Abstract

An Evaluation of the Methods Used by Community Mental Health Clinicians to Assess for Pain in People with Dementia who Live at Home

By Lauren Fordham

Key Words: dementia, cognitive impairment, pain, assessment

Existing literature indicates that healthcare professionals are not adhering to the national guidelines for pain assessment in people with dementia, although this group of people are vulnerable to experiencing unrecognised pain. Unidentified pain can have negative consequences for the person with dementia and in the quality and cost of healthcare services. This project aims to evaluate which approaches community mental health clinicians in one organisation are using to assess for pain in people with dementia who are living at home and it used a questionnaire and a focus group to collect information. Forty-six clinicians responded to the questionnaire and nine volunteered for the focus group. The findings indicate that the clinicians were overall 77.4% adherent to the national guidelines and all participants identified the presence of organisational barriers to achieving effective pain assessment. The focus group identified that a drive for improvement in pain assessment was a core theme and five distinct themes emerged from the data: there is a pervasive belief that pain is inevitable with older age, there are barriers to achieving effective pain assessment, knowing the person with dementia is considered important, the role of the family is influential in pain assessment and there are reservations about the role of pain assessment scales. Clinical recommendations are made.

An Evaluation of the Approaches Used by Community Mental Health Clinicians to Assess for Pain in People with Dementia who Live at Home

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The topic of this thesis was inspired by my work as a physiotherapist working with people with dementia. We often work without verbal language and I find this poignantly rewarding. Thank you to everyone I have worked with for sharing your experiences and for your patience while we surf the spectrums of communication.

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I sit on the committee for the Chartered Physiotherapists in Mental Health and I would like to acknowledge the ongoing work this group undertakes to the profession of physiotherapy in this specialist area. We are few in number, but we touch many lives and have the opportunity to give value to people at their most vulnerable. I hope this thesis can contribute to our specialist area.

The organisation that features in this project financially sponsored this work and I would like to thank the committee for their decision. Discussions with members of the organisation reveal an overarching drive of genuine compassion and desire to improve care for people with dementia. I thank the clinicians that have been keen to reflect on their practice and have had the courage to examine areas where they can improve. Marie Hickman deserves a personal acknowledgement for her diligence in chasing publications from all over the country and for her patience when I lost track of which ones I had and had not requested! Thank you Marie.

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List of Abbreviations

DOH	Department of Health
BPS	British Pain Society
BGS	British Geriatrics Society
NICE	National Institute for Health and Care Excellence
PACSLAC	Pain Assessment Checklist for Seniors with Limited Ability to Communicate
PAINAD	Pain Assessment in Advanced Dementia
Dis-DAT	Disability Distress Assessment Tool
DS-DAT	The Discomfort Scale for Patients with Advanced Dementia of the Alzheimer's Type
MOBID	Mobilization Observation Behaviour Intensity Dementia Pain Scale
MOBID-2	Mobilization Observation Behaviour Intensity Dementia Pain Scale 2
CNPI	Checklist of Nonverbal Pain Indicators
CPAT	Certified Nursing Assistant Pain Assessment Tool
NOPPAIN	The Non-Communicative Patient's Pain Assessment Instrument
PADE	Pain Assessment for the Dementing Elderly
ADD	The Assessment of Discomfort in Dementia Protocol
PBOICIE	The Pain Behaviours for Osteoarthritis Instrument for Cognitively Impaired Elders
FLACC	The Face, Legs, Activity, Cry and Consolability Pain Assessment Tool
PACI	Pain Assessment in the Communicatively Impaired
PATCOA	The Pain Assessment Tool in Confused Older Adults
EPCA-2	Elderly Pain Caring Assessment 2
PBC	Pain Behaviour Checklist

1 Chapter 1 - Introduction

This project is concerned with the recognition of pain in people with dementia and how this is being achieved in a healthcare organisation in terms of adherence to national guidelines. This chapter will define the principal concepts of pain and dementia and will outline them within in the context of the project. External and local drivers will be described and how they are underpinned by motivations to improve pain recognition in people with dementia. The management problems and rationale will be presented and the aims and objectives of the project will be stated.

1.1 Background

The term dementia has been described as pertaining to “loss of memory, mood changes and problems with communication and reasoning” (Alzheimer’s Society, 2012a, p.4). In the United Kingdom, 800,000 people have been diagnosed with dementia and this is predicted to increase to over a million by 2025 (Alzheimer’s Society, 2012a; Dementia Action Alliance, 2010). The incidence of dementia increases with age and so the population with dementia also frequently experience physiological pain as a result of physical ailments common to older people, such as stiffness in the joints (Zekry et al., 2008). The research indicates that between 47% and 66% of people with dementia also experience pain (Zwakhalen et al., 2009; Ferrell et al., 1995; Feldt et al., 1998). The International Association for the Study of Pain (2012) defines pain as “an unpleasant sensory and emotional experience” and Kaasalainen offers the following definition, pertaining to pain in people with dementia, “an unpleasant subjective experience that can be communicated to others either through self-report, when possible, or through a set of pain-related behaviours” (2007, p.571). The most common causes of pain in older people include osteoarthritis, osteoporotic vertebral fracture, peripheral neuropathy, cancer, polymyalgia rheumatic and peripheral vascular disease (BPS and BGS: British Pain Society and British Geriatrics Society, 2007). There is evidence that pain can cause agitation, depression, poor sleep, reduced satisfaction with life, impaired movement ability and can also be associated with a greater risk of falling and disability in people with dementia (Lin et al., 2011; Forsyth, 2007).

There are different types of pain and these can occur in the short-term, termed acute pain, or in the long term, termed persistent pain (BPS and BGS, 2007). The majority of the literature on pain assessment does not differentiate between different types of pain and so it is not feasible to segregate assessment for the different types of pain in this project. The literature on pain assessment also evaluates people with dementia as a homogenous group and does not differentiate between different causes or presentations of dementia, consequently this project is unable to differentiate between different types of dementia.

1.2 Project Drivers

A PEST Analysis was undertaken to collate the drivers and this is illustrated in Appendix A. The management tool indicates that there are a number of national publications that incite organisations to address failings in pain assessment and a failure to manage pain has been cited as amounting to professional neglect (Parliamentary and Health Service Ombudsman, 2011). Other authors have identified how inadequate pain management could result in litigation (Schofield et al., 2007) and have acknowledged pain management as a fundamental human right (Brennan et al., 2007). The BPS and BGS (2007) are responsible for publishing the British National Guidelines for Pain in Older People, and forms the benchmark for this project. The main issue is that the research suggests these guidelines are not being adhered to by healthcare professionals (Allcock et al., 2002; Herr et al., 2004; Williams et al., 2005; Stolee et al., 2007) with the commonly cited reason being that the advocated gold standard for pain assessment is to ask the person if they are in pain, and this can be challenging when pertaining to a person with dementia since their symptoms often include difficulties with speech and expression, impaired recall and difficulty interpreting experiences (Buffum et al., 2007). People with dementia form a majority population of users of the service in question and so it is possible that the poor adherence found in other settings might apply to the organisation that is the focus of this project.

The organisation in question provides healthcare to people with dementia in inpatient facilities and in their own home. No studies have been identified that evaluate pain assessment approaches for people with dementia who live at home and this population is increasing secondarily to local service changes, motivated by national drivers, to help people remain at home longer (Department of Health: DOH, 2009). The consequences of untreated pain might result in the person with dementia living at home becoming unsustainable and so this project will examine the practices in the home setting as the highest priority.

Dementia should be recognised as a terminal condition (Alzheimer's Society, 2012b) and a very current driver is that the Dementia Lead of the organisation in this project is developing a new policy for end of life care, to achieve a systematic approach to preparing a person and their family for end of life. Palliative care recommendations specify that pain assessment is undertaken and if the person cannot verbalise their pain, it specifies that their behaviour is observed (National Institute of Health and Care Excellence: NICE, 2006). The Alzheimer's Society supports this notion and recommends that "all people with dementia should be free from pain at the end of their lives, with training and systems designed to detect and manage pain even if communication is diminished" (2012, p.19). In light of this, for a comprehensive palliative care policy to be implemented, it is essential to ensure that the training and management systems are in place for effective pain assessment and it is not possible to do this until information is known about the existing approaches and their consistence with national guidelines.

