and communicating pain, and demonstrate caregivers’ variable knowledge and skills in recognising and managing pain.

4.1 Overview

Adults with intellectual disabilities

The present results demonstrate that discussions around pain are challenging for adults with intellectual disabilities, requiring the use of complex language and abstract thinking, and because pain is hard for anyone to express verbally (Scarry, 1994). There was huge variability among participants in their ability to discuss pain. While participants in other studies have been recorded as able to describe some pain sensations (Rodgers, 2001) and to provide extreme negative descriptions of pain (Stone Pearn, 2002; Willis, Wishart & Muir, 2011), this may be insufficiently detailed for diagnosis (Beacroft & Dodd, 2010a) and for adults with intellectual disabilities to explain the wider meaning of pain in their lives (Stone Pearn, 2002).

Tools to enhance discussions, including body maps and pain scales (Appendix D3), were available in this study but participants were able to describe pain locations clearly and reasonably specifically without body maps. When using a faces scale for pain severity, participants tended to use the upper half of the scale, not consistent with the suggestion that participants pick the face they like (Defrin, Lotan, & Pick, 2006). Such scales have not been validated for use in this population, and the only study of test-retest reliability of a faces pain scale produced a correlation of 0.66, over a first and second presentation during the course of one interview (Ruddick & Oliver, 2005). The utility of such scales is unclear, with conceptual problems such as ‘no pain’ being represented as a smiling face, which has multiple non-pain meanings. Reluctance by participants to use the lower end of a pain ruler scale (not a face scale) has been observed (Bromley, Emerson & Caine, 1998).

It seems that adults with intellectual disabilities in the current study tended to rate pains as more severe than would be typically expected. This may be the result of several possibilities: the expectations of others are not synchronised with the reality of pain for those experiencing and rating their pain, so consequently others underestimate the severity of pain experienced, and/or participants used the rating scales in more extreme ways than usual which may demonstrate a certain degree of what has been described as “catastrophising” in research with non-disabled populations (e.g. Sullivan, Tripp & Santor, 2000); alternatively higher ratings may reflect a combination of the sensory experience and emotional aspects of pain (i.e. anxiety and distress).

Rating pain as more severe than typically expected may have significant implications for others' responses. Caregivers may discount pain if they judge the person to be exaggerating pain, and consequently sufficient pain relief may not be provided. In the current study some individuals with intellectual disabilities were not believed when they reported pain. Reasons for caregiver's disbelief may include a conviction that pain thresholds are higher in adults with intellectual disabilities, and/or a belief that they are exaggerating pain in order to meet a goal such as gaining “attention” or comfort, or escaping demands.

In previous unpublished research, the volunteering or recollection of pain types in adults with intellectual disabilities has been demonstrated as best conducted using verbal inquiry, and secondly with pictures (Stone Pearn, 2002). In the present study, participants related well to pictures of others in pain and, perhaps unsurprisingly, it was observed that they related best to pictures of pains they had

themselves experienced. Participants demonstrated skills in noting signs of pain, inferring pain intensity, imagining how the person felt, and drawing comparisons with their own pain experiences. The use of images appeared a promising area to support individuals to communicate their pain experience.

Participants held various beliefs about the causes of pain, sometimes bearing no relation to established causes of pain. Several participants who had chronic health conditions appeared to have poor knowledge of the particular pains associated with their condition(s). Education about chronic and episodic pain could help communication with others who may provide pain relief. This supports Beacroft and Dodd's (2010b) conclusion that adults with intellectual disabilities require further education about their bodies.

Participants' repertoire of coping strategies for pain did not appear to include administration of their medication or asking for painkillers, with only one man reporting self-medication. A minority of participants described being refused requests for help such as painkillers or mobility aids. Research has shown that caregivers tend to underestimate health problems by comparison with medical examinations (Beange, McElduff & Baker, 1995; Wilson & Haire, 1990), and it is not unusual to find pain relief not provided when needed (Beacroft & Dodd, 2010a; Willis et al., 2011). Pain relief controlled by caregivers requires their recognition of pain as sufficiently severe to warrant analgesia, but this depends in part on caregivers' own beliefs. Alternative strategies to try to reduce pain were described by most participants, as in a Japanese study (Chou, Lu, Wang, Lan & Lin, 2008) but not a UK one (Beacroft & Dodd, 2010a). Pain management in this population is

seriously under-researched, with only one case study on Cognitive Behavioural Therapy for chronic pain management in a woman with intellectual disabilities (Lewis, Bell & Gillander, 1998). Exclusion of people with intellectual disabilities from trials of all pain treatments means that very little is known about best practices for pain relief or reduction in this population, and it is evident that some pain needs are not met.

In the current study, the most common emotional impact of pain described by participants with intellectual disabilities was anger and low mood, like previous findings (Beacroft & Dodd, 2010a). Anger has been reported as a prominent feature of chronic pain in the general population (e.g. Fernandez & Turk, 1995), but this has not been investigated previously amongst adults with intellectual disabilities. Given the high levels of challenging behaviours in this population, and the frequent finding that being in pain is linked to challenging behaviour (Carr, Smith, Giacini, Whelan & Pancari, 2003; Carr & Owen-DeSchryver, 2007; Donovan, 2002; Kerr, Cunningham & Wilkinson, 2006; Walsh, 2010) the link between feelings of anger, pain and challenging behaviour needs exploration.

Most participants in the current study believed that people such as caregivers can tell when someone is in pain; this may have implications for the efforts they go to in trying to communicate their pain to others, although this was not explored in the present study. A worrying finding was participants' description of hiding their pains from caregivers. This may not be unusual, considering that self-report of pain is likely to be affected by anticipation of consequences from others and social desirability (Craig et al., 2001). Thirty percent of people with chronic pain in the

general population felt that no-one believed how much pain they had, and 20-25% that others were unsympathetic (Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006). It is unclear if these beliefs are held by adults with intellectual disabilities, but based on what they described, they may be concerned with caregivers' emotional reactions: becoming annoyed or upset, antagonistic, or labelling the individual as a 'complainer'. Another possibility is that hiding pains or not reporting them is a learned behaviour, via a process of operant conditioning, after repeated experience of feeling disbelieved or ignored by caregivers, of being stopped from an activity they enjoy when they reported pain, and of pain relief not working. Previous research has found that adults with intellectual disabilities did not want to bother others about their pains (Beacroft & Dodd, 2010a). Possessing verbal skills cannot be taken as an indication that pain will be communicated; there may be feelings of helplessness fostered by an institutionally-created dependence on others (Donovan, 2002).

Caregivers

The current study demonstrates that despite caregivers' efforts, they find recognising and treating pain a complex and often ambiguous situation. Caregivers struggled when initially unsure if pain was the problem and what the cause was; there seemed to be an art to detecting pain by looking for clues and guessing, as found in previous research (Clarke, Thompson, Buchanan, & Combes, 2007). Caregivers sensitively used their skills and knowledge in attempts to understand and manage pain, but they were sometimes unaware of pain. This is unsurprising given that pain is not always recognised in this population (Clarke et al., 2007; Defrin, Lotan & Pick, 2006; Hinder & Perry, 2000; Jancar & Speller, 1994), in part due to caregivers' misconceptions that these individuals have higher pain thresholds and tolerance for

pain (Beacroft & Dodd, 2010b; Kerr et al., 2006). A worrying finding was the minority of caregivers who questioned the genuineness of self-reported pain and thought the individuals were reporting pain to get “attention”, in line with findings from another study with staff (Walsh et al., 2011). This suggests that some caregivers rely on their own judgement of how severe pain is, which has implications for their likelihood to offer support

The Social Communication Model of Pain provides a model of how the person in pain and caregiver interact (e.g. Hadjistavropoulos & Craig, 2004; Prkachin & Craig, 1995; Craig, 2009). In this model, care can be provided only if the caregiver can decode the expressive behaviour of the person in pain and provide care. In the model, the caregiver needs to decode the other’s behaviour, a task that is admittedly more complex in adults with intellectual disabilities as their expressions of pain may be more subtle (Beacroft & Dodd, 2010b). Caregivers in the current study demonstrated awareness of conventional and nonconventional ways in which individuals expressed pain, awareness demonstrated in previous research (Donovan, 2002), and were aware that challenging behaviour can communicate pain. However, pain signs can be misinterpreted or missed (e.g. Biersdorff, 1994) and the signs caregivers look for, such as mood change, can indicate problems other than pain. Caregivers’ descriptions of individuals hiding pain could be due to poor information about signs of pain, for example, keeping still can indicate severe pain but can also be mistaken for being pain-free.

Perhaps understandably, the present study found that caregivers appeared to rely on the person to verbally express pain, with an implicit assumption that anyone

who could communicate verbally would report pain. Research with older adults shows that people refrain from reporting pain for various reasons, including thinking that others do not want to hear (Kumar & Allcock, 2008). One parent observed that people do not talk about pain around people with intellectual disabilities, raising the question of how people with intellectual disabilities acquire appropriate language for pain. Consideration should be given to whether people with intellectual disabilities are 'shielded' from discussions of pain, perhaps as they are not perceived as cognitively competent to participate, or due to concerns that talking about pain may cause upset.

Assessment of pain by caregivers reflects their attentional and attitudinal characteristics, background and training, and setting (Hadjistravropoulos et al., 2004). For example, someone who has a close personal relationship with the person being assessed might provide a different assessment than a health professional (Hadjistravropoulos, Craig & Fuchs-Lacelle, 2004). The present study found that the relationship between service user and caregiver was hugely important to identifying pain, supporting findings on children with intellectual disabilities which demonstrate the importance on knowing the person well to notice subtle changes in behaviour and/or appearance that indicate pain (Carter, MacArthur & Cunliffe, 2002). Caregivers put themselves in the position of the person and think for them, suggesting a sense of connection, as found in nurses (Donovan, 2002).

Some caregivers in the present study described the negative emotional impact of seeing the person in pain, most commonly worry and empathy, as was found with other parents of adults with intellectual disabilities (Clarke et al., 2007). Anecdotally,

informal caregivers in the study who disclosed that they experienced regular pain themselves appeared more inclined to monitor their son or daughter for pain.

In the current study, just three caregivers talked about emotional distress experienced by the individual in pain. Previous research suggests that caregivers underestimate the emotional distress, particularly depression, caused by chronic pain in adults with intellectual disabilities (Walsh et al., 2011), probably because they do not accurately recognise symptoms of emotional distress and may attribute them to pain or to intellectual disability (Reiss, Levitan & Szysko, 1982). New and significant health and/or emotional problems may then be missed.

The study highlights dissatisfaction with the management of pain by health care services. Caregivers in the current study described poor communication between patient and doctor, and not being asked about pain. Research in this area generally concludes that caregivers often find their opinions and assessment ignored by health care professionals although they often have the best understanding and information about the person (DoH, 2008). However, a recent study found that 83.3% of caregivers were 'satisfied/very satisfied' with the doctors' treatment of chronic pain in the person with an intellectual disability that they were caring for (Walsh, Morrison & McGuire, 2011). Involving parents in pain assessment is very important (Clarke & Thompson, 2007), as recognised by the 47.3% of health care professionals who were found in one study to base their assessment of pain in someone with an intellectual disability on what caregivers tell them (Walsh et al., 2011). However, in the present study, caregivers appeared unaware of their vital role and of pain recognition and monitoring tools, with only one staff member saying

their team used health passports. This reflects other research with staff showing that only small numbers use pain tools like the Disability Distress Assessment Tool (DisDAT) (Regnard et al., 2007) and Abbey Pain Scale (Mackey & Dodd, 2011). In the current study, only one staff member said he would like training on the topic; research has shown a general lack of awareness of training about pain for those working with this population (Twycross, 2000).

4.2 Strengths and limitations

The present study has a number of strengths and limitations. In terms of strengths, this study was a positive step towards involving adults with intellectual disabilities in an under-researched area and getting their voices heard. The qualitative approach allowed for exploration of a little researched area, particularly by accessing the experiences of people with intellectual disabilities who cannot communicate verbally by asking their caregivers. The study was not limited to discussion of a particular type of pain, like many previous studies, nor to participants with chronic pain or health conditions.

Involving both formal and informal caregivers meant that different perspectives could be heard and different issues rose, depending on their relationship with the person/people they were caring for. The study allowed for conclusions to be drawn from both people with intellectual disabilities and caregivers, to link these and suggest clinical implications.

In terms of limitations, the recruitment and sample of participants may be a limiting factor as participants were all volunteers introducing unknown biases. In

aiming for depth rather than breadth, the overall number of participants was relatively small. Five out of six parents who volunteered to take part had sons/daughters who communicated with a few words and/or gestures, so the issues they discussed may not have reflected those of caregivers for more verbally able individuals. Interview content inevitably influences what is discussed and what is missed, and the use of pain pictures may have narrowed the scope of pains discussed, particularly where acquiescence and social desirability apply. Whilst every effort made to ensure participants understood the topic by checking out at start of interview the word to describe pain that they were most familiar with, it is important to be mindful of the potential limited utility of the concept of pain for some participants. Pain may mean different things to different people, and it is possible that judgements and knowledge of pain were influenced by social and cultural values and beliefs which were not identified in the study. The introduction of a pain scale may not have been useful to participants as they tended to use the upper half of the scale, regardless of the type of pain being described.

Consideration should be given to the qualitative methods of analysis chosen. A common criticism of all qualitative approaches is that a text always involves multiple meanings and there is always some degree of interpretation when approaching a text (Grandheim & Lundman, 2004). Therefore measures for achieving trustworthiness are important, including credibility checks to see how well the data and processes of analysis address the intended focus.

With regards to IPA, it is considered a lengthy and detailed process that requires a significant amount of time and commitment from the researcher (Shaw,

2001). Some researchers have highlighted the lack of advice available about how much researchers should interact with participants or start to interpret data within the interview, which has led to variation in the information provided (Brocki & Wearden, 2006). Another common concern is that IPA is unable to provide casual explanations of particular phenomenon (Willig, 2008). However this is typically not the focus of qualitative research, and the present study was exploratory rather than looking for causal relationships. Using IPA allows the researcher to unveil phenomena that might not be expected or previously identified by other researchers (Shaw, 2001). Data collection is 'data-driven' and therefore allows for flexibility and more open-mindedness from the researcher, who plays an active role in making sense of the data and must constantly monitor themselves so as to not bias the data by interpreting more than participants have provided (Shaw, 2001).

With regards to content analysis, it is considered by some to be a simplistic technique that does not lend itself to detailed statistical analysis, while others consider that it is not sufficiently qualitative in nature (Morgan, 1993). The method has been suggested to be as difficult as the researcher determines it to be (Neundorf, 2002), with some researchers simply counting words but not interpreting them. Two issues that can affect the utility of content analysis have been identified as faulty definitions of categories, and non-mutually exclusive and exhaustive categories (Stemler, 2001). Therefore the classification procedure should be consistent to increase reliability of analysis. Despite criticism content analysis has an established position in health psychology, and it can be used to develop an understanding of the meaning of communication (Cavanagh, 1997) and to identify critical processes (Lederman, 1991).

The study is potentially limited by no testimonial validity checks where participants indicate that the interpretation accurately described their experience, which was not completed due to time constraints. With hindsight the topic could have used triangulation of adults with intellectual disabilities, caregivers and health care professionals.

4.3 Scientific and clinical implications

The present findings indicate several clinical implications for practice. Recognition and management of pain in adults with intellectual disabilities requires specialist knowledge and a change in attitudes and practice. Common pains experienced by people in this population have been helpfully identified (Bottos & Chambers, 2006) as has the major problem of reflux oesophagitis in this population (Tracy & Wallace, 2001). However, there is always the potential for pain and health problems to be overlooked in the presence of an intellectual disability, as with mental health problems through diagnostic overshadowing by the intellectual disability (Reiss et al., 1982). One particular area where this is particularly relevant is in people with intellectual disabilities who self-injure or behave in challenging ways for which pain may not be considered as a contributory factor, despite several studies showing a connection.

Conversing with adults with intellectual disabilities about their pains is a real challenge; health care staff need to think carefully about the questions they ask, and perhaps a checklist of questions could be created to help with the task of describing pain. Educational groups have shown that adults with intellectual disabilities can

increase their awareness of symptomatology, learn what to do when in pain, and understand pain and the appropriate action to take (Webb & Stanton, 2008), and that they can make use of communication aid cards to inform others of pain (Dodd & Brunker 1999). Education may build familiarity and confidence in using pain language so that more detailed descriptions may be given. Perhaps this could be attempted in more creative ways, such as working with individuals who experience chronic pain to provide narratives of the causes of their pain and previous successes in managing it. Alternative methods could be attempted with individuals who cannot communicate verbally. Such a technique used in one case report of asking the person to draw what the pains feel like, to gain insight into their pain experience (Baldrige & Andrasik, 2010).

Mainstream health care services are required by law to make adjustments for people with intellectual disabilities so that they have a positive experience of health care, but this study highlights that some caregivers are still dissatisfied with the service. Health care staff need to make full use of caregivers' knowledge and observations, and caregivers need to feel able to assert the value of their understanding in health settings. Caregivers can use pain diaries and other tools supplied to patients to help assess the problem, particularly if it is episodic. Caregivers should also be given information about current initiatives, including Health Action Plans, NHS passports (which include a section to describe how the person communicates pain), pain profiles, and the DisDAT (Regnard et al., 2007) which allows monitoring of typical versus pain states. Training could be provided for health care professionals and caregivers in using the Health Status Measure with individuals who can communicate verbally (Ruddick & Oliver, 2005, or the

observation based Non-Communicating Adult Pain Checklist (NCAPC) which has demonstrated high internal consistency (Lotan et al., 2009), high interrater reliability (Lotan, Moe-Nilssen, Ljunggren & Strand, 2009) and can be used in clinical settings (Lotan, Moe-Nilssen, Ljunggren & Strand, 2010).

Caregivers should be provided with information about the limited number of tools which can support conversations around pain such as pictorial communication cards; body maps; pain rating scales/ruler; the 'Feeling Poorly' pack (Dodd & Brunker, 1999); and a simple booklet about pain for adults with intellectual disabilities (Beacroft & Dodd, 2010a). Many of these are freely available. Currently there are two sources of information training for formal caregivers: a practical guide for health workers working with people with intellectual disabilities with chronic pain (McManus & McGuire, 2010) based on cognitive behavioural principles of pain management; and staff training materials on awareness of pain and its communication (Beacroft & Dodd, 2010c). Results suggest that training helped change staff attitudes and improve pain recognition (Mackey & Dodd, 2011).

Future research could involve investigating whether the observed tendency in the current study by some participants with intellectual disabilities to catastrophise pain is more widespread, and whether this is due to language or cognitive limitations, or is in any way linked to the current finding that some caregivers underestimate or disbelieve pain altogether.

Other research arising from the current study could involve focusing on the issue of pain communication, by interviewing adults with intellectual disabilities

about the reasons for deciding not to report pain or hiding pain. Interviews could also be carried out with parents regarding the types of conversations about pain that they have with their son/daughter with intellectual disabilities.

Very little is known about best practices for pain relief or reduction in this population, with the current study finding that some pain needs were not met. A survey or interviews asking caregivers about the use of pain relief would provide information regarding this topic.