A local driver for this project is that unidentified pain in people with dementia living at home has resulted in inappropriate admissions to the mental health inpatient unit. This is because the behavioural signs of pain can mimic other behaviours that might be secondary to the process of dementia and it can also temporarily increase cognitive impairment (BPS and BGS, 2007; Alzheimer's Society, 2012b). An example of this is Mrs. P, a lady who was admitted from home where she was reported to have been resisting staff when being helped to move. When assessed on the ward it was identified that this lady had a painful condition and was only resisting movement because the interventions by staff to help her move were causing her pain. The conflict ceased when her pain was treated. Inappropriate admissions are costly for the organisation, at approximately £264 per person per excess bed days (DOH, 2012). In conclusion, better pain assessment in the community setting might help prevent unnecessary hospital admissions, which have a high financial cost and is detrimental to the well-being of the person with dementia.

1.3 Rationale

The rationale for the topic of this project is that pain is under recognised and undertreated in people with dementia (Horgas and Tsai, 1998) and this has been shown to significantly reduce quality of life for this population (Cipher and Clifford, 2004). The main issue is that this pain assessment practices have not been looked at in the organisation under evaluation and there is no existing literature on what approaches community mental health clinicians adopt to assess for pain.

1.4 Aims and Objectives

This project aims to collect and analyse data on the approaches being used by community mental health clinicians to assess for pain in people with dementia who live at home. The objectives subsidiary to the aim are:

- To complete a literature search to inform the project and guide the methodology
- To identify what approaches community mental health clinicians are using to assess for pain in people with dementia
- To establish adherence to national pain assessment guidelines published by the BPS and BGS (2007)
- To collect information from clinicians regarding any organisational barriers they may be experiencing that are impeding pain assessment practices
- To produce clinical recommendations

2 Chapter 2 - Literature Review

This chapter describes the methods of collecting and collating the literature relevant to the topic of pain assessment for people with dementia. The results of the literature search are presented in a critical review and links are made between the findings and the project at hand. Gaps in the literature are identified. The literature review contains the national guidance publications, literature relevant to pain assessment approaches, methodological approaches to evaluating pain assessment practices and barriers to pain assessment.

2.1 Search Strategy

A basic search of CINAHL was completed using “pain” and “dementia” and the keywords of the first twenty relevant papers were extrapolated to produce the search terms for this literature review. The outcome was the following: (pain) AND (assessment OR scale OR measure*) AND (dementia OR cognitive impairment OR alzheimer* OR non-verbal adults). Three online sources of journal articles were searched: CINAHL was chosen with the aim of identifying relevant practice research, AMED was chosen to identify any literature in the field of rehabilitation and palliative care and Psychoinfo was searched to identify the papers that were categorised into mental health fields. Table 1 presents the results of the literature search and its results.

Table 1: The literature search strategy and results for journal articles pertaining to pain assessment for people with dementia

<table>
<tr><td colspan="4">Inclusion criteria: Literature pertaining to the assessment of pain through behavioural observations, guidelines and reviews on assessing pain in dementia care and literature on barriers to pain assessment for people with dementia.
Exclusion criteria: Literature including assessment through self-report, unpublished literature, teaching articles, articles relating to pain management. Date was not limited as pain is not a new phenomenon and an older study might still be relevant.</td></tr>
<tr><th>Source</th><th>Hits</th><th>Limiters</th><th>Final selection from reading publications</th></tr>
<tr><td>CINAHL</td><td>518</td><td>Adult subjects; Abstract available; Search terms in title
N=138</td><td>(Cunningham et al., 2010; Hadjistavropoulos et al., 2010; While and Jocelyn, 2009; McAuliffe et al., 2009; Tsai and Chang, 2004; Smith, 2005; Epperson and Bonnel, 2004; Herr et al., 2006a; Horgas, 2012; Delac, 2002; Bachino et al., 2001; Snow et al., 2004; Kovach et al., 2001; Huffman and Kunik, 2000; Epps, 2001; Cook et al., 1999)</td></tr>
<tr><td>Psychoinfo</td><td>809</td><td>Terms in major subject heading; Journal articles; Over 65’s; Linked full text
N=87</td><td>(Snow et al., 2004*; Cook et al., 1999*; Huffman and Kunik, 2000*; Bachino et al., 2001*)</td></tr>
<tr><td>AMED</td><td>3173</td><td>Boolean search
N= 85</td><td>(Thuathail and Welford, 2011; Epps, 2001*; Brown, 2009; Smith, 2007; Frampton, 2003)</td></tr>
</table>

*Indicates that this reference is a duplicate finding from another database

The literature findings from Table 1 indicated that a number of publications were grouped under the umbrella of palliative care and so another search of the journal articles was completed using the search terms (pain) AND (palliative care) AND (dementia OR cognitive impairment OR Alzheimer* OR non-verbal adults) so that more relevant literature could be identified (see Table 2).

Table 2: The literature search strategy and results for journal articles pertaining to pain assessment for people with dementia, with modified search terms

Keywords: (pain) AND (palliative care) AND (dementia OR cognitive impairment OR Alzheimer* OR non-verbal adults) Limiters: aged 65 years and older and abstract available, date limited to 2008-2013 to correspond with the introduction of the Department of Health's (2008) palliative care strategy and to produce a manageable and up to date result. Inclusion criteria: literature pertaining to the assessment of pain through behavioural observations. Exclusion criteria: if it pertained to assessing for pain only through self-report, if it was unpublished, a teaching article or if it only pertained to pain management.		
Source	**Hits**	**Final selection based on reading publications**
CINAHL	99	1 (Thuné-Boyle et al., 2010)
AMED	47	0

The basic search terms of “pain” AND “dementia” OR “cognitive impairment” were used in three medical libraries and two national library databases were searched to identify relevant books for the project. Google books, Dawsonera and The Cochrane Library were also consulted with these basic search terms. The reference lists of all selected publications were searched to identify further relevant literature and the author consulted their personal archive of papers. The Dementia Action Alliance were contacted because their conference records made reference to research being undertaken on pain assessment scales. The voice of the person with dementia was sought through a number of autobiographies, a basic search of YouTube and studies for the literature search where the opinions of the person or their carers were sought. Discussion threads were consulted on the Chartered Society of Physiotherapy website.

2.2 Models of Care for Pain Assessment

This section will discuss the literature that pertains to models of care that may form a foundation for pain assessment practices. The literature indicates that debates exist in the literature regarding the use of a standardised approach versus a person-centred care approach. A standardised approach is one that follows the same process systematically for every person, whereas the person-centred approach aims to uphold the individuality of the person and provide tailored care (Kitwood, 1997). The organisation in question advertises that it provides a person-centred approach, though some of the procedures involved in care are standardised, such as the questions on the assessment forms. The national guidelines advise that pain should be treated as an individual phenomenon, suggesting a person-centred approach is preferable, but the guidelines also contain an algorithm procedure for practice methods which suggests a standardised approach (BPS and BGS, 2007). Due to this lack of clarity, the wider literature was consulted and is discussed under the relevant model of care.

2.2.1 The Standardised Model

Epperson and Bonnel (2004) and Schofield et al. (2008) present a standardised approach to pain assessment in their portrayal of algorithms of best practice. The recommendations in the algorithms can be seen in Table 4. Schofield et al.'s (2008) algorithm is purported to be generic to any setting and although it offers a template for pain assessment, it does not specify a timescale for assessment frequency or recommend a particular assessment scale. Conversely, Epperson and Bonnel (2004) specify how often pain assessment should occur in different settings, but do not explain their disparity. The advantages of the standardised approach for management purposes might be that it is easy to measure adherence and it might also be a system to ensure that pain assessment is not overlooked. Snow and Shuster (2006) also recommend a standardised approach to pain assessment through hypothesis testing, and when their proposed method was evaluated in a sample of 114 nursing home residents the hypothesis-testing group had significantly less discomfort behaviours than the group that received a non-standardised approach to pain assessment ($p<0.001$) with the discomfort behaviours of 84% of the residents being ameliorated (Kovach et al., 2001). In summary, some authors advocate a standardised approach to pain assessment, but there is a lack of consistent specifications about when to assess, which assessment scale to use and there is a paucity of clinical testing of the standardised processes.

2.2.2 The Person-Centred Model

The Picker Institute Europe (2002) and Smith, (2007) suggest that organisations adopt a person-centred approach to pain assessment for people with dementia. Malloy and Hadjistavropoulos (2004) reference the work of Kitwood (1997) and assert that the prerequisite of person-centred care is knowing the person with dementia. Smith (2007) develops this concept within the context of pain assessment and reports that, in practice, person-centred care pertains to understanding the history of the person’s pain and its treatments, knowing their usual reactions to pain, knowing what had triggered pain in the past and whether they tended to stoicism. The BPS and BGS (2007) also assert that familiarity with a person’s usual patterns of behaviour may improve the ability to identify pain since the experience of pain, as well as the experience of dementia, are described as being unique to each person. McAuliffe et al. (2009) assert that this approach might not be practical clinically since it can take between one week to three months to get to know a person sufficiently to provide person-centred care, but their assertion may have different implications for different clinical settings, for example, in a long-term care setting spending up to three months learning a person with dementia might be achievable. Person-centred approaches are acknowledged in the literature as advantageous when working with people with dementia (Kitwood, 1997; Perrin, 2008), but the findings of this review suggest there is little evidence for their use in models of pain assessment. Organisational barriers need to be considered when examining the practice of person centred care as, for example, Smith (2005) notes that person-centred care approaches rely on getting to know the person and that is unlikely to be realised if there is a high turnover of staff or early discharge policies.

2.3 The National Guidelines for Pain Assessment

The BPS and BGS (2007) has geographical relevance to the area for evaluation in this project and purports to be a product of the best evidence available from a literature search and a multi-professional working group. The literature search highlighted three additional national guidelines for pain assessment practices and Table 3 summarises the recommendations and compares the similarities and differences between them. The guideline statements in Table 3 were extracted from the BPS and BGS (2007) guidelines and the other publications did not include any additional recommendations in this area. The rationale for why each guideline was extracted as relevant to the project can be seen in Appendix B.

Table 3: A summary of the national guidelines of pain assessment relevant to people with dementia

Guideline	The BPS and BGS (2007)	American Geriatrics Society (2002)	The Alzheimer's Society (2012b)	The National Council for Palliative Care (2012)
Pain to be assessed at every health assessment	✓	X pain to be assessed on initial visit	X "routine practice" (p.18)	
Try to ask about pain	✓	✓	✓	✓
Observe for behavioural signs of pain	✓	✓	✓	✓
Observe for behavioural signs of pain during movement and rest	✓	✓		✓
Use a standardised pain assessment scale	✓	✓	✓	✓
Consult with carers and family	✓	✓		
Be aware of pain-producing diagnosis, e.g. arthritis	✓	✓		
Key: ✓ = guideline features in publication. If blank then the publication does not specify details about this guideline				

The literature search produced a number of studies that evaluate the guidelines of the BPS and BGS (2007) as per Table 3 and these will be discussed under the relevant headings. The recommendations for the key reviews are summarised in Table 4 and the data indicates concurrence with the BPS and BGS guidelines (2007) in their recommendations for asking about pain, observing for behavioural signs of pain and awareness of pain-producing diagnoses. It is difficult to establish the comprehensiveness of a number of the published reviews because the authors do not detail their search strategy (Herr and Garand, 2001; Herr et al., 2006a; Epperson and Bonnel, 2004; Bachino et al., 2001).

Table 4: Summary of the literature reviews on pain assessment for people with dementia.

Guideline	Herr and Garand, 2001	Herr et al. 2006a	Epperson and Bonnel, 2004	Hadjistavropoulos et al. 2007	Schofield et al. 2008	Bachino et al. 2001
Pain to be assessed at every health assessment	Specifies “routine” assessment	Specifies “routine” assessment	Care homes: On admission, quarterly or with any change in status Acute hospital: every 8 hours Primary care: every visit	X Does not specify, but asserts it should be an on-going process	X “monitor”	On admission, if suspected, if condition changes, if new symptoms arise
Try to ask about pain	✓	✓	✓	✓	✓	✓
Observe for behavioural signs during movement and rest	✓	✓	✓	✓		✓

Table 4 continued: **Guideline**	**Herr and Garand, 2001**	**Herr et al. 2006a**	**Epperson and Bonnel, 2004**	**Hadjistavropoulos et al. 2007**	**Schofield et al. 2008**	**Bachino et al. 2001**
Use a standardised pain assessment scale	X More research is needed	✓	✓	✓	✓	✓
Consult with family and carers	✓	✓		✓	✓	✓
Have knowledge of pain producing diagnoses	✓	✓	✓	✓	✓	✓

Key: ✓ = guideline features in publication. If blank then the publication does not specify details about this guideline

2.4 Frequency of Pain Assessment

The BPS and BGS (2007) recommend that pain is assessed for at every visit, but there is disagreement about this amongst the wider literature as illustrated in Table 4. Four of the papers are not specific in their recommendations and use terms such as “routine” and “monitor” (Herr and Garand, 2001; Herr et al., 2006a; Hadjistavropoulos et al., 2007; Schofield et al., 2008). Epperson and Bonnel (2004) suggest that the frequency of pain assessment depends on the clinical setting for the person with dementia, recommending eight hourly assessments for the person in hospital and assessments every visit for the people at home. The latter does concur with the BPS and BGS (2007) guidelines although no explanation is given for the difference in expectation. Bachino et al. (2001) added that pain should be assessed for if the person’s condition changes or if new symptoms arise and both of these require sufficient knowledge of the person’s usual behaviours which the clinician may not have. The benchmark standard for this project will be that an assessment at every visit at home, but it should be noted that there is disagreement as to whether this guideline applies equally to all clinical settings.

2.5 The Assessment of Pain Through Behavioural Observation

The gold standard recommendation for pain assessment is to ask the person if they are in pain (BPS and BGS, 2007), but the national guidelines state that “in people with difficulty in communicating including cognitive impairment…an observational assessment is additionally required” (BPS and BGS, 2007, p.11). The BPS and BGS (2007) report that people express pain through a common set of behaviours namely autonomic changes, such as sweating, facial expressions, such as grimacing, body movements, such as rocking, vocalisations, such as groaning, changes in interpersonal interactions, such as aggression, changes in activity patterns, like sleep and changes in mental status. Stolee et al. argue that behaviour is not just a proportionate reaction to pain intensity but can be reflective of other factors related to the pain experience, such as fear and anxiety (2007). This project will adopt the assumption that the behaviours described by the BPS and BGS (2007) are valid, but it should be acknowledged as a possible limitation since there is a lack of consensus in the literature about which behavioural signs are valid indicators of pain (Bachino et al., 2001).

The BPS and BGS (2007) assert that a pain assessment scale should be used to help observe for pain behaviours, but they do not recommend one particular scale, stating that further research is needed. The literature search identified a number of assessment scales which are listed in Table 5 with the supporting evidence referenced. It is beyond the remit of this project to review the evidence for each scale, but there are a number of literature reviews on existing evidence of the effectiveness of pain scales and the conclusions of these will be discussed in the next section.

Table 5: Pain assessment scales and their sources identified in the literature search

Name of Assessment Scale	Featured Publication
The Discomfort Behaviour Scale	Monroe et al., (2012); Stevenson et al., (2006)
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)	Zwakhalen et al., (2012); Zwakhalen et al., (2006)*; Fuchs-Lacelle and Hadjistavropoulos, (2004); Fuchs-Lacelle, (2007)
Pain Assessment in Advanced Dementia (PAINAD)	Jordan et al., (2012); Mosele et al., (2012); Zwakhalen et al., (2010); Lin et al., (2011)*; Jordan et al., (2011)*; Leong et al., (2006); Costardi et al., (2003); Warden et al., (2003); Lane et al., (2003); Liu et al., (2012); Garre-Olmo et al., (2012); Hutchison et al., (2006); van Iersel et al., (2006)**

Table 5 continued:

Name of Assessment Scale	Featured Publication
Disability Distress Assessment Tool (DisDAT)	Jordan et al., (2012)*; Dello Russo et al., (2008); Zieber et al., (2005)
The Discomfort Scale for Patients with Advanced Dementia of the Alzheimer’s Type (DS-DAT)	Hurley et al., (1992)
DOLOPLUS-2	Zwakhalen et al., (2012); Hadjistavropoulos et al., (2008); Chen et al., (2010); Hølen et al., (2005)
Mobilization Observation Behaviour Intensity Dementia Pain Scale (MOBID)	Husebo et al., (2010)*; Husebo et al., (2009)*: Husebo et al., (2007); Husebo, (2008)*
Mobilization Observation Behaviour Intensity Dementia Pain Scale 2 (MOBID-2)	Husebo, (2008)*
Checklist of Nonverbal Pain Indicators (CNPI)	Ersek et al., (2011); Scherder and van Manel, (2005)
Certified Nursing Assistant Pain Assessment Tool (CPAT)	Cervo et al., (2009); Cervo et al., (2007)
The Abbey Pain Scale	Abbey et al., (2004)*; Van Iresel et al., (2006)*; Abbey, (2003)
The Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)	Horgas et al., (2007); Snow et al., (2004)

Table 5 continued:

Name of Assessment Scale	**Featured Publication**
Pain Assessment for the Dementing Elderly (PADE)	Villanueva et al., (2003)
The Assessment of Discomfort in Dementia (ADD) Protocol	Kovach et al., (2002)
The Hospice Approach Discomfort Scale	Krulewitch et al., (2000)*
Davies et al. (2004) pain assessment tool	Davies et al., (2004a); Davies et al., (2004b)
The Aged Care Pain Chart	Edvardsson et al., (2008)
The Behaviour Checklist	Baker et al., (1996)
The Facial Grimace Scale	Baker et al., (1996)
The Pain Behaviours for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICIE)	Tsai et al., (2008)
The Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (FLACC)	Herr et al., (2006b); Voepel-Lewis et al., (2010)
Pain Assessment in the Communicatively Impaired (PACI)	Kaasalainen et al., (2011)
The Pain Assessment Tool in Confused Older Adults (PATCOA)	Decker and Perry, (2003)
Amy's Guide	Galloway and Turner, (1999)
The Simons and Malabar Pain Scale	Simons and Malabar, (1995)

Table 5 continued:

Name of Assessment Scale	Featured Publication
The Nonverbal Pain Assessment Tool	Klein et al., (2010)
Facial Action Coding System	Lints-Martindale et al., (2007)
Elderly Pain Caring Assessment 2 (EPCA-2)	Morello et al., (2007)
Pain Behaviour Checklist (PBC)	Van der Putten and Vlaskamp, (2011)

* indicates that the study included two assessment scales and have been referenced in both categories

Smith, (2005), Herr et al. (2006b), Stolee et al. (2005) and Thuathail and Welford (2011) completed systematic reviews of the literature on behavioural assessment scales and concluded that most scales were still under development and needed more testing. Despite this, some authors have recommended assessment scales within the current evidence base; for instance, Zwakhalen et al. (2006) propose that the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PASCLAC) and DOLOPLUS2 scales were most clinically useful and sensitive. PASCLAC has items that are scored 0 or 1 if they are not present or present respectively, whereas the DOLOPLUS2 scores 0 to 3 which allows for some measurement of pain intensity. A recommendation by an expert group also acknowledges PASCLAC, but favours the Pain Assessment in Advanced Dementia (PAINAD) as most clinically relevant (Herr et al., 2010). The PAINAD requires a five minute observation of the person in any one position whereas the PASCLAC requires a more lengthy and dynamic observation. Herr et al. (2010) focused on assessment scales for use in nursing homes whereas Zwakhalen et al. (2006) did not specify a clinical setting which might explain the disparity in recommendations. On the other hand, Cunningham et al. (2010) also addressed the care home setting, but recommended The Abbey Scale and the Discomfort in Dementia Scale because they measure the six behaviours set out by their relevant national guidelines (American Geriatrics Society, 2002). Cunningham et al. (2010) further acknowledge the advantages of The NOPPAIN in that it requires the person to be observed during daily activities, but suggests it needs more psychometric testing. While and Jocelyn (2009) make some clinically pertinent observations about the importance of applying the context of the setting when selecting an assessment scale. They note a number of setting-specific factors including the time available to complete the scale and the skills and training required to complete the scale. An example of this is Chatterjee (2012) who recommends the Disability Distress Assessment Tool (DisDAT) assessment scale because it meets the environmental needs of a hospice setting. In conclusion, the evidence does not advocate a gold standard pain assessment scale and this makes it difficult for this project to evaluate whether the organisation is meeting a recommendation. The project will, however, evaluate which assessment scales are being used and, in accordance with the BPS and BGS (2007) guidelines, the standard is proposed that clinicians use an assessment scale.

The assessment scales previously discussed differ in whether they require the person with dementia to be static or moving during pain assessment. The advantage of an assessment scale that specifies that the person with dementia is observed during dynamic activities such as walking and eating, means that the scale encourages adherence to the BPS and BGS (2007) recommendation that pain should be assessed for during movement and at rest. No other findings in the literature review discussed the issue of assessment during movement, but since it is a recommendation of the BPS and BGS (2007) it remains relevant for evaluation in this project.

The literature search identified a small number of studies that examine the frequency of use of pain assessment scales in practice. Abbey (2007) surveyed 2523 Australian residential facilities and found that the most popular scales were The Abbey Pain Scale (63%), followed by DS-DAT (10%), CNPI (32%) and PAINAD (5%) and locally designed scales were used by 21% of facilities. The survey only had a 24% response rate, but this equates to a sample of 598 facilities. Smith and Kennerley (2012) also completed a survey of care homes to which they received 33 responses and found that the most popular scale was the Abbey (42%), followed by DisDat (27%), PACSLAC (12%), Doloplus-2 (3%). The participants reported that the Abbey was appealing due to ease of use and PACSLAC and DisDAT because of their person-centred design. The assessment scales in use amongst mental health clinicians featured as a thread discussion on The Chartered Society of Physiotherapy's website and the NOPPAIN, Abbey and DisDAT were identified as commonly in use (Fordham, 2011). In conclusion, studies show the Abbey Scale (2007) is popular and that other assessment scales are also in use, but that no clear trends are apparent.

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2.6 Involving Carers when Assessing for Pain in People with Dementia

The BPS and BGS (2007) recommend that clinicians consult with the carers and families of the person with dementia when assessing for pain. The reason for this recommendation is that those who know the person with dementia are best placed to know their usual pain behaviours and whether the person's behaviour has changed over a period of time. The findings of Thun-Boyle et al.'s (2010) study challenge this reason since 20 relatives were unable to interpret significant information pertinent to pain, for example, carers were aware that their loved-one had a pain-producing condition, such as a pressure sore, arthritis or acute infection, and yet reported that the person was not in pain. The sample in this study was small and it is difficult to discuss medical cases with limited information, but despite this, the authors assert that having these at-risk factors should be sufficient to trigger an assumption of pain (Thun-Boyle et al., 2010). This project plans to establish whether clinicians are including family and carers in their assessments for pain and aims to obtain qualitative information about this topic, since the literature is inconclusive. However, family and carers will not be included in this project since it requires further permissions, which cannot be obtained in the timescale.

2.7 Awareness of Pain Producing Diagnoses

The BPS and BGS guidelines state that "a full medical history should be taken" (2007, p.12) and this allows for an awareness of possible pain producing diagnoses, such as the presence of arthritis. Other publications for the care of people with dementia have highlighted the importance of obtaining knowledge about physical health needs (NICE, 2006) and the project organisation has a policy for physical health asserting that all people will have their physical needs identified. In light of the organisation’s policy to obtain information about physical health needs, the recommendation is relevant for evaluation.

2.8 Barriers to Effective Pain Assessment

Table 6 summarises the barriers to pain assessment for people with dementia identified in the literature. Only organisational barriers were evaluated in this project as this meets the objectives set out in Chapter 1, but it should be acknowledged that the literature identifies additional barriers that are external to the organisation’s control, such as the methodological qualities of the evidence for pain assessment.

Table 6: The barriers to effective pain assessment for people with dementia featured in the findings of the literature search

Barrier Identified	Source
The service users have impairments in verbal communication	(Frampton, 2003; Sachs et al., 2004; Bachino et al., 2001)
The evidence for the validity of assessment scales is insufficient	(Frampton, 2003; Bachino et al., 2001; McAuliffe et al., 2009)
Some assessment scales are completed at rest and so may miss movement-related pain	(Bachino et al., 2001)
The pain assessment scales are not appropriate clinically	(Frampton, 2003; McAuliffe et al., 2009; Cook et al., 1999; Stolee et al., 2007)
Assessment scales are not easy to administer	(Stolee et al., 2007)

Table 6 continued:

Barrier Identified	**Source**
Research into pain assessment has methodological flaws	(Frampton, 2003)
Assessment scales need further testing	(Frampton, 2003)
Health care clinicians are not using pain assessment scales	(McAuliffe et al., 2009)
There is a lack of training or knowledge in health care professionals about pain assessment	(Frampton, 2003; Sachs et al., 2004; McAuliffe et al., 2009; Cook et al., 1999; Thun-Boyle et al., 2010)
There is a lack of collaboration between dementia care, palliative care and older adult care	(Frampton, 2003)
Carer's knowledge of pain assessment is insufficient	(Frampton, 2003; Sachs et al., 2004)
Lack of encouragement to involve the family	(Frampton, 2003)
Pain assessment is poorly documented	(Frampton, 2003; McAuliffe et al., 2009; Stolee et al., 2007)
Dementia is not seen as a terminal illness appropriate for a palliative care approach	(Sachs et al., 2004; Thun-Boyle et al., 2010)
People with dementia are excluded from pain research	(Bachino et al., 2001)

Table 6 continued:

Barrier Identified	Source
There is disagreement about the relevancy of physiological changes as indicators of pain	(Bachino et al., 2001)
Pain behaviour is misinterpreted as indicative of other problems or as a symptom of dementia	(McAuliffe et al., 2009; Stolee et al., 2008; DOH, 2009; Alzheimer's Society, 2012a)
There is a belief that some people with dementia do not experience pain	(McAuliffe et al., 2009)
There is not enough time to learn people's normal behaviours	(Cook et al., 1999; Malloy and Hadjistavropoulos, 2004)
There is a belief that pain is a normal part of ageing	(Malloy and Hadjistavropoulos, 2004)
Institutionalised and inauthentic relationships are adopted between carer and the person with dementia	(Malloy and Hadjistavropoulos, 2004)
The organisation requires staff to work in a way that achieves operational efficiency and has an inauthentic caring culture	(Malloy and Hadjistavropoulos, 2004)
Clinicians lack a proactive approach to pain assessment	(Kaasalainen et al., 2013)
There is an erroneous assumption that someone who is in bed is comfortable	(Kaasalainen et al., 2013)
Treating pain assessment as a paper exercise and not interpreting information	(Thun-Boyle et al., 2010)

2.9 Methods for Evaluating Adherence to Pain Assessment Guidelines

One of the objectives of the project was to undertake a literature review, the findings of which are to guide the methodology for the management assignment and this section explores the effectiveness of methods used to evaluate pain assessment approaches in other literature. Herr et al. (2004) and Titler et al. (2009) audited medical records to obtain information about pain assessment practices and found that the medical records did not correlate with the clinicians reports. Frampton (2003) reported that poor documentation of pain assessment is a barrier to its effectiveness and auditing medical records would be a challenge within the remit of this project, since the community notes are often kept in the home of the person with dementia.

Herr et al. (2004), Allcock et al. (2002) and Titler et al. (2009) use a questionnaire with a perceived stage of adoption scale to establish the extent of adherence to pain assessment standards. The scale comprises a score of 0 (low adoption) to 4 (implementation). This method has the advantage of offering an anonymous approach to collating information about pain assessment practices, although Allcock et al. (2002) highlight that response rate can be low. The use of a questionnaire poses as an advantageous method for this project as an anonymous approach might help to minimise response bias. Allcock et al. (2002) sent questionnaires to the managers of the service, but suggest that this approach may not have been effective in capturing the everyday practice therefore this project collected information directly from the practising clinician. Herr et al. (2004) and Titler et al. (2009) tested the content validity of their questionnaire by asking three nurse and physician experts in pain which posed as an advantageous method for replication in this project since the topic for evaluation was novel and so content validity had not previously been established.

Herr et al. (2004) and Titler et al. (2009) used The Barriers to Optimal Pain Management Tool that asks nurses to rate whether predetermined issues are barriers or not to which the latter authors found a test-retest reliability of r=.83. This style of questionnaire has the potential to ascertain any barriers, but it is dependent on the researchers identifying the potential barriers accurately. Herr et al. (2004) included three barriers to be rated and Allcock et al. (2002) only asked about communication so both authors may have missed information about other barriers that were identified in this literature review. This project implemented a barriers question that included all the organisational barriers identified in the literature review and provided a section for staff to identify any further barriers they experience that may not have featured in the literature.

Kaasalainen et al. (2013) used focus groups to collect information about barriers to pain assessment and they found it produced discussion, with the participants validating their problems with each other and finding common themes in terms of the quality of care they provide. Stolee et al. (2007) also used focus groups in their study exploring pain assessment issues and they used the groups to validate information gained from a survey. Stolee et al. (2007) were able to produce clinical recommendations from the information produced from their focus groups. The success of focus groups in producing useful information in the area of pain assessment advocates the use of this methodology in this project and it may also contribute to the areas where there is disparity in the literature about certain pain assessment guidelines.

2.10 Extraneous Variables in Pain Assessment Research

The research indicates that the number of years of clinical experience of a clinician and their professional discipline are extraneous variables in approaches to pain assessment adopted in a mental health hospital (Stolee et al., 2007). A questionnaire was completed by 74 clinicians and their findings suggest that the more years of clinical experience they had the less challenging they found pain assessment, and that the nursing profession were significantly more likely to rate pain assessment as being part of their role (Stolee et al., 2007). This project will not limit its inclusion criteria in light of this study, but will measure to see if they are extraneous variables.

2.11 The Voice of the Person with Dementia in Pain Assessment Literature

An acknowledged barrier to effective pain assessment for people with dementia is that the research often excludes people with dementia (Bachino et al., 2001). One of the primary assertions of the 2012 World Alzheimer Report is that people with dementia should be given a voice and the report exampled this by surveying 2500 people with dementia and their family in the development of their publication (Alzheimer's Disease International, 2012). The Alzheimer's Society (2012b) surveyed 306 people with early dementia living at home to produce collective statements for their report, one of which was "I will die free from pain and fear, and with dignity cared for by people who are trained and supported in high quality palliative care" (p.14, outcome one). In her book, Bryden wrote about her experiences of having dementia and implores "look behind our behaviour to its meaning" (2005, p.141) which could relate to the concept of interpreting the behaviour of the person with dementia for signs of pain, though she does not specifically address pain issues. This project has been unable to identify any literature that explores the person with dementia's experience of pain assessment methods and this information would greatly inform this topic for future management projects where the remit allows time to obtain the relevant ethical permissions.

2.12 Conclusions

There is much consensus about the majority of the BPS and BGS (2007) guidelines, but there remains inconsistency in the recommendations for a model of pain assessment, when to assess for pain, the usefulness of consulting carers and which assessment scale to use. This project offers a novel approach since it looks at pain assessment approaches by community mental health clinicians which the literature search results suggest has not previously been explored. Practice based research has also shown that there are organisational barriers to pain assessment which may also be relevant to the organisation in question.

3 Chapter 3 – Methods

3.1 Introduction

This chapter will describe the rationale for the methods and their strengths and weaknesses. The project aimed to select approaches that were best suited to answer the research question and these methods will be appraised by referencing publications from the literature review in Chapter 2 and published works on research methods. There will be an account of how the methods achieve the aims and objectives and information will be presented about the efforts made to optimise reliability and validity.

3.2 Methodological Approach

This project adopts an audit methodology as a management approach to systematically evaluate clinical practice. The literature search suggests that there is a paucity of research into pain assessment approaches for people with dementia living in their own homes therefore it is plausible that unexpected results might occur and Bryman (2008) asserts that findings can be given increased validity if they are confirmed by two methodological strategies. The methods used in this project are a questionnaire to obtain primarily quantitative data and a focus group to obtain qualitative data. The rationale for these specific methods is described under their respective headings and how they answer the aims and objectives can be seen in Appendix C.

3.3 The Participant Group

Potential participants were identified from eight community mental health teams that cover the geographic area served by the project organisation. The teams comprise eight different clinical roles: nursing, occupational therapy, physiotherapy, psychiatry, psychology, health care assistant, physiotherapy assistant and a moving and handling advisor. The participant inclusion criteria required that they had worked in a community mental health team in the organisation for at least three months, which was chosen to coincide with the time it takes to complete mandatory training and to have had three clinical supervision sessions. The inclusion criteria also required that the clinician worked with people with dementia who live in their own home.

The size of the participant group was established using a systematic method, based on the assumption that there will be a non-response rate. Previous studies that recruited participants for pain evaluation studies had an average non-response rate of 29% (Stolee et al., 2007; Herr et al., 2004; Titler et al., 2009; Allcock et al., 2002) and, subsequently, 29% was deducted from the total population to produce an estimated response rate. The population of community mental health clinicians was 105 and therefore the anticipated response rate would be 75, which was considered manageable for data analysis and so a sample was not created.

The participants were contacted by email with links to the online questionnaire embedded (see Appendix D). Steps to optimise response rate were taken as per Bryman's recommendations (2008) and the email explained the research, its importance and why the person had been selected, in addition, guarantees on anonymity were asserted to improve validity by reducing reporter bias. The organisation requires that clinicians communicate regularly by email and this method was adopted to best suit the culture of the target population.

The sample for the focus group was self-selecting in response to an email invitation sent out one week following the questionnaire (see Appendix E). This had the advantage of acting as a prompt to complete the questionnaire as well as a focus group invitation. The self-selecting approach aimed to optimise attendance and ensure consent, but this approach has the potential for bias either because the clinicians are very interested in the topic or because they have another motive (Morgan and Scannell, 1998).