Finally, the link between anger, pain and challenging behaviour needs further research. One way of investigating this would be for Learning Disability services, when receiving referrals for challenging behavioural/self injury, to review the patient's medical history and assess for pain routinely.

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Part 3: Critical Appraisal

1. Introduction

In the critical appraisal I discuss the research topic and reflect on how my own understanding of pain in adults with intellectual disabilities has changed. I then address methodological and conceptual issues that arose whilst conducting the research and evaluate the limitations of the research. Finally I highlight implications for clinical practice, whilst offering suggestions for future research directions. These reflections are based on notes kept in a research diary and reflections made at the conclusion of the research.

2. Research topic

My interest in studying pain in adults with intellectual disabilities came from experiences as an Assistant and Trainee Clinical Psychologist seeing adults with intellectual disabilities with health problems and challenging behaviour. I felt intuitively that these behaviours were possibly a way of trying to communicate that something was wrong. During an initial internet search I became aware of the scale of the issue of health problems amongst this population, with many studies, policies and guidelines. Potential supervisors were approached and an initial literature search into pain in this population was conducted, which revealed that more research was needed in the area of pain in this population.

The research process to some extent modified my view of pain in this population, as over time it became clear that, despite all these health policies and guidelines, pain was still a significant problem, which is not effectively recognised and managed. The reasons for this appear more complex than initially anticipated, and I now understand that improvements will require not only increased knowledge

for adults with intellectual disabilities, but a change in attitudes and behaviour from caregivers and health care professionals.

During data collection I was surprised at the sheer variability of participants, from those who were very conscious of pain and sometimes dealing with significant pains on a daily basis, to those who seemed unaware of and unconcerned about pain. I saw the difficulties that arose between adults with intellectual disabilities and their caregivers in interactions about pain. These included me being placed in the position of mediator between two participants with intellectual disabilities and their respective caregivers when they reported current pains to me (with an ingrown toenail and a bunion), but had not told their caregivers. When we agreed to report this to staff together, I saw first-hand staff's surprise at missing these painful conditions. It is possible that my asking directly about pain served as a prompt to reporting it. One particular incident I recall was when interviewing a woman who staff identified as someone they perceived to be "making up" her pains. During our interview she talked about staff disbelieving her reports of pain and although, with her permission, I fed back her report of pain to staff, I felt very uneasy that she could be in pain and not receiving sufficient pain relief. I also felt a strong sense of unease when caregivers described people with intellectual disabilities as "attention seekers" and as "making up pain".

3. Methodological issues

No real barriers to progress were present as discussions around the research design were thorough during initial supervision sessions, ethical approval was granted on the first attempt, potential recruitment and other problems had been well considered,

enough time had been set aside for the analysis, and timescales set for the project were adhered to. A focus was developed with both supervisors and roles for each supervisor were clarified, with an external Clinical Psychologist approached for support with IPA. Having worked within the Community Team where participants were recruited was likely a real help during recruitment as staff were familiar with me.

Responses to recruitment came quickly, which perhaps reflected participants' interest and keenness to share their experiences. I also gained the impression from what informal caregivers said that they had been waiting for someone to talk about this topic, which was of real concern to them. Several participants with intellectual disabilities fed back that it was nice to meet someone new, and to have an opportunity to speak about an issue which they had not spoken to others about. Some alluded to it being a good opportunity to "get things off their chest" and help them recognise that others experience pain.

I was most impressed by how willing service users and caregivers were to participate in my research and how welcome they made me feel in their homes. Participants likely felt more at ease in their own homes and I imagine it was more convenient for them. However, at times this presented practical difficulties, including noise and interruptions from other people, telephone/door bells ringing, and time constraints. Several tapes had to be stopped whilst participants attended to other demands. Privacy was also an issue, as participants living in group or family homes felt their bedroom was their private space, so three interviews were conducted

there. Lone worker policy was adhered to and a basic risk assessment carried out prior to all meetings.

I was mindful that people with intellectual disabilities lack social networks and that those networks are made up more of professionals than friends (Pockney, 2006). I explained my role as a researcher to try and minimise the possibility of being misconstrued as a friend, but I nonetheless felt moved when participants' social isolation was quite apparent.

The recruitment and sample of participants may have implications for the extent to which generalisations can be drawn from the study. There was no way of reliably estimating the response rate, as it was unclear exactly how many staff offered how many invitations. While the participants brought a diverse range of issues and participants with intellectual disabilities were of differing ability levels, there may have been characteristics present in the sample of self-selecting volunteers who took part which introduced biases. Volunteers for health research are more frequently women, with higher education and cognitive test scores and less likely to use the health service when compared to non-volunteers (e.g. Ganguli, Lytle, Reynolds & Dodge, 1998), or they may have a particular investment in the topic which may result in biases such as higher presence of pain in adults with intellectual disabilities and/or caregivers feeling that pain was present in the people they cared for. Caregivers were recruited from a group so were already playing a more active role in their community, implying other characteristics which could introduce bias. Two informal caregivers disclosed that they suffered with health problems resulting in daily pain, which may have meant they were more sensitive to pain in their

children. Participants were recruited from a particular geographical area and no budget was available for interpreters or translating invitations and information sheets into different languages, which prevented some people from taking part. The overall number of participants was relatively small: however, the study was not designed to be applied to adults with intellectual disabilities as a uniform group as it aimed to look at individual experiences.

Prior to the interviews I worried that my links to the community team may have discouraged participants from feeling able to be truthful about their experiences of health care services in the context of managing their client's pain. But participants seemed comfortable to discuss both the positive and negative aspects of their experiences.

Interviews were open-ended in order for people to tell stories in a familiar way, but they did naturally guide people to focus on particular areas, so other important areas and ideas may have been missed. At times people's speech or accent was hard to understand and although I would rephrase to check, I may have missed parts that were unclear or not followed up where I could have done. As suggested in literature on interviewing participants with intellectual disabilities, when talking about abstract concepts I tried to make these more concrete by using direct questions (Booth & Booth, 1996).

During interviews prompts and tools were intended to foster participation and elicit information, however, the use of specific pain pictures may have had an impact on the data by narrowing the scope of pains talked about; particularly where acquiescence is more likely (e.g. Heal & Sigelman, 1995). Whilst other pictorial cues

were also presented to prompt consideration of other pains, recollection is dependent on autobiographical memory which is generally poor among people with cognitive impairments. The introduction of a pain scale, admittedly without detailed practise tasks, may have been unhelpful by causing confusion, although it was piloted with two participants who had no difficulty responding to it.

Probably the most difficult element was trying to maintain a work life balance, although this was made easier as motivation was maintained on a topic which I found interesting and important. Interviews were mostly conducted after work as the evenings were generally more convenient for participants, which certainly tested my energy and concentration levels.

Regarding the analysis, with IPA the categories were generated from the data through a cyclical process, with new emerging categories tested against earlier data to guard against selectivity in the use of data, therefore enhancing the credibility of the findings. I kept a journal, writing notes to remind me how the categories and links between them had emerged. With the content analysis, categories were built up to describe and quantify the phenomena. A text always involves multiple meanings and there is always some degree of subjectivity when approaching a text and interpreting the data (Graneheim & Lundman, 2004), but the use of authentic citations increased the trustworthiness of the data and showed how the categories were developed. Appendix F demonstrates how transcripts were annotated, and the link between the data and resulting categories for IPA and content analysis are demonstrated in Appendices G2 and G3 respectively. My preconceptions about the

topic and my own background will have shaped both the process of the study and analysis, and so my position as researcher was clearly stated from the outset.

With hindsight, the topic could have been studied using a triangulation of adults with intellectual disabilities, caregivers, and health care professionals, as their paths cross so often in health care services. However, in the context of this being doctoral research, the number of participants in each group would have been very small.

4. Implications

The study has several implications for clinical practice. Conversing with adults with intellectual disabilities about their pains is a real challenge, even for those who are used to working with this population; this indicates that health care staff need to ask clear and uncomplicated questions, with specific prompts to gain more detail. Rephrasing questions or changing the sequence of words can help check that the person understands (Tuffrey-Wijne & McEnhill, 2008). A checklist of questions for health care staff might help with the task of describing pain.

The study highlights that some caregivers are dissatisfied with the service received by the people they care for. Health care staff need to pay more attention to the knowledge and observations that caregivers have to offer about the person. Caregivers can use pain diaries to record the dates/time of pain they observe in the person they care for, which may help GPs when the person in front of them is not in pain at the time, but is experiencing an ongoing problem. Caregivers should also be given information about current initiatives and available training in pain recognition and management. Caregivers should be provided with information about access to

the limited number of resources which can support conversations around pain. Recognition and management of pain in adults with intellectual disabilities requires not only knowledge but a conscious change in attitudes and practice.

5. Future directions

Future research should investigate the prevalence of relatively common painful conditions in this population, such as arthritis, fibromyalgia, and osteoporosis, as well as the prevalence of acute pains experienced, such as those in medical procedures, headaches, migraines and stomach pains. The scope of the issue of pain in this population would then be clearer. Also very little is known about best practices for pain relief or reduction in this population, with the current study finding that some pain needs were not met. Investigations into prescription and non-prescription analgesic use have been carried out with other groups, such as the general adult population (eg. Paulose-Ram et al., 2003), which could be adapted for use with adults with intellectual disabilities.

A focus on the issue of pain communication would also provide useful information, potentially through interviewing adults with intellectual disabilities about the reasons for deciding not to report pain or to hide pain from people in their social network, or interviews/focus groups with parents about if and how they talk to their son/daughter with intellectual disabilities about pain. Research could investigate whether pain is dealt with in the context of discussions with adults with intellectual disabilities regarding their health, and if, and how, adults with intellectual disabilities are enabled to monitor their own health and health worries.

Future research could involve investigating whether the tendency by some participants with intellectual disabilities in the current study to possibly catastrophise pain is common amongst other adults with intellectual disabilities, and whether this is due to language or cognitive limitations, or is in any way linked to the current finding that some caregivers underestimate or disbelieve pain altogether.

Finally, the link between anger, pain and challenging behaviour needs further research. One way of investigating this would be for learning disability services, when receiving referrals regarding concerns about challenging behavioural/self injury, to consider whether carrying out a medical review and appropriate pain assessment affects the intervention and outcome. Such a study could also look at whether pain relief, if appropriate, was given, and if this had an effect on challenging behaviour; in older adults with dementia giving low dose, long-acting opioids to those with ‘agitated’ behaviour can be effective, based on the assumption that pain may be causing those behaviours (Manfredi et al., 2003).

6. Conclusions

Overall this critical appraisal process has helped me to think reflectively about the research process, consider what worked well and what could have been done differently. I found the research process a highly enjoyable one, which not only helped to expand my knowledge and ideas of the topic, but will have an impact on my own clinical practice with adults with intellectual disabilities and their caregivers in the future.

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Appendices

- Appendix A Ethical approval
A1 Letter of ethical approval
A2 Letter of R&D approval
- Appendix B Recruitment materials for participants with intellectual disabilities
B1 Participant invitation
B2 Participant information sheet
B3 Participant consent form
- Appendix C Recruitment materials for caregiver participant
C1 Participant invitation
C2 Participant information sheet
C3 Participant consent form
- Appendix D Interview materials for participants with intellectual disabilities
D1 Illustrations of common pain complaints
D2 Semi-structured interview schedule
D3 Tools available for use in interviews (1. a pain scale 2. a body map 3. body part illustrations 4. emotion faces)
- Appendix E Semi-structured interview schedule for caregiver participants
- Appendix F Annotated transcript samples
F1 An adult with intellectual disabilities
F2 An informal caregiver
- Appendix G Analysis
G1 Table of self reported pains from participants with intellectual disabilities

- G2 Table of quotations for IPA analysis of interviews with caregivers
- G3 Coding tables for content analysis of interviews with participants with intellectual disabilities

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Dear Ms Findlay

Study Title: Meaning and experience of pain amongst people with learning disabilities and carers
REC reference number: 10/H0701/30
Protocol number: 1

Thank you for your letter of 21 April 2010, responding to the Committee's request for further information on the above research and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair on the 29th March 2010 who confirmed that all points raised by the Committee had been complied with.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0701/30

Please quote this number on all correspondence

Yours sincerely

Janet Carter

Rev. Dr. Joyce Smith pp
Chair

Email: janet.carter@redbridge-pct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"
SL- AR2 for other studies]

Copy to: Ms Amanda Williams
[R&D office for NHS care organisation at lead site]

R&D Approval Letter

Newham Primary Care Trust
Petra Nittel
Clinical Governance Manager
Governance Department
Unit 10, Warehouse K
2 Western Gateway
London
E16 1DR
Tel: 020 70596747
Fax: 020 70596753
Email: petra.nittel@newhampct.nhs.uk

Date: 12.5.2010

Ms. Laura Findlay
Research Department of Clinical,
Educational & Health Psychology
UCL, Gower Street
London WC1E 6BT

Dear Ms Findlay

Re: Experience of pain amongst people with learning disabilities

Thank you for providing NHS Newham with information concerning the above study. I am happy to confirm that the Trust has approved the study.

Approval is provided on the basis that you agree to adhere to the Trust's requirements for Research Governance including:

- As Chief Investigator/Principal Investigator for this study you have familiarised yourself with, and accept the responsibilities commensurate with this position, as outlined in the Research Governance Framework (<http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/fs/en>).
- Compliance with all policies and procedures of the Trust which relate to research, and with all relevant requirements of the Research Governance Framework.
- Co-operating with the Trust R&D Office's regular monitoring and auditing of all approved research projects, including complying with requests for written progress reports.
- Informing the Trust R&D Office *immediately* of any adverse events or complaints, from participants recruited from within this Trust, which occurs in relation to this study.

Chair: Marie Gabriel
Chief Executive: Melanie Walker
Professional Executive Committee Interim (PEC) Chair: Dr Ashwin Shah

- Co-operating with the Sponsor organisation in managing, monitoring and reporting of the research study.
- Acknowledge the Trust in any final report and sending a copy of any reports or publications which result from this study to the Trust R&D Office.

Failure to abide by the above requirements may result in the withdrawal of the Trust's approval for this research.

Please contact Karamjeet Chana on 02070596757 or karamjeet.chana@newhampct.nhs.uk if you need further assistance.

Yours sincerely



Petra Nittel
Clinical Governance Manager

Cc Sandra Baum (Head of learning disabilities psychology services)
Unit 7&8 Stratford Office Village
8 Romford Road E15 4EA

Chair: Marie Gabriel
Chief Executive: Melanie Walker
Professional Executive Committee Interim (PEC) Chair: Dr Ashwin Shah

Appendix B

Recruitment materials for participants with intellectual disabilities

B1 Participant invitation

B2 Participant information sheet

B3 Participant consent form

Service user version



My name is Laura Findlay. I am doing research as part of my educational qualification. I want to talk to people with learning disabilities and carers.



I would like to understand what pain is like for people with learning disabilities. We will meet twice – first to talk about the research, and then again to talk about times you have been in pain. We will also look at some pictures of people and talk about them.



We can meet at your home, your day centre or college.

We will talk for 30 minutes to one hour.

[Please read my information sheet.](#)

Do you have any questions? Would you like to take part?

- Please tell the person who gave you this sheet to call me
- OR call me (or ask someone you know to call) on



07880 610 449

or at Newham Community Team for People with Learning Disabilities on

0208 250 500

If am not there leave a message with your name and telephone number. I will call you back when I can.

Thank you for reading this!

Laura Findlay
Trainee Clinical Psychologist

Service user version



INFORMATION SHEET

I am doing research for an educational qualification. The East London 3 Research Ethics Committee said this research is okay to do. This sheet will tell you about my research. It will help you decide if you want to take part.



Sometimes we feel pain or hurt (like when we are unwell or in an accident). I want to understand what pain is like for people with learning disabilities.



I want to hear what you have to say about pain because you are a person with a learning disability. I would like to meet you to talk about this. This might help other people with learning disabilities in the future.

You can choose to take part. It is up to you. The service you get from the Learning Disability team will not change either way.

If you agree to take part:

- We will meet twice at your home, day centre or college.
- First we will meet to talk about the research.
- We will then meet a second time to talk for 30 minutes to one hour about times you have been in pain.
- We will also look at some pictures of people and talk about them.



If you would like more information please contact Laura Findlay, Trainee Clinical Psychologist, University College London. Tel: 07880 610 449 Email: laura.findlay@ucl.ac.uk

If you have any complaints or concerns you can contact Patient Advice and Liaison Service (PALS). Tel: 0207 363 9292 Email: pals@newhamhealth.nhs.uk Address: PALS, Newham General Hospital, Glen Road, Plaistow, E13 8SL

I will tape record what we say. I will destroy the tape after I have listened to it.



Talking about pain can sometimes upset us. If you feel upset we will stop. You don't have to answer all the questions. You can stop taking part at any time.



The things you tell me will be kept confidential (private) and in a safe place.



I will write a report about what you and other people talked about. It will not have your name on it. You can have a copy of the report.



Do you have any questions? Would you like to take part?

- **Please tell the person who gave you this sheet and they will call me**
- **OR call me (or ask someone you know to call) on**

07880 610 449

or at Newham Community Team for People with Learning Disabilities on

0208 250 7500



If am not there leave a message with your name and telephone number. I will call you back when I can.



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If you have any complaints or concerns you can contact Patient Advice and Liaison Service (PALS). Tel: 0207 363 9292 Email: pals@newhamhealth.nhs.uk Address: PALS, Newham General Hospital, Glen Road, Plaistow, E13 8SL



Service user version



CONSENT FORM

Title: Meaning and experience of pain amongst people with learning disabilities and carers

Researcher: Laura Findlay

Before we start you need to agree to take part, to give 'consent'

Please tick box

I have read the research information sheet

I understand what it says

I have asked all the questions I want

I understand my information will be kept

- confidential (private)
- in a safe place
- my tape will be destroyed

I agree to take part in the research

I understand it is OK to stop taking part at any time

Name _____ Researcher _____

Date _____ Date _____

Signature _____ Signature _____

If you would like more information please contact Laura Findlay, Trainee Clinical Psychologist, University College London. Tel: 07880 610 449 Email: laura.findlay@ucl.ac.uk

If you have any complaints or concerns you can contact Patient Advice and Liaison Service (PALS). Tel: 0207 363 9292 Email: pals@newhamhealth.nhs.uk Address: PALS, Newham General Hospital, Glen Road, Plaistow, E13 8SL

Version 2 – April 2010

Appendix C

Recruitment materials for caregiver participants

C1 Participant invitation

C2 Participant information sheet

C3 Participant consent form



Carer version

INVITATION LETTER

I am a Trainee Clinical Psychologist working at Newham Community Team for People with Learning Disabilities, and carrying out research as part of my educational qualification. I want to find out more about the experiences of people with learning disabilities who have been in pain. I want to hear from people with learning disabilities and carers.

I am looking to talk to individuals with learning disabilities who have experienced some kind of pain (such as from illness, accident or self-injury). I am also looking to talk to carers of people with learning disabilities to hear about their experiences of caring for people who may have been in pain.