3.4 The Questionnaire

A questionnaire was used to obtain quantitative information about pain assessment practices (see Appendix F for the first version). The advantage of the questionnaire was that it allowed information to be collected relatively quickly and so was effective to meet the time limits of this project (Bryman, 2008). An additional advantage is that this method was anonymous, which is acknowledged to improve the validity of the data (Hussey and Hussey, 1997) and limit participants giving socially desirable responses (Bryman, 2008). A disadvantage of questionnaire can be if there is a low response rate (Bryman, 2008).

The questionnaire was assembled so that the least threatening screening and demographic questions were placed at the beginning of the questionnaire, as advised by Hussey and Hussey (1997). The questionnaire comprised three screening questions to enforce the inclusion criteria and participants were automatically directed to the end of the questionnaire if they did not meet the criteria. The questionnaire included two demographics questions enquiring about the participants' professional discipline and number of years of experience. The bandings of years of experience was replicated from a methodology used by Stolee et al. (2007) because, although the bandings were not equally spaced, it allowed for a comparison of findings. The other items on the questionnaire were the pain recommendations selected from the BPS and BGS (2007) guidelines as per Appendix B, and each specific practice was scored on a Likert scale of 1 (never) to 5 (frequently) and so the higher the total number the higher the adherence to the guidelines (Likert 1932, cited in Bryman, 2008). The questions about assessment scales in use and barriers to pain assessment both used a checkbox design where participants could select the items that applied to them. The barriers in this project were identified from the results of the literature search in Chapter 2 and the respondents were given the opportunity to provide details of any additional barriers in a comments box. Participants were given two weeks to complete the questionnaire, as recommended by Bell (2005). A one week extension was added to the two weeks to improve the response rate and a further email was sent to encourage participation (see Appendix G).

Titler et al. (2009) and Herr et al. (2004) piloted their questionnaire with three pain specialists to optimise content validity and this project replicated this approach. The questionnaire was piloted with an expert panel comprising one research specialist, one physician pain specialist, one dementia care nursing specialist, three physiotherapists who work with people with dementia, one author of a number of publications on pain assessment and dementia and one health care assistant. The pilot sample were interviewed according to the recommendations of Bell (2005) and the questions can be viewed in Figure 1.

Figure 1: The interview questions for the pilot sample

How long did it take you to complete the questionnaire?

Were the instructions clear?

Were any questions unclear or ambiguous?

Did you object to answering any of the questions?

In your opinion, has any major topic been omitted?

Was the layout of the questionnaire clear/attractive?

Any comments

The feedback from the panel primarily addressed issues of wording and extracts of this feedback can be seen in Appendix H with the rationale for action taken. The amended questionnaire can be seen in Appendix I.

The questionnaire was tested for test / retest reliability so that it could be established whether the method would produce the same scores under the same conditions at two different times. Twelve healthcare professionals from outside the participant group completed the questionnaire and completed it again a week later. The demographics and inclusion questions were not included in the analysis. The multiple choice questions of assessment scales and barriers were also not included in the analysis since their responses were nominal and so are not comparable using this method. Table 7 shows the results of the Intraclass Coefficient using a two way random analysis for absolute agreement for the data. A coefficient of 0.7 or above was accepted as sufficient and all questions achieved this except question 8 “do you observe for behavioural signs of pain when the person is moving as well as at rest”.

Table 7: The results of the reliability testing of the questionnaire

Question	**Intraclass Correlation Coefficient**	***p* value**
Q5: …how often do you consider whether they experience pain?	r = 0.724	0.003
Q6: Do you try to ask the person with dementia about their pain?	r = 0.773	0.001
Q7: Do you observe for behavioural signs of pain?	r = 0.772	0.000
Q8: Do you observe when the person is moving and at rest?	r = 0.459	0.040
Q9: Do you use a standardised pain assessment scale?	r = 0.905	0.000
Q11: …do you ask…loved ones or carers for their insight?	r = 0.884	0.000
Q12: Do you (ask about) possible pain-producing diagnoses?	r = 0.744	0.002

The questionnaire was analysed with descriptive statistics to establish the demographic diversity of the respondents by professional discipline and years of experience. The total score for the Likert scale was calculated for each participant and then were clustered according to discipline and years of experience. The full details of the questionnaire data analysis procedures are reported in Table 8.

Table 8: The quantitative analysis methods of the data from the questionnaires

Item	Method of analysis
Response rate of questionnaire	Response rate as a percentage of the total
Inclusion criteria	Number
Demographics: discipline, clinical experience	Frequencies and percentages
Questions evaluating frequency of set pain assessment practices	Frequency
Questionnaire of barriers to pain assessment	Frequencies and percentages
Comparison of questionnaire results by discipline and experience	Mean total score and standard deviation One way ANOVA test Statistical significance was accepted at $p<0.05$
Test retest reliability	Intraclass coefficient score (0.7 or above considered good reliability)
The null hypothesis for the comparison of the questionnaire by discipline or experience is as follows: There is no relationship between the findings of the pain practice questionnaire and the participants discipline or years of clinical experience	

3.5 The Focus Group

The project undertook a one and a half hour focus group to obtain qualitative information about pain assessment in the organisation. A focus group is “a form of group interview in which: there are several participants; … there is an emphasis in the questioning on a particular fairly tightly defined topic; and the accent is upon interaction within the group and the joint construction of meaning” (Bryman, 2008 p.474). Focus groups have been used in pain studies (Stolee et al., 2007; Kaasalainen, 2013) and the advantage of this method is that they can gather information about perceptions, experience and reveals social constructs (Bryman, 2008). The specific advantage about focus groups as opposed to individual interviews is that they allow the researcher to study the ways in which individuals collectively make sense of a complex phenomenon and construct meanings around it (Bryman, 2008). The focus group was arranged over a lunch period to offer a convenient time for clinicians to attend and an incentive of refreshments was offered to additionally encourage attendance, as suggested by Krueger and Casey (2000).

Coexisting with the advantages of the focus group method, there are a number of associated disadvantages. A significant disadvantage is that it can be difficult to recruit participants (Bryman, 2008) and this project offered an incentive of providing refreshments over a lunch period to help address this. Bryman (2008) notes that focus group data is difficult to analyse due to its subjectivity but also due to inaudible parts of the recording. Strauss and Corbin (1994) acknowledge that there is a risk that focus group data might be subject to the analyst’s own conceptualisations and so the participants were asked to review a summary of the key discussion and provide feedback about the interpretation (see Appendix J). A second moderator was considered but the only volunteering clinicians were from the target sample and attended the group as participants. An interview schedule was prepared beforehand so that leading questions and moderator bias could be minimised (Bryman, 2008) (see Appendix K). The format of the schedule was written as per Bryman’s recommendations (2008) and discussion was allowed to depart from the schedule in order to provide any new insights. The focus group was recorded and transcribed, according to recommendations (Bryman, 2008).

This project adopted the methods for qualitative data analysis as recommended by Corbin and Strauss (2008). The procedure of data analysis for the focus group is fully described in Table 12, where "coding" refers to "deriving and developing concepts from data" and "theoretical sampling" refers to "sampling on the basis of concepts derived from data" (Corbin and Strauss, 2008 p.65). The advantage of this method is that it identifies themes in the data, encourage questioning and so this will avoid conventional thinking and will distance the moderator from applying their own bias. Furthermore this method offers a structure to conceptualise a large amount of data and it can be organised into concepts. A disadvantage can be that coding may result in a loss of the context of the data (Bryman, 2008).

Table 9: The methods used to analyse the focus group data

Tool for data analysis	Detail of Tool
Questioning	Ask questions of the data 1. Sensitising questions: what are the issues? What is their meaning? Is the meaning the same? 2. Theoretical questions: what are the processes? What are the concepts? What is the connection between the concepts? 3. Practical questions: which concepts are well developed? Where can I get more data for evolving theory? Is the concept saturated?
Making comparisons	1. Compare the similarities and differences between concepts. 2. Theoretical comparisons
Consider various meanings of a word or statement	Consider various meanings of a word or statement
The flip-flop technique	Looking at a concept from different perspectives
Draw upon personal experience	Draw upon personal experience when developing concepts
Waving the red flag	Review work for broad generalisations and consider the possibility of bias if featured