An interview with you will be arranged at a convenient time and venue (usually your place of work or home) and will take about 1 hour. What you tell me will be confidential.

As a thank you for taking part you will be entered into a prize draw for £30 worth of vouchers for a supermarket of your choice.

Please find an information sheet about the research enclosed.

If you decide to take part I will arrange a time to meet with you. If you are not sure about taking part I will be very happy to talk to you more about the project and answer your questions, before you decide.

Please let me know if you are willing to take part or would like to know more by calling me on 07880 610 449 or emailing me at laura.findlay@ucl.ac.uk (if I am not available please leave a message stating your name and contact details).

Thank you for your time.

Yours sincerely

Laura Findlay
Trainee Clinical Psychologist
University College London

Version 2 – April 2010



Carer version

INFORMATION SHEET

Title: Meaning and experience of pain amongst people with learning disabilities and carers

You are invited to take part in this project. I am a Trainee Clinical Psychologist completing some research as part of my educational qualification. I am looking to talk to people with learning disabilities and carers about their experiences of physical pain. I want to understand what pain is like for people with learning disabilities. This research has been reviewed and approved by East London 3 Research Ethics Committee.

These are some of the questions you may have before you decide if you want to take part:

What is the aim of this project?

Carers and clinicians often report that they struggle to know whether someone with a learning disability is in pain. This pain might be caused through illness, accident or self-injury. There has been limited research into this. I hope that we can get a better understanding of how people with learning disabilities understand, communicate and manage pain.

Why have I been invited?

You have been invited because you care for a person/people with learning disabilities, perhaps as a paid employee, family member or volunteer. I am interested in what you have to say about caring for people with learning disabilities who may have been or have been in pain. Your help to increase our understanding of pain in people with learning disabilities will be very useful in trying to improve clinical care and ultimately the quality of life in people with learning disabilities.

Do I have to take part?

No, it is entirely up to you. If you decide to take part you are still free to stop taking part at any time. A decision not to take part or to withdraw from the study will not affect the support you or people you care for receive from services in the future.

What will happen if I agree to take part?

You can call me and we will arrange a time to meet. The interview would last about an hour and would take place at your place of work or home. I will tell you more about the project and will ask you to sign a consent form which says you are happy to take part and for our discussion to be tape recorded. Tapes will be destroyed once the interviews have been transcribed. I will ask some brief questions about you. I will then ask you about your experiences of caring for people with learning disabilities who (may) have been in physical pain. As a thank you for taking part you will be entered into a prize draw for £30 worth of shopping vouchers.

Will what I say be shared with anyone else?

Nobody else will listen to the tape recording of your interview. I will write some of the things you say in reports, but I will not say who said these things. Your name will not appear anywhere. The tape recording of the interview will be stored in a secure place and will later be destroyed.

What are the potential benefits and risks of taking part?

It is difficult to recognise and treat pain in people with learning disabilities, and research tells us little about this area. This is a huge concern for carers and service providers. You may be able to help others and make things better for people with learning disabilities and carers in the future. Some of the things I will ask you might be upsetting. You do not have to answer questions if you do not want to. If you do become upset I will try to help you there and then. If we both decide that you need a little more support after the interview I will arrange this.

Will I be informed of the outcome of the project?

Yes, when the research is completed you will be sent a brief report saying what was found.

Thank you for reading this. Please ask any questions you may have.

If you would like more information please contact Laura Findlay, Trainee Clinical Psychologist, University College London. Tel: 07880 610 449 Email: laura.findlay@ucl.ac.uk

If you have any complaints or concerns you can contact Patient Advice and Liaison Service (PALS). Tel: 0207 363 9292 Email: pals@newhamhealth.nhs.uk Address: PALS, Newham General Hospital, Glen Road, Plaistow, E13 8SL

Version 2 – April 2010



Carer version

CONSENT FORM

Title: Meaning and experience of pain amongst people with learning disabilities and carers

Researcher: Laura Findlay

Please tick box

- 1. I have read the information sheet. I have had the chance to consider the information, ask questions and have had these answered.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
- 3. I understand that what I say will be tape recorded. What I say may be shared with other responsible individuals, but they will not be able to identify me. Tapes will be destroyed once the interviews have been transcribed.
- 4. I agree to take part in the above study.

Name: _____ Date: _____ Signature: _____

Researcher: _____ Date: _____ Signature: _____

When completed pass 1 copy to participant and 1 to kept for researcher file

If you would like more information please contact Laura Findlay, Trainee Clinical Psychologist, University College London. Tel: 07880 610 449 Email: laura.findlay@ucl.ac.uk

If you have any complaints or concerns you can contact Patient Advice and Liaison Service (PALS). Tel: 0207 363 9292 Email: pals@newhamhealth.nhs.uk Address: PALS, Newham General Hospital, Glen Road, Plaistow, E13 8SL

Version 2 – April 2010

Appendix D

Interview materials for participants with intellectual disabilities

D1 Illustrations of common pain complaints

D2 Semi-structured interview schedule

D3 Tools available for use in interviews

(1. a pain scale 2. a body map 3. body part illustrations 4. emotion faces)

Interview schedule

Service user version

- | | |
|---|------------------------------|
| ➤ | Questions |
| ○ | Prompt follow
up question |

1. Check the person is still happy to consent and gain informed consent.
2. "I am interested in what people think about pain. I'm really interested in hearing what you have to say. This interview will last from 30 minutes to one hour. If you want to finish or take a break just tell me. If you don't want to answer a questions just tell me. I am going to tape record what we say. Does that all sound okay? Do you have any questions?"
3. "I have three pictures that would like us to look at together. Have a look and I will ask you some questions". (*Show three pictures one at a time, use pictorial tools to help the interviewee when needed*).
 - What does this picture make you think about?
 - What is going on here?
 - What could s/he do about that?
 - How might s/he feel?
 - How can you tell?
 - Who would know that?
 - Would just s/he know?
 - Would other people know?
 - How could they get help?
 - Could they tell someone?
 - Could they find out what is wrong? How?
 - What would you do?
 - Have you had a pain like that?
 - Tell me what you remember.
 - How often do you get that pain?
 - Do you get any other pains?
 - Can you remember a time when you had a headache, toothache, a fall or an injection? Tell me a bit about that.
 - What happened?
 - How did you feel?
 - What did it feel like?
 - How bad was it? (*pain rating scale*)
 - What did you do?
 - Did you tell anyone?
 - Why did you get that pain?
 - Did you g to the hospital/Doctors/chemist/ring NHS Direct/got treatment?
 - Did they say what was wrong?
 - Did you take medicine?
 - How did you feel afterwards?
 - Did the pain go away?
 - Do you still get that pain?

- *(If they cannot remember a time:*
- *Imagine that you have a bad tooth ache and it really hurts. You want it to go away. What would you do?*
- *Would you tell people?*
- *How would you do that?)*

1. "Now I would like to find out what you think about pain in general."

- Can you tell me what pain is? *(Check they understand)*
- When you have a hurt or pain somewhere, what do you call that? *(Ascertain what word they use to describe it)*
 - If you want to tell someone you are in pain what do you say?
- What is not nice about pain?
- Is there anything good about pain?
- Where can we get pain?
- When does pain happen?
- Are there different pains?
- What causes pain?
- What makes pain better or worse?
- If you are in pain, what can you do?
- If you had a friend who said they were in pain, what would you say to them?
- How can people find out more about pain?
- Would you like to know more about pain?

2. "Thank you for answering my questions. I want to finish by telling you how other people might think about pain and where to get help. Pain can happen for different reasons, like when we are ill or hurt in an accident. The pain comes from damage to our bodies. Pains feel different, like an injection feels sharp but a tummy ache feels like a dull throb. Sometimes people can see that we are in pain, like seeing blood or someone crying. But sometimes people can't see pain, like if I hurt my back I might sit very still and be quiet, so people won't realise I'm hurt. We can do things to feel less pain like taking medicine, going to our Doctor, and other things like relaxing or exercising. I have a leaflet for you about pain" *(Give leaflet about sources of help when in pain).*

- Is there anything else you want to say or ask me?
- When I have finished the research I can send you a copy. Would you like a copy? Where should I send it to?

**Appendix E Semi-structured interview schedule for caregiver
participants**

Interview schedule

Carer version

• Prompt questions

1. Can you tell me about a time when you knew X was / one of your clients were in physical pain?
 - How could you tell?
 - What did you/they think was going on at the time?
 - What, if anything, did you do about it? (Did you talk to them? Did you try to find out more? e.g. seek advice, go to library, look on internet, ask other carers, think about past similar instances, identify possible causes, try pain relief or cure).
 - How did you feel about seeing the person in pain?
 - Do you think it was managed well? Any obstacles? Anything that helped?

2. Can you tell me about a time when X was / one of your clients were in pain but it took a while for anyone to realise, or perhaps no one realised?
 - What did you/they think was going on?
 - What, if anything, did you do about it? (Did you talk to them? Did you try to find out more?)
 - How did you feel about it at the time?
 - Do you think it was managed well? Were there any obstacles? Anything that helped?
 - Is there anything you would do differently now?
 - Has the experience changed how you view this person and how they show pain?

3. If X / ones of your clients start behaving differently what do you consider is going on?
 - For example, if they appear unhappy and withdrawn or behave in a more challenging way than usual.
 - What are other likely reasons why they might be behaving differently? Which are you most/least likely to consider?
 - Might you try to find out if they are in pain? How? Is there anything you look out for?
 - What signs suggest that X is in pain?
 - How do they communicate that they are in pain? Can you give some examples?

4. When it is likely that X / one of your clients may experience pain, like after dental treatment, do you monitor for pain? How?
 - What about after a procedure where any analgesic would have worn off?

5. Do you think X has / your clients have the same threshold to pain, and tolerance of pain, as the general population, or not?
 - What leads you to think that?
 - Do you think people with learning disabilities in general have that pain threshold and tolerance of pain?

6. Do you think it is easy or difficult for X to get his/her pain recognised by others and treated?
 - What are the obstacles? What helps?
 - Do you think people with learning disabilities in general experience that?
 - How well do people with learning disabilities communicate their pain at the Doctors/hospital?

7. How do you feel about X / your clients taking painkillers?
 - Do you have painkillers on the premises? Who can access these?
 - Who decides if and when people get painkillers? How is that decision made?
 - Do you feel that way about people with learning disabilities in general taking painkillers?

8. Can you tell me about the last time you remember being in pain?
 - What did you do? (Take painkillers? Do you usually do that?)
 - With your own family, do you feel the same about painkillers?

Appendix F

Annotated transcript samples

F1 **An adult with intellectual disabilities**

F2 **An informal caregiver**

Appendix G

Analysis

- G1 Table of self reported pains from participants with intellectual disabilities**
- G2 Table of quotations for IPA analysis of interviews with caregivers**
- G3 Coding tables for content analysis of interviews with participants with intellectual disabilities**

Participants' self-reported experiences of pain

Name	Past experience			Current pains
	<i>Past accidents/injuries</i>	<i>Ongoing health problem</i>	<i>Pains</i>	
SU1		Diabetes, Water retention and catheter, Retinal dysfunctional generative disorder		Catheter
SU2	Back injury, Broke both arms, Damaged foot, Sprained ankle	Migraines	Bellyache	
SU3		Arthritis	Toothache, Knee pain, Earache, Period	
SU4	Hip operation after fall	Epileptic fit, Bunion, Swollen leg, Chest pain	Headache	Back pain
SU5		Appendicitis, Rheumatism, Constipation	Chest pain, Leg pain	
SU6		Arthritis in back, Finger prick test for diabetes, Epileptic fits	Headaches, Epidural, Labour pains, Caesarean, Period, Feet,	
SU7		Ulcers, Heart attacks, Migraines	Foot pain	Hernia, Leg pain
SU8	Broken hand	Arthritis in hands, Facial pain, Foot ulcers, Heart problems	Leg pain, Back pain	Headache
SU9	Bee sting, Facial injury, Broken arm		Period, Labour pain	Bee sting
SU10	Ankle injury, Food poisoning, Injury to forehead, Groin strain	Migraines		
SU11			Stomach ache, Hip pain, Leg cramp/shins, Headache	
SU12	Banged arm	Indigestion	Leg cramp, Headache,	
SU13	Burn	Catheter	Back pain, Headache, Toenails cut, Foot pain	Bunions, Catheter
SU14		Eczema, Epileptic fits, Arthritis in hips	Headaches, Back, Period pain	Knees
SU15	Knee injury		Period pain	Earache, Sore throat
Total pains	16	29	33	10

Table for Interpretative Phenomenological Analysis- quotations (FC = formal caregiver, IC = informal caregiver)

Name of Theme	Supporting Quotes
<i>Not recognising pain</i>	<p>FC1 - "...Had I noticed? Yeah. No no it's just because she verbally, she said it."</p> <p>FC1 - "she was complaining of pain on under her arm, and she was complaining of pain, and we thought it was because she had broken her ribs because she had a fall a couple of days earlier. So I took her to A&E and they did some tests and x-rays and they came out with the fact, with the diagnosis, that it was pneumonia."</p> <p>FC1 - "there is one that I don't remember ever seeing her in pain."</p> <p>FC1 - "And when someone's non verbal, I mean they most likely - I don't think this situation has come up. But I guess we wouldn't take the liberty of giving it to the person, we'd probably wait for medical."</p> <p>FC2 - "I never saw no one crying. No one crying with pain. Even screaming. Because we never had...physical pain."</p> <p>FC2 - "...another one is just suffering from pain but we can't tell nothing. Maybe, for some reason, sometimes, some people are just scared for doctors. And they will never tell."</p> <p>FC3 - "he had a hernia. And you couldn't tell whether he was in pain or not '... you never knew quite how much pain he was in."</p> <p>FC3 - "It's difficult in a way because you've, if you don't know someone's in pain you tend to almost ignore it".</p> <p>FC4 - "You can't see that they are in pain, you know what I mean. Everything is alright."</p> <p>FC4 - "And I think things will be missed at times because you just don't know what it is."</p> <p>FC5 - "We didn't see it, the advocate seen it and I didn't see it. And it was for a week and he didn't show me, not for a week, but for a few days maybe."</p> <p>IC6 - "And you would not have thought there was anything wrong with her. Still going out for her music, eating, drinking. Going to the centre. Coming home happy."</p> <p>IC6 - "So when I went to the dentist with her he asked if everything's okay. So I said, "as far as I know"</p> <p>IC6 - "I mean it's, there's never been a time when I thought she as in pain to give to her"</p> <p>IC6 - "And didn't even cry."</p> <p>IC7 - "Don't flinch at all."</p> <p>IC6 - "I don't think she cried with hurt"</p> <p>IC9 - "I didn't know certain things was going on. Like if somebody scratch her or something like that"</p> <p>IC9 - "I don't know because X haven't had too many, too many pains. As I said, she hasn't been in severe pain like...I've never seen her vomit.(Q) No she hasn't had much pain."</p> <p>IC10 - "you think that you know everything but sometimes things just slip... why didn't I know this?"</p> <p>IC11 - "But with her, she still move on...so that's what something I'm really frightened of because she can stand pain. So if anything happens to her really really bad, she'll show it but you don't know how painful she's in."</p>
<i>Not voicing pain</i>	<p>FC1 - "In fact he actually his shoulder was dislocated or whatever it was and he wouldn't complain about it."</p> <p>FC1 - "...And he would start bleeding and he wouldn't complain about it."</p> <p>FC1 - "...we know he would not be likely to express it. I mean I've never heard him complaining of any pain."</p> <p>FC1 - "...some might not even express it..."</p> <p>FC2 - "... if she having a pain, because she can't explain".</p> <p>FC2 - "So she's, so she can't even, you know, explain...So and if something happened with her, she couldn't even explain what's happening. So I think this is only one, one person I had in my career who can't explain what is pain."</p> <p>FC3 - "With S he registers pains, but I'm not quite sure he knows how to explain it."</p> <p>FC4 - "It's very--with one person you can't get anything out of it. Absolutely nothing. You know. Absolutely nothing."</p> <p>FC4 - "whereas someone, someone else won't be able to communicate."</p>

FC4 – “Probably, it was because she wasn’t willing to communicate. And if she communicated with them, maybe something could have been done.”

FC4 – “The ones who can’t communicate is always going to be difficult.”

FC5 - “I didn’t see many of them telling that there is something physical!”

IC6 - “She’s never really complained has she?”

IC6 – ““And I thought ‘if she got that, she wouldn’t complain. She’d carry on.’ So you wouldn’t know till the rash come out”

IC6 - “She said she was alright. She wouldn’t answer.”

IC7 - “And I cannot remember any time that she has actually cried for actual pain at all”

IC7 - “And she didn’t complain about the pain at all.”

IC7 - “she did have a fall down the stairs. And she didn’t really complain about that at all.”

IC7 - “but she didn’t complain about the pain at all.”

IC7 - “She didn’t complain as such... As such she didn’t complain about it at all.”

IC7 - “with her monthly periods she doesn’t complain about any pain whatsoever. She’s never asked for any medications to.. get over the pain at all”

IC7 - “But she didn’t complain about it. You know, she was rough for a week but she wasn’t complaining.”

IC7 - “she’s never asked for painkillers at all”

IC7 - “She doesn’t,.as I say you..just doesn’t complain about it at all.”

IC7 - “They haven’t got any way to communicate. As you know if someone has got a language problem, they get a translator in but they cannot get anyone in for X. Because there’s no way that they can communicate with her.”

IC8 - “he won’t go to the doctor and describe that to them. Because they’ll ask him more questions and he can’t answer them. I think that’s the issue.”

IC8 - “he won’t express that, you know, it’s something that’s happened and triggered it”

IC8 - “Because people think that he’s able to express himself, that he can come and tell us. And that’s what I get, well what he should tell us. But he doesn’t

IC8 - “Well, actually, he doesn’t (tell how long the pains been there”

IC8 - “Again, I don’t think he expresses his pain, as much as he could.”

IC8 - ““But, again, he, you know, he doesn’t really express how many times his asthma’s bothering him.”

IC9 - “she don’t want to come to us and say what’s going on, are you ok, have you got pain?”

IC9 - “she’s not going to let us know.”

IC9 - “She keep quiet, say “nothing wrong””

IC9 - “I have never heard me say, “my belly ache”.””

IC9 - “they cannot express their feelings to tell their parents ‘my belly ache.’ Probably they’ve never heard their parents say - ‘My belly’s hurting me’ - so this is a new thing for this person. The person is not going to tell, the disabled child is not going to tell them – ‘My belly ache’ - because she, she or he has never heard them say in the house - ‘I’ve got a headache, I’ve got a bellyache.””

IC9 - “ if she had heard from somebody, “my belly’s hurting me,” you keep repeating that in the house, “my belly’s hurting me”, then, or “my head is hurting me”, then she would know. But this I have, is my head it hurt, so you can tell your mother or your dad, whatever, “my head is hurting me”. But she never heard mum and dad say anything about head hurting.(Q)... But if you never talk about it, their brains is not functioning enough to tell them to say ‘you have a headache’, because they don’t even know what you talking, what they have. But the parents of say, or even, to talk to them – “Is your head hurting you, does it hurt, have you got pain, pain?” ... if you let them know the name of pain, they would in return tell you they have pain. But if you never tell them, I don’t think they will tell you.”

IC9 - “I know I never mention pain in the house so I don’t expect her to tell me. Because this is something, nobody tell anybody they have pains.... So it’s just the same with a person with disability, with learning disabilities. They would know they have a pain, but what to say? What to say? Because I have this discomfort in my belly, I feel funny, but what to say, I don’t know what to say?”

	<p>IC9 – “I think it’s the parents responsibility to let their sons and daughters know that they’re in pain, and show them from the time they’re growing little, start talking and educating your child about pain and discomfort. Because as soon as X’s period came, we start telling her - ‘Hey X you have period’ - everybody say - ‘you have period X!’ And we didn’t hide this, but there’s people they hide this stuff away from their kids.”</p> <p>IC9 – “It’s more the language, because if they cannot tell you that they never heard it, they can’t talk about it. They talk about things they hear every day. They might quicker come and tell you they want make up, they want a film, because that’s in their place all the time. But the pain, nobody ever tell them that, nobody ever teach pain. I don’t think some of them even tell them about their periods. It’s just that they know there’s something different coming, but what is this? I, they don’t know what it is.”</p> <p>IC11 – “But still, she didn’t complain that she’s in pain.”</p> <p>IC11 - “Cos she wouldn’t tell you, she wouldn’t show you anything .”</p> <p>IC11 - “But for her to tell you, she won’t.”</p> <p>IC11 – “But for her to tell you, no.”</p> <p>FC11 – “she never said my tooth is hurting or anything but all that she say is hate that doctor”</p> <p>FC11 – “But with her because she’s not able to tell you wherever it is,”</p> <p>IC11 – “with F because she never says I’m in pain.”</p>
<i>Hiding pain</i>	<p>FC4 – “She started off with the limping... And then she would pretend to be, you know, walk properly, you know, all that....”</p> <p>IC6 – “If she’s feeling rough she will still carry on eating. She wants to eat the food and she wants to have everything as normal....And she hates being sick. She will swallow it as such... She doesn’t like to show any form of pain. And she always wants to be alright. So everything is going to be normal. But..so that she can do what she wants to do all the time.”</p> <p>IC6 - “She wants me, you know like..it’s like..no fuss, no fuss, just want to carry on. And everyone around is going like “is she alright?” They know not to make a fuss. X doesn’t like fuss. Just doesn’t like fuss.”</p> <p>IC6 - “She won’t lay down and she won’t go to bed. She comes down she has to get up, get dressed and do the things as normal but she’s at home”</p> <p>IC7 – “she’ll know I’ll keep her home from the centre and take her to the doctor’s. So in order that I don’t keep her home and take her to the doctor’s she thinks, she says she’s alright.”</p> <p>IC7 – “she wasn’t in the class, she was in the toilets....And as we walked through those doors and come outside, she absolutely broke down.”</p> <p>IC7 – “ we know that she’s in pain but she won’t take anything at all. And if she falls over she would get up, dust herself down and carry on as though..as though nothing has happened”</p> <p>IC7 – “We talk about it to her as well (pain). And, but she just says no and she’s all right...She gets quite annoyed actually. She shakes her whole hand.”</p> <p>IC9 – “But I’m not going to go as far as saying she’s hiding the pain, which I heard that coming from a few people who’ve said their daughters are hiding pains. I don’t think they are hiding pains. They are misjudging the person and I think that hiding pain is just to say that they are in pain, but this is something different that is happening to them, and they cannot express their feelings to tell their parents”</p> <p>IC10 - “they can hide pain. S can hide pain. Even when they have pain they don’t want you to know... (Q) Yeah she can hide, because as I said, I mentioned the other day when you were there that she had this boil in her armpit, and she hide it so long and I didn’t even know because she went away with the group for two days I think that’s when she got that, I didn’t find out. (Q) Coz she didn’t want me to see. (Q) That’s what I was saying that sometimes these children they hide things. They hide pain.... But look, she hide it, and god knows how long that thing was there and I myself didn’t even find out until that day.....”</p> <p>IC10 – “I know that she can hide pain.... Because S can hide pain, and really hoard pain. So.. I don’t know, maybe, I don’t find it straight away...”</p> <p>IC10 - “It is high (pain tolerance) because that’s what I was saying, that she hides pain.”</p> <p>IC10 – “because I know that she’s good in pain, she can hide pain....”</p> <p>IC10 – “Yeah she can hide... she had this boil in her armpit, and she hide it so long and I didn’t even know”.</p> <p>IC10 – “She doesn’t want you to look up, she doesn’t want you to keep an eye contact or make it an issue... sometimes she’ll hide herself in her room...., And if you go to her room she pushes you back and she’ll push the door on you and you can see her sitting down quietly and sometimes tears will drop out.”</p>
<i>Verbal complaints of pain</i>	<p>FC1- “...She verbally, she said it”</p> <p>FC1 - “By... they can verbally because a lot of them can.”</p>

FC1 - "So some are good.." (at communicating verbally)

FC2 - "So A, she can tell and K, she can tell, straight away, when she, when they are in pain"

FC2 - "Yeah, they can let me know, they can explain where is the pain. And how it feel."

FC2 - "She told. She told straight away"

FC2 - "Because of X, she's quite able to understand and speak. For herself."

FC2 - "I think this is the main point, actually, because she can explain, she can, ...So it's good because she can explain. "

FC2 - "She's telling, oh I have pain with my stomach, can I have paracetamol"

FC2 - "sometimes I think she's not telling when she has some little pain. Or when she's saying something, it's like a talk, you know, conversation about something else and she will mention about her pain"

FC2 - "Some of them are saying it, you know. Straight away. As soon as you open the door."

FC2 - "Because they're saying, because it can be real pain. So when they start to talk straight away, so you have to, you, you, you need to react. Because they're really in pain. Because if they're starting it from somewhere in the middle of a talk of some about clothes or shopping or something it's insignificant, so it's not really important.(Q) They, you will be, you will be starting first all talk, you know, and you will start talking about something and you will find out finally.(Q) We will be seeing. Somewhere in the middle of all this, you know, stories. You have to listen."

FC2 - "She will be saying."

FC2 - "So if not, you will see how they, how they explain to you, so, "oh I feel very very big pain in my ear, or in my stomach, really big""

FC3 - "She's very vocal when she's in pain."

FC3 - "she'll tell you every morning "I couldn't sleep because of the pain"

FC3 - "But he's very vocal about when it's hurting... He's very vocal and he'll tell you."

FC3 - "But G is always vocal"

FC3 - "with S you don't need to ask R she'll tell you."

FC3 - "J sometimes. But J although he's got verbal skills, he's not coherent as some of the others"

FC3 - "I mean sometimes it can be that they'll be very vocal about it."

FC3 - "but she's quite verbal so she can tell you"

FC3 - "or he's says he's got a funny throat"

FC3 - "he can at least ask to get it treated"

FC4 - "Oh because he can communicate and he can identify where the pain is, and he can describe what kind of pain he's in."

FC4 - "because he can communicate. And with L, out of most, if not all, he's more, he can talk on you, you have a mutual wish to understanding with X, you are on the same level, you know. 'Cos he can talk and explain for himself."

FC4 - "sometimes X would come and complain he's having tummy ache"

FC4 - "I mean he would tell you as he can communicate for himself, you know. And he will come and tell you "If I could have a word with you" and I say "Yeah. Okay. Somewhere private?" And then he will ask you "What should I do? I am in pain" and things And then he just say "Do you mind if I see a doctor?"

FC4 - "But the bottom line is he can communicate"

FC5 - "always her complains about pain in her legs ... she's here 10 to 15 times a day, and she's complaining a lot."

FC5 - "when she is complaining..."

FC5 - "she is always saying it, telling that always, always."

FC5 - "Because X talked to the advocate"

FC5 - "they do not have the confidence to tell"

	<p>IC8 – “So, it like, you know, if he is in pain, and he’s saying back pains, and sometimes, you know they, when you listen to them in the day, he’s saying, you know, “I’m getting indigestion””</p> <p>IC11 – “She’ll say, well with her ways, or every question is yes. To her... Whether what she’s saying is right, if it’s yes or no. ‘Cos everything’s yes.”</p>
<i>Communicating pain non-verbally</i>	<p>FC1 - “They would by non verbal communication..”</p> <p>FC1 - “And the other one bites himself so if he’s stressed that’s how he’ll communicate it, his hand.”</p> <p>FC2 - “She show me with, with hands, with fingers, with, you can see with body, you know, all her, what, how to say it, mimic, everything.(Q) Yes, she will point, she needs , shaking her head. She will be showing physically and manually.”</p> <p>FC2 – “People who can’t communicate, some people,... they even can show you”</p> <p>FC3 – ““He will tell you, even if he just goes like that and scratches his throat, you get a hint that there’s probably something wrong with his throat.”</p> <p>IC9 - “If she is in discomfort and sometimes she show me signs, she will rub her forehead and I’ll see she do that many times, and I’ll say – ‘You’re head is hurting you?’. And probably I’ll know her head is hurting her because she keep on doing that.”</p> <p>IC9 – “when the foot is hurting her probably she will feel discomfort with the shoes, she’ll remove the shoes and maybe want another pair. ... So these are all signs telling me ‘I am not comfortable in that shoe, I don’t want it’ and that means it’s hurting me, whatever, it’s not comfortable or it’s hurting me or something and she doesn’t wear the shoe and if you put it for her, right, she just take it out.”</p> <p>IC10- “S doesn’t have any understanding of no and yes or any word like no or yes and sometimes what I find is that when I touch her somewhere that is painful then she pushes me up. She takes my hands off from her.”</p> <p>IC11 – “Put her hand on it. ...But her actions.”</p> <p>IC11 – “If something, by yes touching. Like a tooth or something”</p>
<i>Communicating with the person about pain</i>	<p>FC1 – “ Maybe ask him, but then again because people are just not in the habit of asking people - people are not in the habit of asking people... people could maybe just ask them but I guess you’re not really focused on people having pain. And just simply you could ask people “are you feeling ok, do you have any pain in your body”; it’s just not socially acceptable. Maybe in this environment you should but we don’t.”</p> <p>FC1 - “...and they sort of asked him if whether he could move his arm and this and that...”</p> <p>FC2 – “ And just try, try to ask her where she, why she’s like that and where she’s feeling pain”</p> <p>FC3 – “You might talk to them if you can talk to them. (Q) Well just ask them is there a problem, is there something wrong, that sort of thing. Are you in pain?”</p> <p>FC3 – “Well just ask them is there a problem, is there something wrong, that sort of thing. “Are you in pain?””</p> <p>FC3 – “and if you ask him he’ll tell you”</p> <p>FC3 – “and if you ask him if he’s got a sore throat he’ll start off by just going like that (gestures)”</p> <p>FC4 – “And when anyone asks her, she can communicate, very well and she’d understand, you know. And she will answer "Are you okay?" and say "Yeah I'm alright." "What's wrong?" ...And you say, "are you alright?" .. You know there is a problem so usually give them their space for a little bit and then go later on and say "Are you okay? You like going out and doing these things, you know. Is there a problem?". You know what I mean. “Cos that’s really unlike you, you know... He ends up saying things what we both know. ... saying "Are you okay?" It's just--it's trying everything you can.”</p> <p>FC4 – “And when anyone asks her, she can communicate, very well and she’d understand, you know. And she will answer "Are you okay?" and says "Yeah I'm alright. What's wrong?"”</p> <p>FC5 – “So when we ask her shall we make an appointment to go to the G.P and “ yes, alright”, but a few times she says “no let’s wait”.”</p> <p>IC6: As I said..yeah I said, “Is your belly hurting?” and she says “I’m alright, I’m alright”.</p> <p>IC7: We talk about it (pain) to her as well. And, but she just says no and she’s all right...</p> <p>IC8 – “And I said to him, I said to him, “What’s going on”..... ..and I say ‘is your belly hurting you?’ ...a after a little while’, I say, ‘your belly still ache’?.... and I say ‘I think you’re coming on your period’.....so I said: ‘but what’s wrong, why are you like this now, why are you so angry?’”</p> <p>IC9 – “And she has a pain, and I tell her – ‘Are you in pain, is your belly hurting you?’”</p>

IC9 – “Which I always tell her all the time – ‘Mummy loves you. Do you love your mummy?’ (sound) ‘Do you love your mummy? Yeah?’ So I don’t know if it is a yes or if it is a no she’s saying, because she’s not coming out and saying ‘yes’ or ‘no’, and then she embrace me and kiss me, so I know that’s a yes. And that’s the way I understand her pain, and I say ‘Your belly don’t hurt anymore?’ She embrace me, she kiss me.”

IC9 – “So when we see these things now we say, ‘X what happened to you, what happened to you?’and speak to them, because some people have their a disabled child, they didn’t talk to them and instead of having to talk to them, they aggravate them.....and I’ll say – ‘You’re head is hurting you?’ she don’t want to come to us and say what’s going on, “are you ok, have you got pain?””

IC10 – “I keep saying that then I will see, I will check her body and say “S pain here?””

IC11 - .” she was limping so I thought, "F what’s wrong?" Say "I forgot to tell you".”

IC11 – “But then you have to ask her, is that a big toe, small toe? Or whatever. Then with this time, she said it’s the small toe. If you ask her, she’ll say. But for her to tell you no, she wasn’t. But it’s a little bit of improvement that she’s doing a little bit”

IC11 – “Actually, I’ve never asked her (about period pain). With that, I’ve never, I’ve never asked her about that, yeah. Or I’ve never talked to her about it.”

IC11 – “So then the doctor will be touching her stomach. Is the pain there? She said no. Is there, your chest? Cough. She coughs. Does it hurt? She says no but it’s odd to ask her with her, with the doctors.”

IC11 – “I say is it painful? No. Is it hurt? No. This side? Yes. So with that bit. Yeah, ask her questions, she’s alright with that. It’s before when she wasn’t saying when was a difficult bit”

IC11 – “Is it period pain? She say yes.”

Monitoring for changes

FC1 - “...maybe because we know that might be his reaction we are on the lookout sometimes when we know he’s anxious or tense that he might do that.”

FC1 - “...we keep a close eye on his level of stress and situations of that nature..”

FC2 - “you just go in and sit in there. Because I’m interested in all this stuff, I’m sitting and I’m just watching how they reacting on every single, every single move. (Q).... I like to see how they reacting....how body, with body movements, how they sitting, how are their eyes contact, where they’re looking”

FC2 – “I notice little things like a change in the mood or they have something inside or they bored of something, so pain is similar”

FC2 – “I think all what you need to do, just you need to look them and just to learn how they are behaving”.

FC2 - “you have to look how they react and how they behaving”

FC2 - “and they sitting in their loo or they go in there and, you know, making noises, you, so you, you understand.”

FC3 – “Well the main thing is she doesn’t sleep. She doesn’t sleep at all. ...She winces. She makes a lot of fuss. Doesn’t generally want to do things. And it sometimes means that she’ll walk and then drop off to sleep in the day.”

FC3 – “If its someone whose normally happy sometimes there mood can change. They can either become completely ecstatic or they can be quiet, and they can be a bit more confrontational, not want to do things.”

FC3 – “And then you’ll pick up on his changes in behaviours if there’s something wrong.”

FC3 – “When he’s uncomfortable he’ll be uncooperative. He will not want to do things”

FC3 – “But it comes out in other ways when he’s uncomfortable he tends to moan a bit more, he tends to be a bit more confrontational. He tends to move, he has a bowel condition, nobody seems to know what it is. And every time he needs to go on the toilet he gets a pain in his stomach. And he gets very agitated about it, very anxious about it”

FC4 – “I think for anybody on shift in this business, to be honest, you’ve got to be vigilant at all time, you know. I’m shift leader most of the time when I’m on shift, you know. So it’s my responsibility to be vigilant and to just be very observant. ‘Cos little behaviours--you’ll miss something out, you know. So I try to think, it’s--you’ve got to be vigilant. Yeah. I mean, everything else who comes after or if you observe. Because, you see, the trigger’s always there for you to see something’s not right here. (Q) Yeah. As I said, behaviour. The meals, especially, the meals – are they eating their meals well? Drinking? Their urine and faeces? If you’ve got a chance if you can, especially like if there is, for example so you can give access to see all those things, you know what I mean. You gonna--you just have to look out.....”

FC4 - “We notice things. It’s not just that, he’s not himself.”

FC4 - "Yeah. I mean, everything else who comes after or if you observe. Because, you see, the trigger's always there for you to see something's not right here."

FC4 - " He will be very clingy on days when it's not really... if he has a problem he will always come to you"

FC4 - "you've got to keep an eye on them."

FC4 - "I think one of the behaviour is her being withdrawn, not doing things she used to like to do... And when they start saying "No", you know definitely there is a problem. For example, someone who loves going out to eat, and they're saying "No" to their food."

FC4 - "Well the behaviour changed later on"

FC4 - "But what happened eventually, maybe behaviour change. She's more withdrawn, spending a lot of time in her bedroom, you know, possibly her activities are more physical that she wasn't like that before she was interested."

FC4 - "And it's out of character. It's not on a--it's not like a habit. You know, it's really out of character."

IC6 - "It's just..again it's just monitoring, isn't it?"

IC7 - "Yeah. It's monitoring all the time"

IC7 - "It's for us really, to watch..to take note of any change within her character. That's when we know that we've got to do something."

IC7 - "we know how X is. Her..how she is during the months. And if the..she is acting sort of different then we know there's something up."

IC8 - "from his aggressive language that he uses, and then his mood, you know his mood, he's angry. ... You can see from his facial expression that there's something not right with him"

IC8 - "He'll not get out of bed. He won't, he'll have a restless night. He won't sleep, his sleep pattern changes completely. He'll want... sometimes it's hard work getting him to eat. He'll go off his food, or it's the other way. It fluctuates. You know, it goes from one extreme to the other. Sometimes, he'll just binge eat because he's in pain to make himself happy....(Q) ...you don't get a rest really."

IC8 - "I monitor it, and I write it down....."

IC8 - "Well I know, like with he, with his brittle bones when he was getting that before he got the diagnosis, that he'd wake up and he'd be in such an angry mood and then like when you'd find out because I... from that I know that there's something up for him. He's not able to express it using language, but he does tell me that way."

IC8 - "Well, for my older son, it's like, when he's in pain he gets very angry."

IC8 - "Well, I know if he's in pain, right, he won't, he won't want to go out. He won't want to do things."

IC8 - "You know, if he just looks really sad and withdrawn, and wouldn't want to do things. Or it will be one extreme to the other, it might be where he'll get angry and speak out, and verbally abuse, abuse to me."

IC8 - "The acute (pain) is when he's very frustrated and very angry and it's unbearable for him. So then it's aggressive in his language, you know, it's aggressive in his behaviour. You know, things like that.(Q re chronic pain) Yeah, more, more where he'll just sleep in. He'll go off food. Or it'll be the other way round. You know, it's one extreme to the other".

IC9 - "She wouldn't behave like that again.(if pain gone)"

IC9 - "she would scream and get angry (claps hands). Angry clap her hands, she's going up, going down (Q) Yeah she claps. No, she, it's not a (clap). (Q) An angry clap"

IC9 - "Cos I did a lot of that. Which I still do. Look after whatever, and I keep an eye on what's going on...."