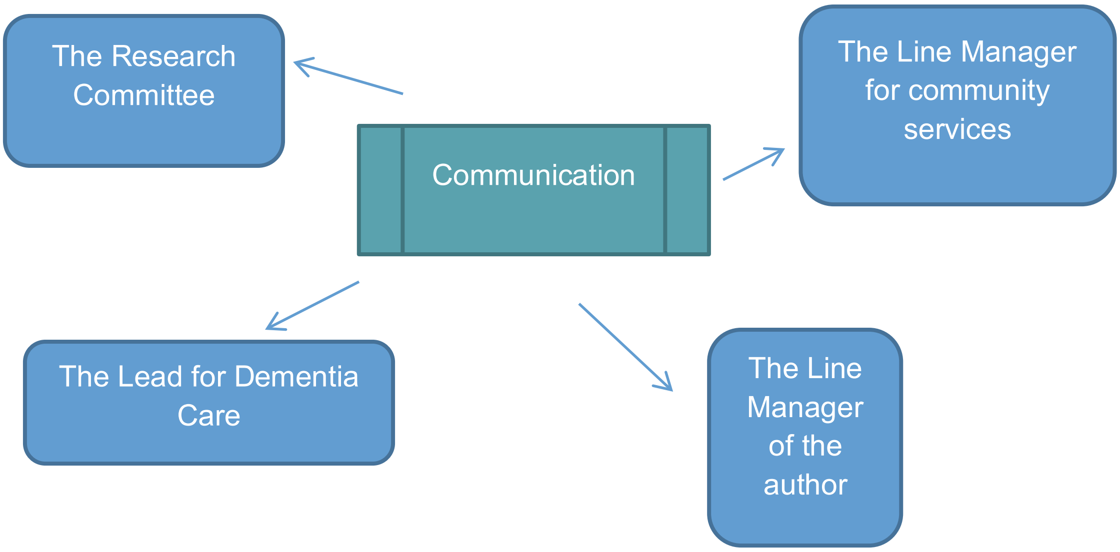
Table 9 continued:

Tool for data analysis	**Detail of Tool**
Look at language	Examine choice of words and look for in-vivo codes, in other words code titles that the participants themselves inadvertently introduce
Look at the emotions that are expressed	Look at the emotions that are expressed
Look for words that indicate time	Indicator of change or shift in perceptions
Examine metaphors and similes	Examine metaphors and similes
Look for the negative case	Examine concepts that do not fit the pattern and consider explanation
Look at the narrative	Consider the order in which discussion emerges
Other	What are the assumptions, cultural beliefs and knowledge base of the participants
Analysing for context	Paradigm: identify relationships between the context and processes and the conditions/circumstances, interactions/emotions and consequences
The conditional/ consequential matrix	A diagram to help identify the macro and micro issues of a concept
Analyse for processes	Consider the participants shape themselves to solve a problem (psychosocial, educational etc.)
Refine the theory	Review for internal consistency and gaps in the logic Fill in poorly developed concepts Trim excess concepts Analyse how well the abstraction represents the raw data (email summary to participants for feedback)
This data analysis is cyclical and was concluded when a sense of concept saturation was established.	

3.6 Ethical Approval

The data was collected between June 2013 and August 2013. The author was advised that ethical approval was not required for the project since it addressed service improvement and did not seek to obtain data from service users. The methodology was approved by The University of Bradford's project supervisor. The data was stored anonymously as a feature of the computer program used to design the questionnaire and the focus group attendees were identified only by their profession. Figure 2 shows the people within the organisation that the project methodology was communicated with.

Figure 2: The people within the organisation in question that the project methodology was communicated with



4 Chapter 4 – Results

This chapter presents the findings from the questionnaire and focus group on the approaches being used to assess for pain in people with dementia who live at home. The demographics of the participants will be described and the findings will be presented in tables, graphs, textboxes and concept maps.

4.1 Results of the Questionnaire

4.1.1 Demographics

The questionnaire was completed by 46 participants and 45 were included in the analysis as one participant was excluded because they only completed the first two questions. This represents a 42.86% response rate of the target population. Pertaining to questions Q1 and Q2 in the questionnaire, none of the participants were excluded due to not working with people with dementia nor due to having worked in the organisation for less than three months.

4.1.2 Question Response Rate

Table 10 shows the response rate for each question with the results being adjusted for the automatic “skip function”, for example if a participant answered “never” to question nine “do you use a standardised pain assessment scale?” it automatically skipped question 10 “if you do use a standardised pain assessment scales please indicate which ones below”.

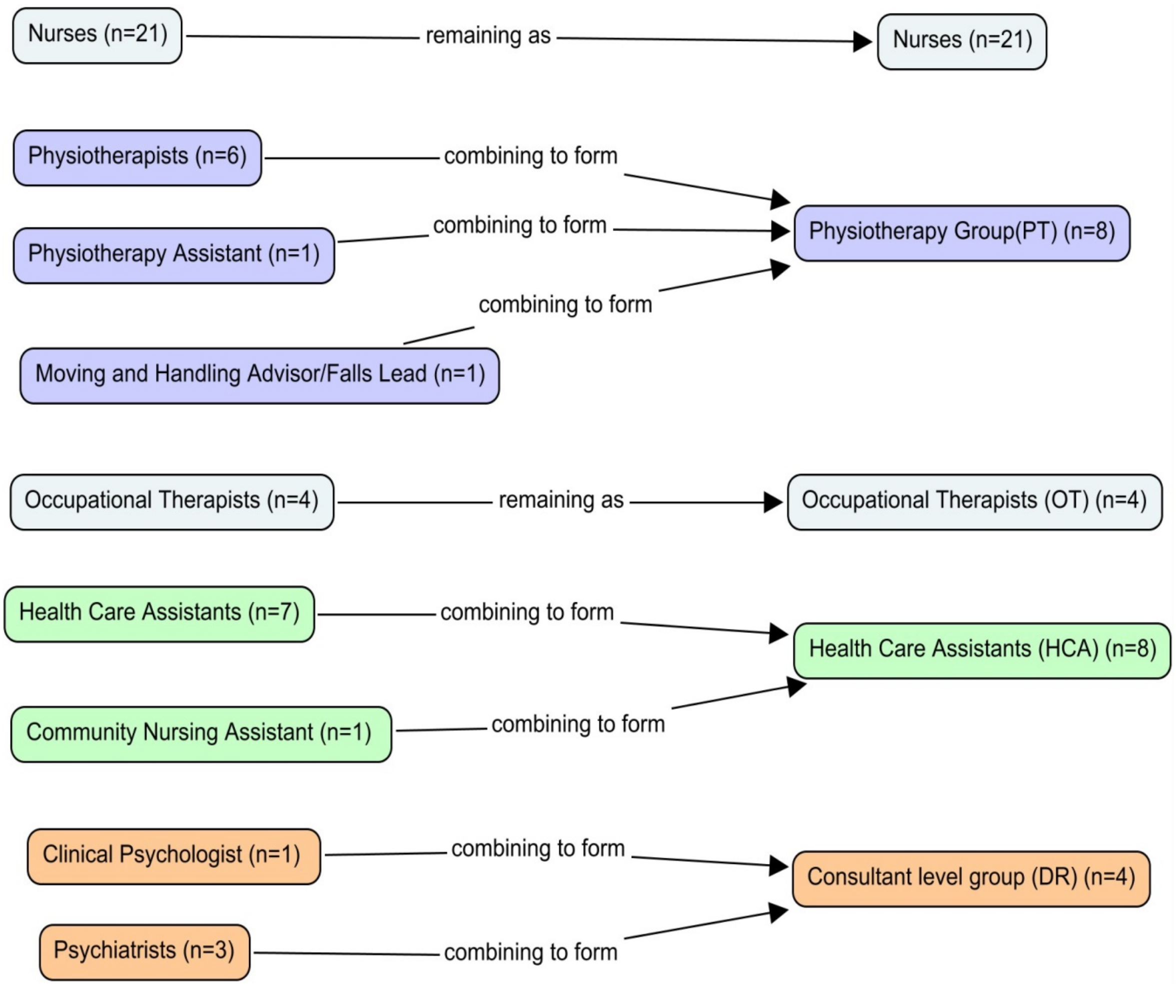
Table 10: Response rate to each question in the questionnaire

Question	Response frequency	Response rate
Q1. Do you work with people who have dementia who live in their own homes?	45/45	100%
Q2. How long have you worked with people with dementia for in this organisation?	45/45	100%
Q3. How long have you worked with people with dementia in any organisation?	45/45	100%
Q4. Which of the following best describes your current occupation?	45/45	100%
Q5: When you are visiting a person with dement how often do you consider whether they experience pain?	45/45	100%
Q6: Do you try to ask the person with dementia about their pain?	44/45	97.78%
Q7: Do you observe for behavioural signs of pain?	44/45	97.78%
Q8: Do you observe when the person is moving and at rest?	42/45	93.33%
Q9: Do you use a standardised pain assessment scale?	44/45	97.78%
Q10. If you DO use pain assessment scales please indicate which ones below	22/25	88%
Q11: When assessing for pain, do you ask the person with dementia's loved ones or carers for their insight?	42/45	93.33%
Q12: Do you obtain information about the person's possible pain-producing diagnosis?	42/45	93.33%
Q13: This question aims to produce information about any organisational barriers to identifying pain in people with dementia who live at home. Please tick any of the following that you perceive apply to your place of work.	41/45	91.11%

Question Q3 asked how long the person had worked with people with dementia in any organisation and the results indicate that one respondent had less than one year experience, 16 respondents had between one and five years of experience, four people had between six and 10 years of experience and 24 respondents had over 11 years of experience. Since only one participant indicated that they had less than one year of experience, this respondent was grouped to make a 0-5 year group so that statistical analysis could be undertaken.