IC9 - "She only go (grunts). Or sometimes I would suspect she's in pain because she, the behaviour, she stay quiet and she wants to isolate herself.... and she would be (groan, groan, groan). She might not want to get dressed and she wouldn't show you she won't want to get dressed, she just walk away."

IC10 - "I check her a lot to find out because I know that she's good in pain, she can hide pain. So I take that to know more about her or check her more often to find out how she's doing"

IC10 - "I think that (monitoring) tells me a lot when she's not well"

IC10 - "With her foot or her body pain then maybe it's, I notice that S will another thing, like she will change completely.. she gets like uhh.. well, my sister said that maybe it's in my mind." IC11 - "when she's ill she just sit quietly and go like that down like that you know. But this time she just went like that, OK the head just drop down like this. And so just sitting"

	<p>down quiet”</p> <p>IC11 - Just goes very quiet. Anytime she’s very very quiet then, she’s a quiet person but there’s different, when she’s quiet then actually I know there’s something wrong with her.”</p> <p>IC11 – “if she’s got a tooth ache, she normally goes like that, quiet”</p> <p>IC11 - But when we go home, quiet the same quiet, so this mean that every four hours that I ask her does the tooth hurt ‘cos where they took, they pull it out, it was sore”</p> <p>IC11 – “so looking at her and the pain, OK, the way she’s quiet and she’s hot, I thought it was malaria”</p> <p>IC11 – “Well, that she’s quiet and anything that’s something in pain or she’s not well or something, she goes quiet.”</p>
<i>Noticing signs indicating pain</i>	<p>FC1 - “In some cases you know the way they would sit down or touch a particular part of their body, or hold it.”</p> <p>FC1 - “Those would count as signs. Signs of discomfort, sign of... what’s the word... feeling tenderness, that kind of thing.”</p> <p>FC1 - “...in terms of you know like I said the way they would walk or the way they would hoist, the way they sit”.</p> <p>FC1 - “...people notice that he has in fact be peeling his skin off.”</p> <p>FC1 - “...for the way he reacted sitting down made the carer aware that he was that there was something probably wrong with his arm...”</p> <p>FC1 - “We have a tenant tends to, whenever he’s anxious or stressed he will self inflict wounds. Like he will scratch his skin and peel his fingers.”</p> <p>FC2 – “She, you will be seeing on her mimic (expression), on her face.”</p> <p>FC2 – “And you can see on her mimic, like she, when she’s sitting, and she can’t walk properly”</p> <p>FC2 – “You can see on her mimic, on her face”</p> <p>FC2 – “a person who’s not really listening you, and just somewhere inside their mind they just completely lost. You just looking at them, and if you ask something, sometimes, they’re even not listening because they’re listen pain.”</p> <p>FC2 – “she just laughs, or, when she is in pain also she’s putting her hands up and down, up and down”</p> <p>FC2 – “And when she start walking up and down it’s something else and when she’s talking with herself, it’s not always the pain, but something bothered her.”</p> <p>FC2 – “you will see bruise or something”</p> <p>FC2 – “I can see on her face that something’s wrong or not.”</p> <p>FC2 – “You will see her, you know, mimic, not like usually,”</p> <p>FC2 – “But when they do colouring and they still sitting with something, you know, in the face, or any hands movements or body language, you, you, you will see they need a painkillers”</p> <p>FC3 - “he’s beat himself up, bashing his head on the walls”</p> <p>FC3 – “if we notice a cut or abrasion”</p> <p>FC3 – “But you’re kind of reliant on staff with visible skills to actually see things there.”</p> <p>FC3 – “we’ll notice when he’s got pain in his back ‘cos hell sort of arch his back and he can’t get up and stuff”</p> <p>FC3 – “and he’ll tell you that , ‘cos he’ll either start coughing a lot more or he’ll start crying. He will tell you, even if he just goes like that and scratches his throat, you get a hint that there’s probably something wrong with his throat.”</p> <p>FC3 - “With J you’ll either hear him crying or coughing or something”</p> <p>FC3 - “But you kind of reliant on staff with visible skills to actually see things there.”</p> <p>FC4 – “And you could tell by the, his facial expression”</p> <p>FC4 - “The facial expressions.”</p> <p>FC4 – “you know it just like that (snap) from the moment you know that he’s upset. He’s not happy about something. Facial expression, and sometimes the eyebrows, you know, you can tell the face becomes tense, eyes. One resident uses that flickiness—the fingers--as communication”</p> <p>FC4 – “the way she walked, instead of walking, like limping”</p> <p>IC6 – “All she did was like an Elvis Presley. Lifting that (gestures lifting lip)”</p>

IC6 – “her face was badly bruised”
 IC6 – “She was coughing like and breathing..it was her breathing actually”
 IC7 – “Well only a bit like know signs she’s generally ill, the eyes and its eyes. And the..well mainly the eyes and the running nose...”
 IC8 – “And then the other thing you can see is very visually, is that they start limping if it’s their knees playing up, is that they start limping or walking funny.”
 IC8 - “But you look at it and you observe their, you know, body language. ... And then you know like this year he was having problems with his legs, and he was walking funny.”
 IC9 – “All you can do is when she’s in pain, and when she’s in pain I just do something for her because she give me a sign.”
 IC9 – “you can hear her (moaning sound)... and probably her belly be bloated”
 IC9 – “If she is in discomfort and sometimes she show me signs, she will rub her forehead and I’ll see she do that many times”
 IC9 – “Looking for signs”
 IC10 – “I see from her face”
 IC10 – “But she gets a pus on her mouth, like a cold sore on their face and the mouth and I notice that she’s not very well”
 IC10 – “She’ll usually bite her mouth.”
 IC10 – “when she’s crying then I know that she’s very, very in pain”
 IC10 – “I noticed that sometimes when she’s in pain the lower part of the leg would sometimes would swell up especially when she does walking loads. You can see that’s she’s limping a little bit and you notice that she’s in pain and you see that, as I said, because I always look at her face”
 IC10 – “I saw tears coming from her eyes and I noticed that she couldn’t even lift her hand.”
 IC10 – “That’s another way that I notice that she’s in pain. She will sit on her bed and fold her arms like that. And just not watching the telly. And she folds her like this.”
 IC10 – “I noticed that at the weekend when she was eating she was juggling food from here to here and I noticed that this morning when she was brushing her teeth”
 IC11 – “I can see from her face, the way she looks and she’s a bit quiet... ‘Cos it’s the face I normally find out that, she goes quiet and a bit ooh”
 IC11 – “Well the face, she get a smiley face. Yeah, and normally a sad face, ‘cos when I say you got a sad face then if she doesn’t say no then I know that something’s actually wrong with her. Yeah. Then after that, giving her the paracetamol or something and then she’ll be smiling and I say oh god, the smiley face is back.”
 IC11 - The moment I’ve noticed that there’s something wrong with her, being quiet, dropping the head one side or forward”
 IC11 – “So it’s just her face I have to watch because her movement, even if she’s got a stomach ache like period pain and everything, she wouldn’t stand up and go like that or anything”
 IC11 – “With pain, no the pain, she wouldn’t do anything. She just it’s the face bit.”
 IC11 – “I just look after her, the way she moves. And if there’s a little bit change in her”
 IC11 – “But the, the moment she’s looking at it, the needle goes there, she goes like that. Squeeze the face. Yeah, she does that after that. With another way she look at it then goes cch”
 IC11 – “I saw in the face.”
 IC11 – “when she’s ill she just sit quietly and go like that down like that you know. But this time she just went like that, OK the head just drop down like this. And so just sitting down quiet
 IC11 – “With a cough you know that she’ll be coughing so it’s a cough, but something inside is when the face comes.”

Guesswork/being a detective

FC1 - “It could be a lot of things...”
 FC3 – “just you have to deal with it, whichever way you can, You go through the processes. You rule out things one by one. And hopefully our left with the answer.”
 FC5 – “No not physical. It’s emotional.”
 FC5 – “So first you check that he has all his medications, yes ‘cos sometimes, you cannot force them to have medication and sometimes they are missing medication.(Q) Yes, ‘cos obviously that’s the most of the time the reason, yeah that they haven’t taken it.
 IC8 – “So then I become like the detective and you find out.”
 then you feel, well actually is it, am I treating the right thing? Was it his back or was it the indigestion? Do you see what I mean? I’m not a doctor. So, I’m just, you know, doing what I can.

	<p>IC10 – “I will check her body and say “S pain here?” And maybe I will check her ankle because in that happening at first. Sometimes I see that, sometimes it’s a little bit different, and I said “oh yeah S”. Or if it’s like a body pain or headache then if you touch the head maybe you’ll see a little bit warm or sometimes when you touch her arm then maybe...”</p> <p>IC10 – “I guess things from her like when she’s in pain”</p> <p>IC10 – “as I said it’s just guess guess guess guess.. and you can’t guess one thing and just drop you, it have to guess in the end”</p> <p>IC10 – “I was trying to see more, trying to find out if she will open up more for me to see more to see properly. She didn’t. She didn’t. And then I noticed that there was something wrong, and it jumped back in memory to the weekend when she was eating and I was sitting next to her and she was struggling to eat.”</p> <p>IC10 – “You just have to guess.. and guess.. sometimes it will take a few days then you will just get it, “ooooh maybe it was this”. You don’t get it all, it’s very very difficult. It’s very very very difficult. You don’t... It’s not easy. It’s not easy at all. it’s very very difficult”</p> <p>IC11 – “Well, with that one it’s a guesswork”.</p> <p>IC11 – “But it’s for me to detect”</p> <p>IC11 – “That’s what I thought, something to do with her head because normally always the only pain that she gets is either OK when the boys step on her toes but mainly it’s the period. Time that she had because if it’s stomach ache, nerves. So all the time sit back and go like that and this time, upright with the head dropped down so that’s why I thought it, it might be changes of pain”</p> <p>IC11 – “I don’t know this is a bit odd so I thought let me see, check temperature in the normal, usual way so I put hand there and the head was hot.”</p>
<i>The individuality of pain expression</i>	<p>FC1 - “I think it’s the thing that helped would be talking to people who deal with them... because they know the ... person with learning disabilities.”</p> <p>FC3 – “As you got, as I got to know D you could tell he as uncomfortable. Whether he was actually in any pain or not...”</p> <p>FC3 – “I think because obviously I’m G’s key worker obviously I’m aware that he’s in pain a lot of the time”</p> <p>FC3 – “It just depends on person to person”</p> <p>FC4 – “it’s all down to individuals, you know. They are all different.”</p> <p>FC4 – “it’s like he is enjoying it. He will smack himself on the chest so hard. Very, very hard. And then keep on doing over and over again, and you can see the pleasure, you know, on his face.”</p> <p>FC4 - “Also like I said, if you know them very well, you never go wrong most of the times.”</p> <p>FC4 – “We are quite familiar with them as well.”</p> <p>FC4 – “But those who know him will know something’s not right you know.”</p> <p>FC4 – “so you’ve got to know him very very well to know all that kind of screaming... So you’ve got to know if he’s in pain, or he’s just in himself, you know. So you’ve got to know. And I think that’s the key to be honest. Working with them for a while, getting to know them, you know. As individuals. That’s the key.”</p> <p>FC4 – “someone who has worked here for quite long will know definitely something’s not right.”</p> <p>FC4 – “you know what they like”</p> <p>FC4 – “It helps, if you know them very well.”</p> <p>FC4 – “that’s where it comes back to the idea of you knowing the person”</p> <p>FC4 – “But we are familiar with... Yes, the speech.”</p> <p>FC5 – “you know your service users, you know their background and you are basically living with them”</p> <p>FC5 – “if you know the person. So you have to know them.”</p> <p>IC10 – “but maybe because I’m her mother, that I’ve been living with her for all these years”</p> <p>IC11 – “No, no, I always tell because. (Q) Been living with her all these years.”</p>
<i>Staff support, knowledge and consistency</i>	<p>FC1 - “...support from other colleagues which sort of organised the tasks so I could allocate time to go with her to take her there”.</p> <p>FC4 – “So I think the key word on that is consistency within staff. You need to keep the staff. If you have new people coming in and out, they will miss things”</p> <p>FC4 – “It’s keeping that consistency, right. “</p>

	<p>FC4 – “Cos if you don't have the consistency they will soon affect, and things will be missed as you said and the very important details”</p> <p>FC4 – “most of the agency really, you know, they come and do their job but they are not really part of the team isn't it, you know? It's not the same as being permanent, full time. 'Cos agency will go there and the next day they're at another place. Next day they're already gone. So there's no consistency there.”</p> <p>FC4 – “also bring the manager also for advice and guidance and discuss with colleagues as well on the floor that day and just see everyone's opinion and then we agree on one thing”</p> <p>FC5 – “if it's hard for one staff then the other one would find out. There are lots of people here and they are talking all the time so someone would get the information. Tell to, to the, they pass the information to a key worker.”</p>
<i>Awareness of the risks of missing pain</i>	<p>FC4 - It's too much of a risk, especially with someone who can't talk, who can't communicate, you know.</p> <p>FC5 – “you're always risky with X”</p>
<i>Training and education</i>	<p>FC4 – “I think staff training could make a difference”</p> <p>FC5 – “they give us some training about X, you know, your colleagues, because they knew X better than I was”</p>
<i>Confidence/certainty in recognising pain</i>	<p>FC1 – “I imagine I would think it would cause him pain...”</p> <p>FC2 – “Because you can, you can tell, when she's really in pain. Yes, you can tell when she's really in pain but when she's not because I know when they in pain, really in pain, and when they're not.”</p> <p>FC3 – “And you couldn't tell whether he was in pain or not”</p> <p>FC3 – “It's difficult in a way because you've if you don't know someone's in pain you tend to almost ignore it. Not intentionally but you don't know.”</p> <p>IC6 – “And she'd had fillings so she must have been a bit sore. I don't know.”</p> <p>IC6 – “They can't rely on my answer, can they?”</p> <p>IC6 – “I know that she's not well she must be in a little bit of pain.”</p> <p>IC8 – “there have been times, sometimes when I've not been quite sure because I've been dealing with him asthma, but not recognised actually it's this thing”</p> <p>IC8 – “and then you feel, well actually is it, am I treating the right thing? Was it his back or was it the indigestion? Do you see what I mean? I'm not a doctor. So, I'm just, you know, doing what I can.”</p> <p>IC9 – “I know that was asked of me once, by a psychologist I think who came to see her and I said 'I don't, I'm not quite sure if she's in pain”</p> <p>IC10 – “So I always say, I wish there was another way that they can treat these to know where the pain, or whatever, to treat, I mean I know they are not god but...”</p> <p>IC11 – “But that's when I knew that she was really very in pain.”</p> <p>IC11 – “No, no, I always tell because (Q) Been living with her all these years”</p> <p>IC11 - “To know that when it's a mild pain or severely very very, it's very difficult with her.”</p>
<i>Questioning genuineness of pain</i>	<p>FC1 - “...this tenant is a bit of a hypochondriac and she tends to, she tends to, make she comes up with any reason to go hospital. For any reason, I don't know, because she likes the hospital environment... when it turns out there wasn't anything wrong with her.”</p> <p>FC1 - she would build it up to a situation where she would want to get her objective, which is staying at the hospital, and exaggerating , not exaggerating, but actually acting out in front of the doctor which she would not otherwise in front of the carers, because she would want to convey that she is in extreme agonising pain.”</p> <p>FC2 – “A, she's complain all the time. Because, one reason, because she like attention. And maybe she's actually in pain sometimes. When she need attention, she want someone to care about her.”</p> <p>FC2 – “And she likes to be around doctors. Because she likes to go to hospital. So maybe sometimes I think it's not so much pain, like she try to make it.”</p> <p>FC2 - “ but when she's not she just playing up ... maybe a little bit lying, just to be around people”</p> <p>FC2 – “Because I think she's just make in her mind that she's in pain sometimes.”</p> <p>FC2 - “in my opinion, because she's playing up. ... Because I think sometimes she just playing to find attention.”</p> <p>FC2 - “because I know about X, she can, she can play”</p> <p>FC2 - “because she can explain, she can, maybe she can play sometimes, but it doesn't matter.”</p>

	<p>FC2 – “She’s saying things which is for us sometimes silly, you know, I feel pain here or here or here, everywhere. And it’s coming like a huge bucket with pains, but actually it’s maybe just a little pains somewhere in one place, so she likes, so she’s making a lot of stories.”</p> <p>FC5 – “Sometimes they have plan to go out, she has to go yesterday shopping and she is feeling lazy so she is complaining about her legs, many of them they do that. X, the day that he has to go to the gym, he’s feeling pain, feeling screechy. (Q) Yes it’s an excuse, sometimes it’s an excuse; I mean obviously A is in pain, but sometimes we don’t know, you know if she’s really in pain, she was to be taken to the hospital or the G.P, not the hospital, to the G.P and most of the time she doesn’t need it.</p> <p>FC5 – “And start to, you know, sometimes it is an excuse and sometimes not. How do you know? Because you can feel it. You can feel it like ‘ah’ or you can ask them ‘Oh do you not want to go to the gym?’ and they say, if they don’t want to do something they say ‘oh, can you do this for me? Can we do it online?’ So that’s not a real pain.</p> <p>FC5 – “You just need to guess when it is a real pain and when it’s not.”</p> <p>FC5 – “I think they will tell you even if, it’s more because they want to keep your attention, I don’t know. There’s another service user, but most of them, they are attention seekers, yes”</p> <p>FC5 – “they are more attention seeker.”</p> <p>FC5 – “sometimes it’s attention seeking.”</p>
<i>Coping, pain thresholds and tolerance</i>	<p>FC1 - “...But apparently he’s become tolerant of that, or that has always been a mechanism for him to deal with stress...”</p> <p>FC1 – “...he just doesn’t he doesn’t seem to be bothered about it because it’s probably something he’s already become tolerant of or has mentally adapted to it.”</p> <p>FC1 - “...He seemed to be quite tolerant or oblivious of it.”</p> <p>FC1 - “Because I’ve seen people who are very (inaudible) about pain, and those with and without learning disabilities, people who seem to tolerate it, and there are some others in both sides that would tell you “I’m dying” and it’s just a minor pinch, you know, so it goes both ways”.</p> <p>FC1 - “I think the same.”(tolerance for pain as the general population)</p> <p>“...if it requires her to be in hospital she would be able to deal with it in home or get on with it.”</p> <p>FC2 – “they feel, I think, when they need to tell stuff, and they, or, or, when they will be coping fine themselves.”</p> <p>FC2 – “So and they can manage their pain ourselves.”</p> <p>FC2 – “Like I’m, I’m saying like about stomach pain, they can control it. ...They just forget it. ...And they just, you know, relax, and they calm down. And everything’s stopped.”</p> <p>FC2 – “So this is the scariest thing, because when she’s violent, she don’t feel nothing. I think she just, she’s just losing all feelings, it’s all, I think if even when she’s, you know, she’s not understand when she’s running in the street, in the middle of the street a car can hit her. And I don’t think she even will feel if someone will, you know, even push her or something. I don’t think so because her mind is completely shut. When she is in a, not in a good mood.”</p> <p>FC2 – “Because when they psychologically, you know, pushed or something, then they, I don’t think they have any pain. They don’t feel nothing. Because I noticed how they reacting, you know, when they angry they don’t feel any pain, because they just, you know, they just angry.</p> <p>when they become angry, they don’t feel nothing.... I don’t think they’ll feel pain.”</p> <p>FC3 – “But you realise that she actually manages quite well with it. She manages it a lot herself. She knows and she still tries to do things. She still likes to go out and walk around. But you realise it must be uncomfortable for her.”</p> <p>FC3 – “But a lot of it she manage herself....But she knows if it’s hurting she has to sit down or have a rest.”</p> <p>FC3 - “Um like all people some have high tolerance some have low tolerance.”</p> <p>FC4 – “Pain is--I think sometimes I find people with learning disability--some people that I come across--say they don't feel the pain, some of them. Or they get fixation or a thrill out of a pain, do you know what I mean, you know.”</p> <p>FC4 – “And I don't think he can take pain, with him.”</p> <p>FC4 – “In my experience I have--it's very--quite high. What I have seen.(pain threshold)</p> <p>FC4 – “it's like he is enjoying it. He will smack himself on the chest so hard. Very, very hard. And then keep on doing over and over again, and you can see the pleasure, you know, on his face.”</p> <p>FC5 – “I thinks it’s the same. (pain threshold) (Q) I think the pain is the same, but the way how they can cope with it is different. (Q) ...It’s how the people can cope with it.(Q) They</p>

cannot cope in the same way that I and you do. So isolated, they feel more stress, they stressing even if they have just a headache, you know, can get stress, irritable.”

FC5 – “They they find that they are more stressed, more agitated, ...They come in here, they’re telling whenever you go to the pharmacy and get an ibuprofen or Paracetamol, whatever they need, they just want your action immediately.(Q) Exactly. They cannot cope like.

IC7 – “she can accept great pain actually without complaining”

IC7 – “And she just seems to accept if there is a pain there that is norm because actually you know some people have got different pain thresholds”

IC6 – “Once..once she knows I’m taking her to the doctor’s, she gives in (Q) She admits to it. I say to her, “ You’re coming home. I’m phoning up. We’re going up the doctor’s. Booking a cab. We’re going up the doctor’s.” Once she knows it’s like that it’s as if she sits back and says ‘well actually I know I’m..I ain’t well, am I?”

IC8 – “he tends to try to forget it. That’s his way of coping with it, because, you know, he’s fed up of it. He’s fed up of his life sometimes. You know, because it’s been ongoing for him all his life.”

IC8 – “He’s got quite high threshold, I’ll be honest with you, very, like me. Again, that’s something we’ve built up, because if we didn’t, we wouldn’t have been able to live our life the way we have. So, you know, he’s got very high pain threshold.”

IC8 – “Again, that is, he tolerates a lot...Before he gets to that crisis.(Q) Because, because the thing is, I listen to a lot of people with learning disabilities, and what it is, is they say, well if you go to the doctors whenever heard, so then you’ve just got to develop it. This is your, you know, a way of living your life. It’s a mechanism.(Q) They’ve got no choice, really, because nobody else is valuing them. Or really listening to them. Or understanding them.”

IC9 – “Her tolerance is ok, she will tolerate the pain. Tolerate the pain and I will not say is hiding the pain, because you don’t know...”

IC9 – “Tolerance she can tolerate that, she can tolerate the pain.”

IC10 – “It is high (pain tolerance) because that’s what I was saying, that she hides pain”

IC10 – “Well because, S is a person that likes going, so when I see any difference then I know that she can hide pain. So maybe the time I find out that she’s in pain, then she must be really in pain.(high threshold)

IC10 – “I think their pain is more painful than ours because we feel the pain so quick and we take something to do something about it but they have to wait for you, they have to wait for us to you know, to do something for them, so I think they go through a lot. It’s very painful”

IC11 – “she can stand pain so if anything happens to her really really bad, she’ll show it but you don’t know how painful she’s in. Yeah, because she shows that you know that she’s in pain but if it’s really really bad, she still moves. Yeah, so it’s a bit different from us.”

IC11 – “I think that she can handle more pain than me. She could because when she’s in pain she wouldn’t say it. So she can handle. Because like even needle with me I’m going, she doesn’t do anything, just give her the arm. So she can even control pain more than me”

Understandings of pain

FC1 - “...some of them would not understand the concept of cause and effect, and some of them would, not, might be impaired to understand how one thing leads to another...”

FC2 – “like J, she’s not really understand she’s in pain because she have, don’t have any feelings.”

FC2 - “And all other resident which I work with, they all quite able to understand the pain.”

FC2 - “So, because we know, she’s understand so we give paracetamol”

FC2 - “Because of X, she’s quite able to understand and speak. For herself.”

FC2 - “They do understand when they need to bother someone and when they don’t.”

you know they feel, I think, when they need to tell stuff,”

FC2 - “I think the pain for them, it’s a pain, even if it’s a little pain, if it’s a big pain. It’s just a pain.”

FC2 - “Some, it’s I think it’s different in place only when it’s tooth pain. Or knee pain, or stomach pain. They’re not really bothered about stomach pain, I noticed, because they know when they eating something, they know it will stop, because they’re experienced. But like tooth pain, something, you know, something in the mouth, they starting, you know, panicking. Because this pain is not really experienced.”

FC4 – “He ends up saying things what we both know.”

FC4 – “he can talk on you, you have a mutual wish to understanding with X, you are on the same level”

FC4 – “I don't know if it's because we are more conscious, you know, of pain than them. Oh, and you thinking about, ‘oh what happens after?’. I think there are a lot of things--you consider a lot of things where it's probably, but they don't.”

IC8 – “this is this whole smoking issue, because he suffers from sinuses, and I'm wondering whether that's have, but how do I, you know make him understand that”

IC8 – “So then he is able to, you know, understand it, and then he's just able to choose that he doesn't need to, and he can have paracetamol.

IC9 - Yeah, to say what is wrong with them. But if you never talk about it, their brains is not functioning enough to tell them to say ‘you have a headache’, because they don't even know what you talking, what they have. But the parents of say, or even, to talk to them - ‘Is your head hurting you, does it hurt, have you got pain, pain?’ Talk to them, because in their mind they understand what you are saying, it's just that they don't verbally bring it out, some of them who cannot talk, but some who does that can talk, and if you let them know the name of pain, they would in return tell you they have pain. But if you never tell them, I don't think they will tell you.”

IC10 – “I think it's very hard for her to understand (period pain) so.. some might say that because of that problem they have taken some like, the doctors have given her some tablets to stop the period completely”

Mediating with Healthcare professionals

FC1 - “...So I took her to A&E and they did some tests and x-rays and they came out with the fact, with the diagnosis...”

FC2 – “Make appointment and go to hospital.”

FC2 – “We are going usually, we are phoning GP, if it's really emergency we are going to emergency hospital, yeah.”

FC3 – “obviously we go to the doctor a lot more and get the professional opinions”

FC3 – “I mean D was just sit there ‘cos there two of you so between you, you explain what the problem is. If D will let the doctor the doctor will check things. Then the doctor has to make a what, I suppose an educated guess more than anything.”

FC3 – “But generally your reliant on the fact that you've hopefully got a good GP who can spot things. Or at least we've got district nurses who come in every now and again to make sure people are ok.”

FC3 – “The only difference is sometimes the way NHS staff can treat people with learning disabilities, because the y don't treat them in the same way they would treat someone who, sort of, came in and properly tells them where the pain is, what's hurting, why it's hurting or whatever. So sometimes it is about the NHS and how they treat people rather, it's the fact that, certainly Newham is not brilliant at treating our guys. And the last one we had that went into hospital, G, was sent home after three days and he wasn't back to normal so.”

FC3 – “I think sometimes they get, certainly as front line services they don't get the same level of treatment. Once they're on the ward it's slightly different, there's obviously a bit more time. But they just don't get the, I don't think its deliberate, I think that obviously it's a bit more difficult to treat someone who can't tell you where it hurts. They've got to go and find it. And they've got to worry about personal space and whether it's a male or female. But we've got, we now have things, paperwork in process, which clearly show what his needs are, what his abilities, all that sort of stuff. And we took it out with last time we went to hospital with his epilepsy and they didn't even bother using it.”

FC3 – “The also time G went in half the stuff he needs they didn't have even though they've got it. And they didn't treat him right. We had to stick in a complaint.”

FC3 – “She has once already on a lower dose, and it got to, on the dose she's on, she's probably on the highest dose, so I don't know where they go from there. Will they change the painkiller or? I mean we are pushing for her to have the operation, but obviously that is down to the doctors and what they can do.”

FC3 – “Well we are liaising with the physio's but there's not much they can do. We, I'm gonna try going to the doctors to see if there's a gel or something.”

FC3 – “As far as anything internal goes he'll have regular medicals at the GPS for checks and things like that.

But with others it invades personal space so if it's something we can't visibly see and they are uncomfortable, then you have to go down that route with the doctors.”

FC3 – “you get a process sent through from their dentist, that said you know for 24 the time before you've gotta do this and the time after you've gotta do that...So you certainly, I mean with S you follow the process to follow the sugar water.”

FC3 – “When someone when I go into hospital I can tell them what the problems are and they can go from there... Although we've told them they've still got to do investigations.”

FC3 – “Again some of them are okay. Generally with G they come here, his doctors, and G is generally very good at talking with them and conversing with them.

FC3 – “And they will investigate whether anything's wrong with D”

FC4 – “Usually we don't leave; we don't leave it to us to make the judgement. We leave it to the professionals, the doctors, so we just ring up the doctors, if it's a, if the surgery is open; if not, we ring NHS direct for advice and guidance.”

FC4 – “or went to hospital, or went to see the doctor, phone the NHS direct phone because of what you can see, and then leave the professional to make that decision.”

FC4 – “If it's health issues just try and get them to be seen to by the professionals.”

FC4 – “But as I say, with the doctor--the communication, from doctor to the patients, brilliant in my experience.”

FC5 – “we haven't done the GP appointment for a while because she misses the appointment”

FC5 – “So when we ask her shall we make an appointment to go to the G.P and “ yes, alright”, but a few times she says “no let's wait”.”

FC5 – “Yes, well we support them to go to the dentist, full support, so we take all these instructions from the dentist and we follow up with them, you know if they have to have any antibiotics”

IC6 - They, they know, they know they can trust me. I know how far to let X go

IC6 - The doctor understands. He, he trusts, he knows I know how far to let her go.”

IC6 – “Oh very good. He is, isn't he? Very good.”

IC6 – “They were excellent”

IC6 – “Well the, I think the particular member of staff that took her..I do wish they'd have phoned me at the time and just got me involved. But the member of staff that took her wasn't particularly..wasn't one particularly..a member of staff I liked and one that was particularly kind with X and I think she must have..when she had her stitches..I..I can't imagine she was treated with compassion. That's what I think it is. That's what I think..I'm not saying staff at the hospital. But I'm thinking that the member of staff that took her.”

IC6 – “I mean It was kind that they actually thought to do that”

IC6 – “They really were thorough with her at (hospital). Couldn't fault them at all, could we?”

IC6 – “See as long as you know you can get on that phone to somebody and they will listen. This happens, we, we are very fortunate c'cos you hear of people that..they phone up and they like..don't really wanna know. That is when we'd have a problem. I think if we didn't, if we had no one to talk to, I mean the doctor..we can talk to the doctor...”

IC6 – “We've been very pleased.”

IC7 – “He's the, the surgeries that we go to really is very good indeed, you know. Just no..no problem at all with them. Anything that you do want they will sort it out”

IC7 – “We called up the doctor. And..very good, very quick.”

IC7 – “No the, both hospital and also doctors have been very good. You know, cannot fault them at all.”

IC8 – “A good, you know, consultant would be actually having like I say, a care pathway. You know this is what, you know really should have happened.”

IC8 – “So, I worked with him and he did that, to school, and the teacher just said, as if, you know, and joined it, so he never went back, because they said well, they think, they think it's all in my head.”

IC8 – “even GPs don't understand some of his disabilities, you know, and understand his limitation. It, you know, recently I had a conversation with, my GP's really nice, but even he said, you're trying to make him out more sick than he is. And I'm thinking, why would I want to do that? But I do know that he struggles. But it's like that, you know, they just don't grasp that part of it, the fluctuation part.”

IC8 – “Again, work with him, and try and get him to the GP, or trying to get him to the relevant person and talk to them. But it's really, really hard.(Q) And for them to understand where he's coming from. That please he won't open up.

and I tell the professionals.”

IC8 – “I've come to the GP first, and told them bits, and then encourage him to tell them bits, so then they've got a bigger picture.”

and then I referred him to the physio.”

IC8 – “I think people with learning disabilities struggle because they sometimes feel that they go to the GP and they don't get heard. So they think they are not doing anything for us anyway. Which is sad.(Q) Yeah, that's, well that has been for my son as well sometimes. Around his asthma as well, not recognising how life threatening it is, and how it is for him, you know, that impacts on his life.”

IC8 – “I'll tell you what, it's really frustrating, it's quite frustrating, because I don't think the health professionals don't see how difficult it is for a parent of learning disabilities. One time he was having an asthma attack, a life threatening asthma attack, and he didn't want the GP to come home, and he didn't want to go to the hospital. And I was scared, you know,

what am I going to do? So I had to phone NHS direct and say this is a dilemma, what do I do? She said well, you know, you've got to talk him into going. I said I've tried it, it's not working. Sometimes it works, sometimes it doesn't. What do I do? So then she said, "Well, I've got to talk to him." So then I took the phone up to him, in his bedroom, and then she talked to him, and then he listened. Sometimes they listen to other people more than they listen to you."

IC8 – "Yeah, with, throughout his medical life, we've had had some really good doctors, consultants with his asthma. But we've also had some people that haven't really understood him, as well. But I'd say majority of them, when I've looked back on them, we've had some really good doctors as well. It's just that they, you know what's the problem with doctors and consultants, is they just deal with one item. They don't look at them as a whole person. And especially for people with learning disabilities, because they only want to go to that one appointment, and get it over with. Because that's hard enough for them. But it's like people don't see that, they want them to go to this one, to that one, and they can't handle it. And they don't understand that."

IC8 – "that's really hard for me because my son's missing out on what he needs. Health wise, you know. I found out when you have brittle asthma, which is life threatening, that you're supposed to be on a multi-discipline care pathway. My son's never had that. Ain't that bad?"

IC8 – "You see this is the thing the hospitals don't even recognise. And I took him in one year with an acute asthma attack, and then he, you know, he had to have oxygen and whatever, and he started swearing at me, and the nurse thought he was being rude at me. And I'm saying he's not being rude, that's how he expresses himself. But they couldn't understand it, they don't grasp it."

IC9 – "if it is very bad I'll take her to the doctor"

IC9 – "But if the doctor never asks if you are in pain, and you cannot tell – you can tell the doctor you are in pain, but if somebody's not talking, and the doctor is doing his professional work, he probably should say 'are you in pain?'. But that was never asked of her, or me to say - 'Yes I think she's in pain, or no I don't think she's in pain.'"

IC9 – "The doctor...is able to, well she would interact when the doctor is doing his thing, and she wants to do her own as well. But the doctor will do what he has to do. He never mentioned to me she's in pain."

IC9 – "because I had to take her to the dentist to see why she was having this pain in her mouth, and he realised she had some bad tooth in her mouth. Well they had to put her under anaesthetic and tidy up the mouth for her; put filings and clean the tooth, teeth and whatever, and now she's sees the dentist every year because I can't check her. She would not sit in a dentist's chair. He had to do it for her while she's walking about and she move about in the surgery and well they try to keep her quiet but she do it at her own pace, she would go there over a period of time before she could actually take the toothbrush and she's brushing her teeth now for the dentist, and now she's sitting in the chair."

IC9 – "Just like the same way when I take her to the doctor – she not going to sit on no chair, don't put her in no chair. And she will stay there, and I remember she was a little girl, I bring her to the dentist, to the doctor, and the doctor actually say 'why you on my chair?' because she was in the doctors chair, so she sat in the doctors' chair and she take her stethoscope, she had the stethoscope in her hand being the doctor. And the doctor said ok you want to do it so the doctor was very patient and help her, and after a while he took the stethoscope and looked after her, and she was quite happy."

IC9 – "Yeah the people in there that are working probably will not know her pains, because these people are not experienced enough."

IC10 – "Yeah they couldn't see anything from it, I wasn't happy about that because they didn't get a clear picture coz they couldn't hold her. So, all they can say to me is "oh don't worry, we don't think there's anything wrong" but they didn't change anything and I'm so worried till now, so we've been seeing on and off with Dr.D and now we've see a chest specialist at [Place] centre and that's our 4th time to see him and him to have tried changing the pillow"

IC10 – "It's not easy. And it's always hard. I don't think she gets the real treatment like any other ordinary person will keep saying "listen, I'm taking this one and it doesn't go with me" and S is always like try and let her finish this and we'll see.(Q)Yeah, and let's try this and let's try this, so it's difficult. While any other person would say, "look I tried this and I don't like this because the pain goes to this part, the pain is there, I notice this way".(Q) Yes, and the difficulties that the doctors don't understand, I think they don't understand and I think they don't do proper checkups, they don't have any specialists, or whatever, or any other ways to go.. you understand me, through these children.(Q)... Well, not satisfied but I have to take it like that. I have to, what can I do? I can't do anything.(Q) Well... I mean, as I said the pain is not completely treated because she always hear that there's nothing that we can do to change S, she will be S for the rest of her life."

IC10 – "now the doctor has put us Doctor X, his name, is like when she's eating, so he sends some physio person we saw, her name was, I think M, last month, so she came to us to how S eats and see that if the cough is to do with how the food goes down. And I told her plain that S is a person that wouldn't rush food. Anywhere that she goes I always tell them I said

	<p>“please she takes time to chew what is in her mouth”</p> <p>IC10 - “for the past about 5 years now we have a new doctor, she’s a lady doctor so she understands a bit. So anytime when I find out any little difference or chance that S is not very comfortable or S is a bit funny she is always asking to bring her and she says to me now “tell me how she is?” or sometimes when I take her she doesn’t want to even go in the room to see her then maybe Dr.L will let her sit down and we go to the little small room and she will come to her and talk to her and maybe a smile will come from her face and she’ll maybe say let’s try this on her and everything will be alright, if not just bring her back. Like this woman now they have trying for the last three years, they don’t know exactly, but she’s been coughing coughing coughing and I was in such a stressful way because S can’t say “oh mum its chest pain” or whatever so that the language was, the GP was trying a lot of different ways. A cough mixture, antibiotics, we try all sorts of ways. So last year they sent us to [Place] to have like a chest S-ray and because S wouldn’t stay still for them, because you have to breathe in and hold the breath in before they can you know, it didn’t work. We were there for about an hour on and on they were trying put a jacket on, they need to stand on the back to do it with her and with me it didn’t work but the nurse said they would try and see whatever they did get and guess, whatever..”</p> <p>IC10 – “And maybe I’ll try the next day to book an appointment with the GP. She will always use every system as a check up and see like, blood pressure, weight, we were doing like, blood tests, but blood test are not easy to do with S..”</p> <p>IC10 – “And it’s always hard. I don’t think she gets the real treatment like any other ordinary person will keep saying “listen, I’m taking this one and it doesn’t go with me” and S is always like try and let her finish this and we’ll see.”</p> <p>IC10 - “the difficulties that the doctors don’t understand, I think they don’t understand and I think they don’t do proper checkups, they don’t have any specialists, or whatever, or any other ways to go.. you understand me, through these children.(Q) Well, not satisfied but I have to take it like that. I have to, what can I do? I can’t do anything.”</p> <p>IC10 - “Even not then, it’s always in my mind, coz these doctors don’t understand, I don’t think they do”</p> <p>IC10 - “Yeah and sometimes it’s like nobody’s listening to me and you think you’re on your own”</p> <p>IC11 – “Cos those times, I was taking her to the hospital, doctors more often because I don’t know what’s wrong with her. I know she’s ill. But I don’t know what’s. So the best thing is to take her to the doctors. For her....So I take her, the doctor exam her and still the doctors know what they are doing, yeah.”</p> <p>IC11 – “then I think there’s something wrong, so the best thing’s to take her to the doctors.”</p> <p>IC11 – “And if there’s a little bit change in her, then I take her to the doctor.”</p> <p>IC11 – “but all that she say is hate that doctor. So when we go to the London, he doesn’t check on her anymore. Yeah because she probably said, because I don’t like him. So because when she wake up I was there and the doctor was there trying to check pain the way she is. So she saw the face and said I don’t like him.”</p>
<i>Involving parents</i>	<p>FC3 - “But then with J his family come as well, one of his family members comes as well so they can help express it for him as well.”</p> <p>FC3 – “Liaise with his family”</p> <p>FC4 – “his mum is really involved in his day-to-day life. So we give her a ring, just tell her the situation, you know, she’ll help us as well. 'Cos she knows him better than any of us.”</p> <p>IC10 – “Well I hear about some of my parents the same way I’m talking to you, even if you did listen to the other time when you were there, I hear about you know, saying the same similar things as what I’m saying”</p>
<i>Thinking/talking for the person</i>	<p>FC3 – “If we take D in obviously we’re telling for him.”</p> <p>FC3 – “D we will do the talking for him”</p> <p>FC4 – “Cos you gonna have to start thinking for them.”</p> <p>IC6 – “I do help out but obviously I help for X to do what they want her to do. It’s no good me giving an answer for her.”</p> <p>IC6 – “They can’t rely on my answer, can they?”</p> <p>IC9 - “I know she’s not like me who’ll be able to talk, and I have to talk for her. So her voice is my voice. And my voice is her voice. That’s how I look at me and her, we are married together. And if she’s in pain, I’m in pain”</p>
<i>Trying medical and alternative solutions</i>	<p>FC1 - “obviously you’d take care of pain”</p> <p>FC2 – “Oh, they not taking themselves, they are given, when they need them.”</p> <p>FC2 – “take a medication, maybe it’s just something really easy and simple, just give the paracetamol or something. Sometimes, I am think, for X, if you give even, even, you know, a sweet or something, and you will tell her it’s a help. She, I think, her pain will stop.”</p> <p>I think it’s a good idea to do all this experiments, ...So I think it’s a good thing to give someone just a sweet sometimes and check is it pain stopped or not.”</p>

FC2 – “so we give paracetamol or something to cure the pain. And it’s just sometimes we don’t give nothing, so I just say, you know it’s not very good to give medication all the time, if it’s stomach pain just after food for example, and just ask her to go to lie down, and just wait and see what’s happen. If it’s not stop in two hours I will give you tablet.”

FC2 – “So sometimes I think we can avoid medication.”

FC2 – “So this is why I’m saying maybe you need to try, even give them some water in drops sometimes, and say it’s medication which will help you, and one day they will be healthy. I think it’s, everything will stop because they will be believing this is a medication, which are helping them.”

FC2 – “I don’t, they not understand so you can give anything to them. And if you will tell, it will help, they’ll believe it. They will believe you and they will be, you know, they will be better. So I, I think this is because X, she’s having just a, just accustomed big medication. And something for sleeping. Something to, to, you know, to, to calm her down or something like this. She’s, you know, if you will, if you will tell it’s from your stomach pain, so I don’t think she will have more pain in her stomach, because she will believe we are giving stomach medication for her stomach. So anything what you’re giving to them, you can explain what it’s particular, which kind of pain it will kill and they will believe you. And everything will stop”

FC2 – “I wait a bit. I try to calm them down, ask maybe we need to do something else, to take their mind in different direction, to talk about something else, go to draw or go colouring or do something. And you will see, you know, sometimes the pain, they just starting to do something and the pain is gone, you will see she’s not, no more conversation about pain.”

FC3 - “we’ve got a lady who does massages for some of the others”

FC3 - “we try to motivate him and get him to do things”

FC3 - “If he needs something we go and get it for him.”

FC3 – “To be honest there hasn’t been much we can do”

FC3 - “As far as it goes managing it goes as the staff team there not a lot we can do.”

FC3 - “Well we are liaising with the physio’s but there’s not much they can do”

FC3 - “So there’s not a lot they can do about, so it’s just something you have to manage with”

FC3 - “I believe’ is one I’m looking to look into with the doctor.”

FC3 - “We, I’m gonna try going to the doctors to see if there’s a gel or something. There must be something.”

FC4 – “It’s just--it’s trying everything you can. But if you strongly think that they are in pain, you could give them paracetamol”

FC4 – “You could try it. And see if that doesn’t work. Then probably fetch some colleague, GP, NHS direct for advice and guidance...”

FC5 – “trying to encourage her to go do some walks”

IC6 – “I make a cup of hot honey and lemon. And I know that she’s not well she must be in a little bit of pain. (interrupted) That’s when I give it to her. And I don’t..well I don’t give it to her unnecessarily.”

IC6 - “After she’s had the tooth..tooth thing I think I did. Probably. Just to be on the safe side”

IC8 – “he doesn’t like to take a lot of painkillers. So, you know, another suggestions should be made to him. But there’s never alternatives”.

IC8 - “I think it’s better than people are suffering in pain, so if he is in really bad pain, I’d rather him have the painkiller”

IC8 - “he’ll say to me, “Mum, can you do reflexology?”(Q) And it’s better than pain killer. And he prefers that himself. His choice, yes. Respecting his choice really.”

IC8 – “Well, I’ve had to use other methods, isn’t it? I’ve actually trained myself to do reflexology on him. I do the Indian head massage on him. I do a lot of like body massage on him.... we found that the cranial osteopathy worked for him, and I managed to wean him off a lot of the drugs.

it’s like encourage him to go swimming. And that helps him stay mobile and, you know, much more flexible. So, you know, that, so, again, it’s like listening to him, and then like encouraging him to do an activity that helps him.”

IC9 – “I rub her belly with my hand and she relax. I rub her belly and then she’s relaxed a little bit... so I give her two paracetamol and I’ll look into the mouth and maybe get a toothbrush, brush the teeth for her”

IC9 - “give her some paracetamol and she will settle herself”.

IC9 – “get something for her pain”

	<p>IC9 - "And I rub her belly"</p> <p>IC9 - "I will give her paracetamol and help her there, or even take a bit of oil because I have got...lavender oil and pass it on her forehead or on her foot."</p> <p>IC9 - "but if it's not very bad I just give her little hot drinks, rub her with Vicks or I've got some oil, and rub her feet and keep her warm and if I see the sign of a cold coming before I give her two paracetamol and the cold disappear."</p> <p>IC10 - Well when she has the pain what I do to make myself, you know, not to get too much stress, like I stop it, when to the centre coz I don't know, I say to myself what I would do they will do it. I know definitely it wouldn't be the same thing because it's not only her they're looking after at the centre but because now S has a one to one carer that I can tell her that this is what I want you to do."</p> <p>IC11 - "Normally, I will start with the doctor, OK"</p> <p>IC10 - "I don't give her painkillers all the time, I always try to do some other things with her like, massage especially when the foot is paining, massage the legs, or give her oil massage on her back. Recently I bought this headache oil that this man were selling at one of the meeting they say you just have to rub it on their chest for it."</p> <p>IC10 - "When I notice that she's still, the pain is not still not, past maybe half an hour and she's not still sitting down, then I add the painkiller on it."</p> <p>IC10 - "So I always try, she doesn't like tablets, so I was trying to hide it on her food, food that she eats but she found out and she doesn't like me to do it"</p> <p>IC10 - "Yeah she's not happy with that, so it takes time but then I cut it with like... 'cos she sees me taking some tablets out so I always take it with her, let her see that it's not going to harm her, like "look mummy's one". We make a little song, she likes music, and then she'll give me a smile and she'll take it in her mouth and I'll give her her favourite drink to go with it"</p> <p>IC10 - "get painkillers or do something with her and now I notice that she likes massage, so I'm trying to use some of her money to take her to private massage every month. "</p> <p>IC10 - "during period time, and I've started to use the foot bath thing, I just bought one last week for her foot, so see if it will massage her foot. And umm, next week we are going to start a special swimming lesson, as they said its good for her, for her lungs and all that."</p> <p>IC11 - "So, I just took her to the doctor. And I told the doctor you know we been to Ghana and back, by (med), we took all the tablets and everything and the injections and everything, we did. ...But with, with the (med), so I took her to the doctor, it wasn't malaria, but and so the doctor say OK. 'Cos they're not giving her the painkillers, if it continues she has to go for a scan."</p> <p>IC11 - "if it continues, before long there's still the same face and everything, then I take her to the doctor. Then I know it's really really bad."</p> <p>IC11 - "Something that need operation but my doctor says nothing that will hurt her, harm her. So if I like, I should let nature take its course."</p>
<i>Comfort</i>	<p>FC2 - "then you say "OK you will be fine""</p> <p>FC3 - "so you just support him".</p> <p>IC9 - "I try to give her comfort and help her and calm her down"</p> <p>IC9 - "Just sit down, comfort her... Give her comfort. Make her feel assured and I'm there for her."</p> <p>IC9 - "and I would cuddle her, you know, put my arms around her and hold her tight and say 'my X, my X' and rub her and kiss her,"</p>
<i>Perceived impact on the person in pain</i>	<p>FC2 - "Because they're watching you. So it's, it's all reaction of us, if we will be panicking or if we encourage them to do something quickly, straight away, the pain is even, it's become even worse."</p> <p>FC3 - "And it does limit what he can do."</p> <p>FC3 - "Obviously he's got goals that he would like to achieve but at the moment a lot of them can't happen."</p> <p>FC3 - "It makes it hard because he doesn't get out like some of the others."</p> <p>FC3 - "He's lucky if he's out once a week. Which means he gets a bit claustrophobic."</p> <p>FC3 - "But I think if he's in a lot of pain he'll sit down all day and won't do much."</p> <p>IC8 - "When, when he's having an asthma attack, and he's in pain and everything, because it all plays up. I'm sure it all triggers everything up, when he has an acute asthma attack. And he just wishes he's dead. He says that to me, he said, "Mum, I wish, you know, that I was dead"."</p>
<i>Impact on the caregiver</i>	<p>Frustration</p> <p>IC8 - "I'll tell you what, it's really frustrating, it's quite frustrating"</p>

Anger

IC10 – “And I was so so very very angry that I couldn’t find out”

Sympathy

FC5 – “You mean sorry for...I don’t know, I mean...(Q) If I see that she is really in pain, obviously yes. Obviously it’s part of your job, you know. And you see it every day or almost every day. It’s part of your job and obviously you feel sorry for someone you look after or you care.”

Worry/concern

FC5 – “I was actually more worried for him. I was worried for him”

FC6&7 – Well naturally we are concerned about it.

FC10 – “I’m so worried till now”

IC10 – “And then I said to the carer, I’m worried about S’s teeth”

Shock

FC3 – “At first it was a bit of a shock, ‘cos obviously never seen her like that before.”

Frightened

IC 10 – “because it really frightens me”

Painful

IC10 – “It’s still painful, but then there’s nothing I can do and there’s no way that you can...”

Stress

IC10 – “t is very stress, it’s very very painful.”

Upset/low mood

IC6 - “And that was upsetting”.

IC8 – “Yeah, they just ignore them really. And I think that’s sad. Think how can another human being treat another human being treat another human being like that? That kills me really, to be honest. I get very upset when that has happened to him. I get depressed about it”

With him, me and him, actually sit down and we do have a good cry.

IC10 – “That’s the one I don’t like, that’s when I get really, really down when I see her tears”.

Vicarious pains

IC9 – “When she’s in pain, I am in pain. It is just like when I’m doing for her, I get up in the morning to brush her teeth, I’m brushing my teeth. And the same way I feel I want my teeth cleaned, I want her teeth cleaned the same way. And the same way when she has pain, if she’s having the pain, I’m having the pain too. My belly aches, my heart aches... because I am in pain myself. My pain is not the abdominal pain she have, but it’s another kind of pain which I am feeling that ‘what can I do for her, what can I do to release her from the pain she’s in? Is there anything more I can do?’ And there is not much an answer than that for me. And the same pain she’s feeling, I’m feeling it. Because sometimes I stay home and it itches me for me to say she’s okay. I don’t like to see she’s in pain.”

No emotional impact

FC1 – “I’m sort of used to dealing with it so you pretty much react by taking action, taking the person to GP or the A&E, whatever the case. Was it distressful? Was it? No just probably my job I guess, I’m used to”

FC2 – “I’m not really worried... But, because I know them, so it’s not really for, it’s not really bothering...”

Content analysis coding tables

Overall question	Coding	Sub-coding	Description	E.G. of reference to transcript
What are adults with intellectual disabilities experiences of being in pain?	Descriptions of pain	Descriptions	Ache	SU1: 509
			Agony	SU3: 402
			Appalling	SU1: 54
			Bad	SU3: 266
			Badly	SU15: 352
			Burn	SU10: 212
			Burning	SU11: 245
			Cramp	SU1: 62
			Excruciating	SU4: 212
			Gyp	SU1: 230
			Right bad	SU3: 424
			In pain	SU2: 56
			'ow'	SU1: 16
			Painful	SU9: 12
			Paining	SU14: 250
			Pound	SU3: 368
			Horrible	SU6: 204
			Hot	SU14: 98
			Hurt(s)	SU15: 250
			Hurting	SU7: 172
			Jack	SU15: 60
			Killed	SU3: 616
			Killing	SU14: 294
			Rough	SU5: 52
			Scrunching	SU8: 336
			Shooting	SU3: 446
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			Splitting	SU6: 307
			Stabbing	SU1: 233
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Suffering	SU5: 270			
Swollen	SU4: 212			
Swelled	SU4: 214			
Swelled up	SU8: 269			
Sharp	SU5: 96			
Sharpness	SU1: 233			
Squeezing	SU6: 78			

		Terrible	SU4: 244
		Tighten	SU6: 210
		Thump(ing)	SU7: 104
		Trouble	SU11: 239
		Unbearable	SU1: 168
Descriptions of pain	Location	<u>Head/face:</u>	SU15: 134
		Earache	SU15: 180
		Throat	SU4: 444
		Head	SU8: 322
		Head(ache)	SU6: 116
		Jaws	SU8: 344
		Neck	SU3: 484
		Ears	SU8: 344
		Tooth(ache)	SU7: 108
		Around eyes	SU1: 345
		Eye socket	SU1: 333
		Across the eye	
		<u>Limbs:</u>	
		Arms	SU14: 112
		Leg	SU11: 167
		Knee	SU3: 28
		Feet	SU7: 162
		Hands	SU8: 104
		Toe	SU6: 307
		Knee	SU15: 300
		Hand/nails	SU8: 231
		Knees	SU14: 72
		<u>Torso:</u>	
		Back	SU2: 40
		Lower back	SU6: 72
		Chest	SU4: 254
		Tummy	SU15: 56
		Stomach/bellyache	SU3: 268
		Tummy(ache)	SU8: 321
		Shoulder	SU11: 151
		Hip	SU14: 185
		Ankle	SU10: 84
		Foot	SU10: 86
		Shin	SU10: 84
		Back	SU2: 2
		Hip	SU11: 36
		Bottom	SU11: 36

		Shoulder	SU12: 50
		Groin	SU14: 216
		<u>Internal structures:</u>	
		Arteries	SU5: 204
		Bowels	SU5: 110
		Heart	SU5: 154
		Spine	SU8: 50
		<u>Other:</u>	
		Underneath (catheter)	SU13: 204
		Here (gestures)	SU13: 398
		Top bit (of back)	SU4: 258
		Across and up sides (of back)	SU7: 4
		On the side	SU7: 146
Descriptions of pain	Negative connotations	Worst	SU10: 102
		Unbearable	SU1: 6
		Uncomfortable	SU4: 498
		Horrible	SU11: 229
		Terrible	SU7: 302
		Murder	SU8: 114
		Killed	SU3: 616
		Takes life away	SU10: 304
		Not nice	SU8: 340
		No fun	SU1: 236
		Hate	SU11: 251
		Not nice to see	SU10: 208
		Dislike	SU10: 290
Descriptions of pain	Severity	2	SU3: 271
		4	SU4: 573
		5/6	SU2: 212
		6	SU1: 463
		6/7	SU2: 278
		8	SU1: 258
		7/8	SU6: 335
		9/10	SU14: 169
		10	SU7: 216
		big	SU9: 380
		very	SU13: 468
		a bit	SU5: 10
		mild	SU3: 408
		little	SU4: 120
		thin	SU5: 284
		strong	SU14: 268

		so much	SU14: 120
		loads	SU8: 86
		Not too bad	SU4: 452
Descriptions of pain	Imagery	Like a knife sticking in	SU8: 118
		Swelled up like knives	SU8: 269
		Like electric	SU8: 336
		Like needles	SU8: 336
		Kicked like a horse	SU7: 10, 14
		Like someone kicked me	SU7: 172
		Electric shock going through system	SU7: 290
		Red hot	SU1: 60
		Like a fire, a red hot furnace	SU1: 62
		Hot molten ash	SU1: 58
		Drag/scrape across the wound	SU1: 238
		Like something shooting through the head	SU1: 14
		Like a fountain pen in one side of my face	SU12: 110
		I hear some bells	SU2: 112
		Hear the telephone ringing in my ears	SU10: 182
		Someone actually knocking on one of your bones	SU10: 182
		Someone's cutting them off (legs)	SU10: 96
		Like losing your favourite leg	SU10: 102
		Like someone knocking on your forehead	SU10: 102
		Like someone stabbed me through the belly	SU10: 116
Responses to pain	Medical investigations/treatment: Helped Sometimes helped Did not help	I felt my brain start to burst	SU10: 212
		Like having your head pinched in with something	SU10: 250
		X-ray	SU9: 558
		Operation	SU5: 98
		Hospital	SU5: 100
		Blood test	SU2: 46
		Medication	SU15: 160
		Stitches	SU9: 514
		Tablets	SU11: 149
		Eyes tested	SU3: 176
		Paracetamol	SU9: 346
		Plaster	SU15: 318
		Wore a support	SU3: 366
		Ice	SU11: 270
		Gel	SU8: 100
		Painkillers	SU12: 155
		Tablets	SU6: 58
Antibiotics	SU1: 248		
Cast	SU2: 208		
Pharmacy	SU2: 108		
Cream	SU11: 399		

		Bandage	SU10: 252
		Chiropodist	SU6: 315
		Ambulance	SU9: 558
		Glue	SU10: 316
		Scan/ultrasound	SU3: 254
		Ibuprofen	SU10: 44
		Dress it	SU8: 253
		Cooling pack	SU8: 179
		Physio	SU5: 18
		Walk in clinic	SU8: 24
		<u>Helped –</u>	
		Medication	SU5: 214
		Tablets	SU3: 136
		Eye test	SU3: 189
		Paracetamol	SU3: 300
		Antibiotics	SU1: 62
		Physio	SU10: 56
		Antibiotics	SU2: 16
		Antivirals	SU2: 32
		<u>Sometimes helped –</u>	
		Medication	SU4: 466
		Painkillers	SU2: 264
		Cream	SU9: 34
		Paracetamol	SU6: 305
		<u>Did not help -</u>	
		Medication	SU4: 220
		Meds give more stress	SU11: 207
		Not given when needed	SU8: 128
		Injection – made it worse	SU3: 290
		Painkillers	SU14: 134
Responses to pain	Emotional impact	Angry	SU13: 430
		Down	SU3: 500
		Tired	SU3: 286
		Irritable	SU3: 368
		Bored	SU15: 404
		Miserable	SU13: 380
		Worry	SU14: 256
		No worry	SU13: 398
		Pissed off	SU7: 204
		Shout	SU1: 351

		Bang pillow	SU1: 507
		Frustration	SU1: 274
		Uptight	SU1: 66
		Unhappy/not happy	SU6: 297
		Depressed	SU1: 505
		Annoyed	SU2: 234
		Happy	SU9: 268
		Relieved	SU9: 268
		Irritable	SU6: 415
		Depressed	SU5: 252
		Feel sorry for yourself	SU5: 109
		Confused	SU3: 226
		Grumpy	SU4: 128
		Sad	SU5: 64
		Browned off	SU4: 68
		Feels sorry for self	SU10: 162
		Not happy/unhappy	SU11: 101
		Upset	SU13: 70
		Loose temper	SU1: 208
Responses to pain	Tell/do not tell others	Did not tell others	SU8: 56
		Sometimes tell	SU9: 362
		Told father	SU13: 264
		Told staff	SU13: 432
		Kept it quiet	SU5: 216
		Tell nurses	SU2: 42
		Tell Doctor	SU6: 60
		Told governor	SU7: 14
		Told mum	SU15: 160
		Chemist	SU3: 104
		Tell someone	SU11: 220
		Ask family	SU14: 16
		Call	SU14: 96
		Told friend	SU10: 74
		Told sister	SU10: 86
		I said Im in pain	SU10: 220
		Tell others – little bit of pain. Don't tell if I'm not in pain	SU9: 368
		I think its not worth letting them know	SU8: 213
		He's got no one to turn to	SU1: 32
		Tell someone	SU10: 154
		Friends	SU4: 160
		Tell family	SU10: 46
		Tell mum	SU8: 16
		Tell a Professional	SU15: 84
		Partner/wife	SU9: 230

		999	SU9: 232
		Ambulance	SU12: 20
		Tell anybody	SU2: 174
		Mum	SU6: 152
		Psychologist	SU9: 250
Responses to pain	Impaired mobility/activities	Cannot fall	SU4: 198
		Cannot walk properly	SU8: 110
		Cannot lay down	SU4: 306
		Hard to sleep	SU4: 309
		Cannot sleep	SU10: 194
		Cannot shop	SU11: 163
		Cannot bath properly	SU4: 161
		Dressing	SU4: 604
		Running around	SU15: 360
		Laying down	SU15: 364
		Cant go out	SU15: 364
		Cant lie on side in bed	SU8: 304
		Cant get up by self	SU8: 344
		Stops to go shops	SU7: 306
		Stops to do things	SU7: 308
		Hard to get up	SU14: 114
		Can't get up	SU14: 112
		Out of school	SU2: 234
		Couldn't move	SU2: 40
		Limp	SU10: 70
		Couldn't move leg	SU10: 104
		Crying	SU10: 250
		People don't want to go out	SU12: 222
		Stops you walking, going out	SU14: 322
		Stops you doing housework	SU2: 299
		Miss stuff	SU2: 301
Responses to pain	Alternative pain management:	Cold cucumber on face	SU14: 68
		Showered	SU13: 444
		Relax	SU14: 96
	Helped	Take mind off	SU3: 290
	Did not help	Lay down	SU12: 124
		Try and shut it off	SU8: 296
		Gargle salt water	SU3: 408
		Watch TV	SU10: 124
		Time off work	SU7: 24
		Go for a walk	SU11: 195
		Sleep	SU10: 178
		Sit down	SU7: 144
		Drink water	SU14: 58

		Stretch	SU10: 98
		Hot bath	SU10: 98
		Take your mind off the pain	SU10: 150
		Eat fruit/bran	SU14: 90
		<u>Helped –</u>	
		Frame for support	SU7: 174
		Sleep	SU10: 182
		Sit	SU7: 286
		Glasses	SU6: 123
		Relax	SU14: 45
		Rehydrate	SU14: 45
		Water	SU9: 34
		<u>Did not help –</u>	
		Cushion	SU4: 318
		Walk with frame	SU8: 152
		Put feet up	SU8: 152
		Take it easy	SU2: 122
		Sleep/lie in bed	SU14: 202
		Crawl	SU1: 80
		Leave it for 24 hours	SU1: 84
		Lay off the sherbet	SU1: 90
		Salt and tonic	SU1: 90
		Water	SU12: 90
Responses to pain	Response of others	Find it funny	SU4: 232
		Laugh	SU4: 234
		Disbelief	SU4: 238
		Mum helped	SU15: 322
		Upsetting others	SU1: 272
		They wouldn't like it	SU13: 122, 190
		Gets upset	SU13: 192
		I don't wanna hurt them/to be near me	SU1: 605-609
		Worried	SU10: 106
		Got nurse	SU13: 294
		Not worth it (letting them know)	SU8: 213
		Wrote it down	SU3: 294
		Told Doctor	SU9: 358
		Sometimes he comes (Doctor) sometimes he says no	SU8: 156
		They don't take no notice	SU8: 158
		They say you've got to wait you've had some PK	SU8: 60
		Sometimes they give me paracetamol	SU8: 66
		She says 'put water and cream on'	SU9: 364
		They didn't do nothing	SU2: 220

			They didnt find nothing wrong with it 'take it easy' Supermax needed. They don't get no supermax. Say I want to take the stick but they say no People make me go sleep so that pain will finish Making me walk Story re: broken arms Ignore me, let me suffer They take no notice They think its all in my head They don't help Nothing much happened (after telling someone) She just lets me sit and suffer Staff don't want to help – have favourites I know they can't do nothing for it They can't take it away, get annoyed They are trying to help me through the pain barrier Dont want to wake anyone up Friend – turning it into a joke and laughing She said 'why don't you go to Doctors' Massage it She ask you to take meds	SU2: 218 SU12: 120 SU14: 74 SU14: 222 SU14: 270 SU14: 218 SU14: 272 SU2: 218 SU8: 213 SU8: 136 SU8: 136 SU4: 618 SU4: 282 SU8: 134 SU8: 96 SU7: 238 SU7: 240 SU1: 507 SU1: 32 SU10: 106 SU10: 106 SU10: 128
	Responses to pain	Hiding pain	I can sort of hide it I hide it a bit I keep that one private, to myself You don't know if he's hiding or pretending I try not to show my pain so my manager wont know I'm injured It's hard to tell someone Cos I don't tell someone do I? I'd wait don't want to waste their time Not telling someone your in pain too frightened to, how they'd react, angry, my sister acts,	SU7: 228-230, 232 SU1: 365 SU1: 467 SU1: 46 SU10: 88 SU1: 6 SU1: 22 SU1: 30 SU1: 557 SU6: 248-266
	Responses to pain	Questioning genuineness	Are they putting it on? They think it's all in my head They think I'm making it up Are they putting it on? Thats no fake That looks real genuine You don't know if he's hiding or pretending He doesn't look convincing to me They can tell what is genuine pain and what is not	SU4: 626 SU8: 326 SU8: 326 SU4: 626 SU1: 82 SU1: 182 SU1: 46 SU1: 48 SU1: 42
What meaning do adults with intellectual disabilities give to pain?	Cause of pain	Health problems Physical environment	<u>Health problems</u> Arthritis	SU3: 4

Injury	Arteries	SU5: 148
Bodily function	Asthma	SU5:1 70
Movement	Appendicitis	SU5: 192
Weather	Bunion	SU4: 556
Unknown	Catheter	SU13: 190
Damage to body	Cough	SU4: 182
Just happens	Constipated	SU14: 98
	Rheumatism	SU5: 192
	Being overweight	SU7: 8
	The nerve	SU8: 285
	Ulcer	SU7: 178
	Wisdom teeth	SU3: 480
	Hernia	SU7: 6
	Migraine	SU2: 102
	Retinal dysfunctional degenerative	SU1: 321
	Catheter	SU1: 144
	Infection	SU1: 44
	Epilepsy (fits)	SU6: 372
	Finer prick test for blood sugar level	SU6: 353
	IBS	SU2: 110
	Eczema	SU14: 154
	Migraine	SU1: 126
	Indigestion	SU3: 206
	Infection	SU7: 76
	Blood clot	SU7: 76
	Heart attack	SU1: 78
	Stroke	SU1: 82
	Headache	SU1: 98
	Brain tumour	SU1: 94
	Gout	SU1: 531
	Tonsillitis	SU1: 533
	Infection	SU11: 249
	<u>Environment</u>	
	Noise	SU13: 124
	Food went off	SU6: 136
	Fast rides	SU3: 540
	Lights	SU3: 562
	Not wearing glasses	SU6: 116
	Keeping working	SU14: 66
	Working brain too hard	SU10: 108
	Too much to drink	SU10: 178
	Bad curry	SU10: 190
	Boots too small	SU10: 100

Unknown/desired

Just see the real reason its happening	SU8: 144
What can they do?	SU7: 358
Why wont they go away?	SU1: 437
Why go through it? Why am I punished?	SU1: 625

Injury

Slipped disc	SU3: 54
Sprain	SU7: 16
Strain	SU8: 316
Knocked down	SU7: 295
Break legs	SU7: 295
Someone kicks you	SU7: 295
Knock/bump into things	SU7: 295
Cut	SU1: 503
Bruise	SU14: 288
Break bone	SU14: 292
Slip over	SU14: 256
Burn	SU13: 424
Fall downstairs	SU4: 200
Dropped item on foot	SU7: 16
Foot crushed	SU7: 14
Twist foot	SU7: 172
Broken arm	SU9: 562
Tripped over	SU9: 560
Bang arm	SU2: 56
Cut hand	SU14: 244
Knife attack	SU9: 516
Slipped	SU10: 74
Crate thrown	SU10: 236
Stepped on toe	SU10: 220
New shoes	SU13: 534
Toenails being cut	SU13: 535
Bee sting	SU9: 2
Shot	SU12: 150
Something drops on it	SU10: 286
Objects falling	SU10: 286
Slip over	SU14: 40
Run over	SU9: 508

Just happens

'Just do'	SU4: 336
Don't know really, just does (go away)	

SU7: 288

Weather

Weather
Hot weather SU5: 188
Cold weather SU4: 397
Hot SU3: 350
The sun SU3: 350
SU3: 126

Movement

Walking SU10: 92
Walking too quickly SU12: 54
Bending down SU8: 271
Getting out of bed SU13: 522
In wheelchair SU8: 78
Moving around SU8: 88
Sitting down SU1: 224
Didn't bend knees SU1: 224
SU10: 36

Body function

Diet – not enough fibre
Going to the toilet SU5: 228
Breathing SU13: 344
Eating SU5: 152
Age/getting old SU13: 364
Period SU3: 266
Labour/child birth SU5: 182
Wind SU3: 258
Pregnant SU12: 146
SU6: 403

Emotions

Sad pain – when you loose someone, when you loose a limb
Nice pain – won some money SU1: 559
When my cousin passed away, hurt me alot, SU1: 561
Pain is something, can be physical or an emotion SU10: 724
Stress SU10: 270
Somebody died SU2: 126
Upset SU9: 130
Unsettled SU11: 233
Sad SU11: 233
Unhappy SU11: 235
When you do something wrong SU11: 235
Worried SU9: 602
Anger SU9: 608
SU12: 198

	Coping with pain	Control	I just try and shut it off best I can It shouldn't be that way, I should feel ok I got to control that Help him have things controlled, losing control Just chuck it in the bin. I have to do myself.	SU8: 296 SU11: 184 SU11: 149 SU11: 89 SU7: 240
	Coping with pain	Helplessness	It doesn't go away I just have to sit and wait till its time for my PK They're non-stop – they never go away Hopefully it will go away If you do anything you get pain I don't know when the pain will finish He probably couldn't do that much (about the pain)	SU8: 114 SU8: 203 SU8: 324 SU7: 284 SU7: 304 SU14: 256 SU2: 26
	Coping with pain	Not bothered	It doesn't bother me I just went on about my day as usual I've got to get over the pain – like it's not meant to happen I don't care about the pain (wants to play football) Whether it hurts I'd just take it I enjoy football so I've got to get over the pain that's how it is I live with the pain. I play football with the pain. I'm quite used to it. Pain is not a big deal Things never stop me, I'm stubborn, always want to play with my pains	SU5: 200, 202 SU10: 202 SU10: 90 SU10: 88 SU10: 60 SU10: 90 SU10: 206 SU10: 312 SU10: 206
How do adults with intellectual disabilities understand pain?	Concepts regarding pain	Reduction	Don't know Lie on bed Special bed Pop feet up Bath Massage Relaxation Painkillers Take mind off it Swimming Listen to relaxing music Hot shower Sit down Lose weight Walk around Fruit and veg Physio Hospital Report to staff X ray Cream	SU15: 367 SU8: 384 SU8: 374 SU8: 384 SU3: 656 SU3: 660 SU3: 596 SU7: 322 SU3: 710 SU3: 642 SU3: 648 SU7: 320 SU7: 244 SU7: 244 SU13: 476 SU5: 290 SU5: 222 SU12: 224 SU3: 694 SU5: 318 SU13: 456

		Bath	SU7: 340
		Massage	SU7: 266
		Sleep	SU14: 364
Concepts regarding pain	Induction	Fall over	SU4: 598
		Hot weather	SU13: 383
		Bending too much	SU3: 632
		Overdoing it	SU3: 628
		Sitting about in chair	SU8: 378
		Exercise	SU8: 382
		Jogging	SU3: 613
		Sit ups	SU3: 613
		Bikes	SU3: 612
		Bend over	SU7: 328
		Hotter room	SU2: 142
		Sit around	SU6: 431
		Walk without relaxing	SU14: 280
		When you think about it	SU9: 618
Concepts regarding pain	Urgency	Straight away	SU1: 114
		No hanging around	SU1: 96
		Go straight to A&E	SU1: 180
		Urgent treatment	SU1: 158
		Tell someone urgently	SU9: 232
		Dr if its an emergency	SU2: 168
		You should get treatment right now	SU2: 172
		You shouldn't wait till it gets worse	SU10: 316
Concepts regarding pain	Prevention	Prevention – burning	SU13: 556
		Look where you are walking	SU7: 318
		Look where you are going	SU7: 318
		Look after yourself	SU7: 222
		Be careful what you eat	SU7: 222
		If you go early, you can prevent it	SU1: 533
Concepts regarding pain	Wait and see	It its worse go and see Doctor	SU10: 44
		If its not that serious	SU10: 54
		If next morning still pain... Dr ,stretcher	SU10: 62
		Not too serious give painkillers, when worse call ambulance	SU7: 332
		Painkillers - if got worse ambulance	SU7: 56
Pain in other people	Signs:	Facial	
	Facial	Face tightened	SU6: 285
	Limbs	Clenching	SU1: 367
	Holding	Squinting	SU1: 367
	Actions	Face drops	SU3: 588
	Symptoms	Mouth	SU2: 154
	Misc	Eyes	SU2: 156
		Crying	SU4: 72

Grimace	SU13: 164
Face	SU8: 2
Clenching teeth	SU5: 6
Gritting teeth	SU1: 20
Face screwed up	SU8: 243
Teeth showing	SU8: 2
Eyes shut	SU7: 138
Eyes lopsided	SU1: 76
Head	SU1: 108
Lip dropping	SU6: 106
Facial expression	SU2: 6
Face scrunched up	SU6: 10
Eyes closed	SU6: 14
Distress in face	SU2: 8
Face bloated	SU12: 130
Face moody	SU12: 48
Moving mouth	SU10: 156
<u>Limbs</u>	
Arms	SU7: 84
Fist	SU13: 58
Hands	SU8: 261
Arm down there	SU4:148
Scratching arms	SU5: 6, 8
Put hands up	SU11: 8
Knees bent	SU6: 166
Feet up	SU9: 196
Standing awkward	SU10: 162
Put hand on head	SU14: 52
<u>Holding:</u>	
back	SU4: 20
legs	SU5: 104
stomach/belly	SU1: 148
it	SU3: 206
head	SU1: 94
side	SU7: 34
curled up	SU7: 138
Clinching belly	SU2: 148
Shoulder	SU12: 46
Touching his back	SU10: 15
Touching forehead	SU10: 156

Actions

		Scratch	SU1: 44
		Making a funny noise	SU15: 238
		Tummy screeching	SU3: 12
		Going 'oow'	SU3: 70
		Going 'uhhh'	SU11: 99
		The way he's walking	SU11: 69
		Growling	SU10: 210
		<u>Symptoms</u>	
		Dizzy	SU1: 155
		Illness inside	SU1: 152
		Crouching down	SU1: 108
		Blood rushing	SU1: 156
		Pale	SU2: 4
		Clenching stomach	SU14: 2, 6
		Marks on back	SU9: 196
Pain in other people	Recognisable by others	Only him /her	SU7: 48
		Parents	SU1: 188
		Mum	SU8: 245
		Father	SU11: 107
		Family	SU8: 167
		Staff	SU3: 150
		Caregiver	SU11: 30
		A&E staff	SU3: 38
		Friend	SU5: 28
		Doctor/nurse	SU1: 114
		Someone should surely know	SU1: 184
		Others	SU9: 146
		People they live with	SU2: 80, 166
		A little bit (would know)	SU12: 96
		Family shes surrounded by	SU10: 164
		Anyone who he was showing	SU10: 40
Pain in other people	Recognitions of similar pain	I get that	SU11: 2, 4
		Same place as theirs	SU13: 136
		Ah this is me	SU15: 234
		Just like I do, exactly	SU1: 20
		I know what that's like	SU1: 24
		That's how I felt	SU1: 194
		I know exactly what he's going through	SU1: 182
		When I have pain..	SU6: 2
		I had a pain like that	SU6: 178
		That's what happened when I..	SU10: 36