Question Q4 asked the participants to identify their professional discipline and the responses comprised nurses (n=21), psychiatrists (n=3), occupational therapists (n=4), physiotherapists (n=6) and health care assistants (n=7). In the comments section four participants added community nursing assistant (n=1), physiotherapy assistant (n=1), clinical psychologist (n=1) and moving and handling advisor/falls lead (n=1). Some of the professional groups were too small for statistical analysis and so were grouped in other categories as indicated in Figure 3. Enquiries were made with the community mental health teams and it was reported that the role of community nursing assistant equated to that of healthcare assistant and that the role of moving and handling advisor most closely related to the role of the physiotherapist. The psychologist was grouped with the psychiatrist to form a consultant level group.

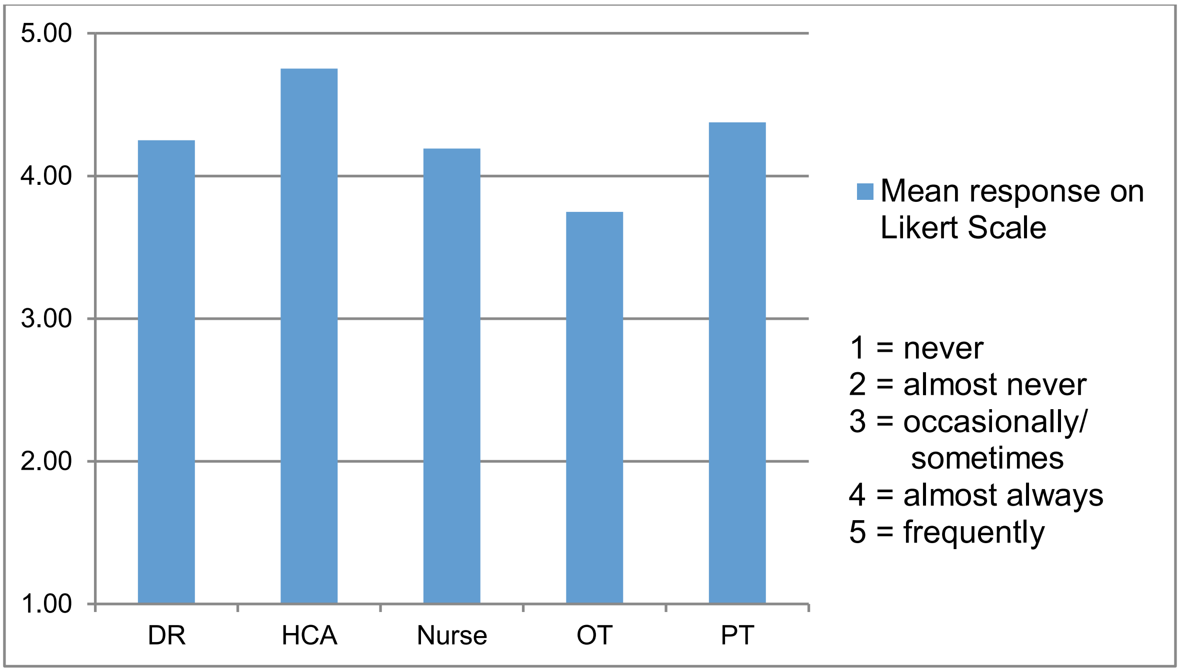
Figure 3: Map of the grouping of the participants' professional disciplines



4.1.3 Frequency of Pain Assessments

In response to question Q5, 20% of the participants reported they assess for pain occasionally/sometimes (n=9), 33% assess almost every time (n=15) and 47% assess frequently (n=21) and none of the participants said they never or almost never considered pain. A one way ANOVA test was conducted to see if there were group differences in the frequency of pain assessment and it was found that there were no significant differences between professional discipline $p \leq 0.05$ [F(4,40) = 1.30, p = 0.29] nor between the groups of number of years of experience $p \leq 0.05$ [F(2,42) = 0.68, p = 0.51]. Figure 4 presents the results for the professional groups because, although there was not a significant difference, it shows there were some trends between the professional groups with the HCA group reporting they assessed for pain the most and OT group assessing the least.

Figure 4: Bar chart of the responses to how often the different groups of professional discipline assess for pain



There were a number of comments written under this section to identify any further triggers to assessing for pain. The textbox in Figure 5 contains these comments.

Figure 5: Textbox of comments left regarding question Q5 and the frequency of pain assessment

At every visit

Not sure about the response alternatives - "almost every time" is more often than "frequently". My personal answer is "always"!!

Always as part of a detailed assessment

Always as a differential diagnosis.

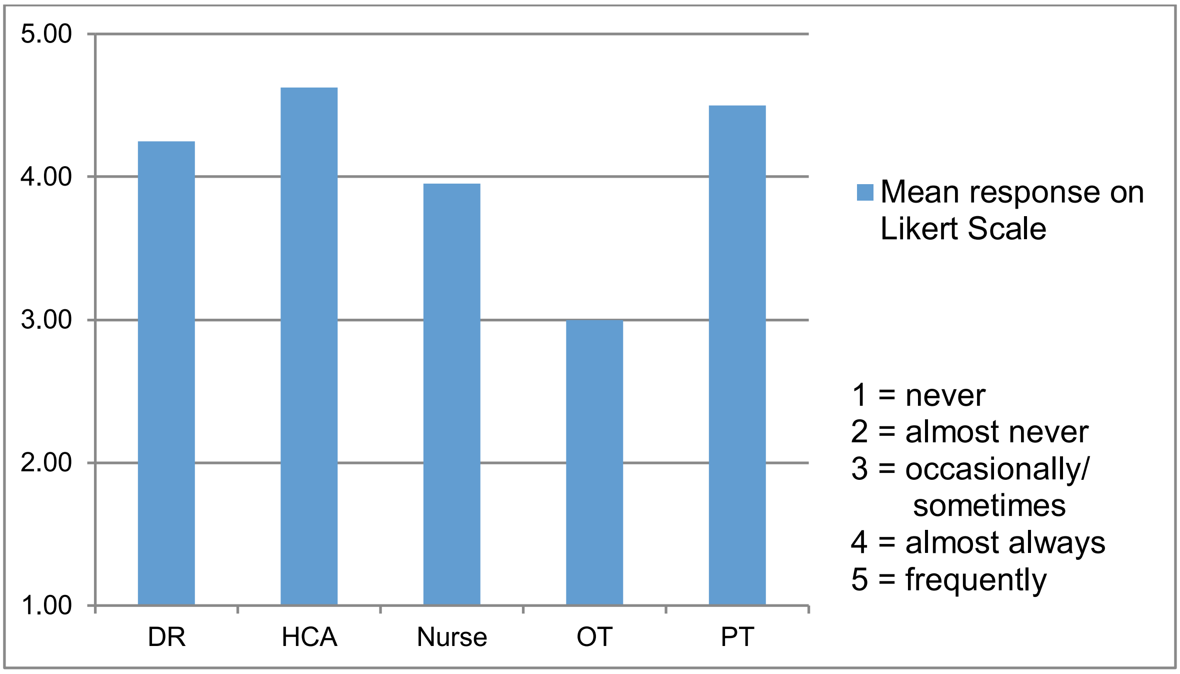
If the person has an increase in their confusion/cognitive abilities, or their mobility /agility alters

Depending on clinical indications

4.1.4 Frequency of Asking about Pain

In response to question Q6, 23% of the participants reported they ask about pain occasionally/sometimes (n=10), 36% ask almost every time (n=16) and 41% ask frequently (n=18) and none of the participants said they never or almost never asked about pain. A one way ANOVA indicated that the frequency of asking about pain was not significantly different between professional groups $p \leq 0.05$ [F(4,40) = 2.50, p = 0.06] Nor years of experience $p \leq 0.05$ [F(2,41) = 0.9, p = 0.75]. Figure 6 presents the results for the professional groups since there were trends, although not significant, with the HCA group reporting they asked about pain the most and the OT group the least.

Figure 6: A bar chart of the mean responses by the professional groups as to how often they ask about pain

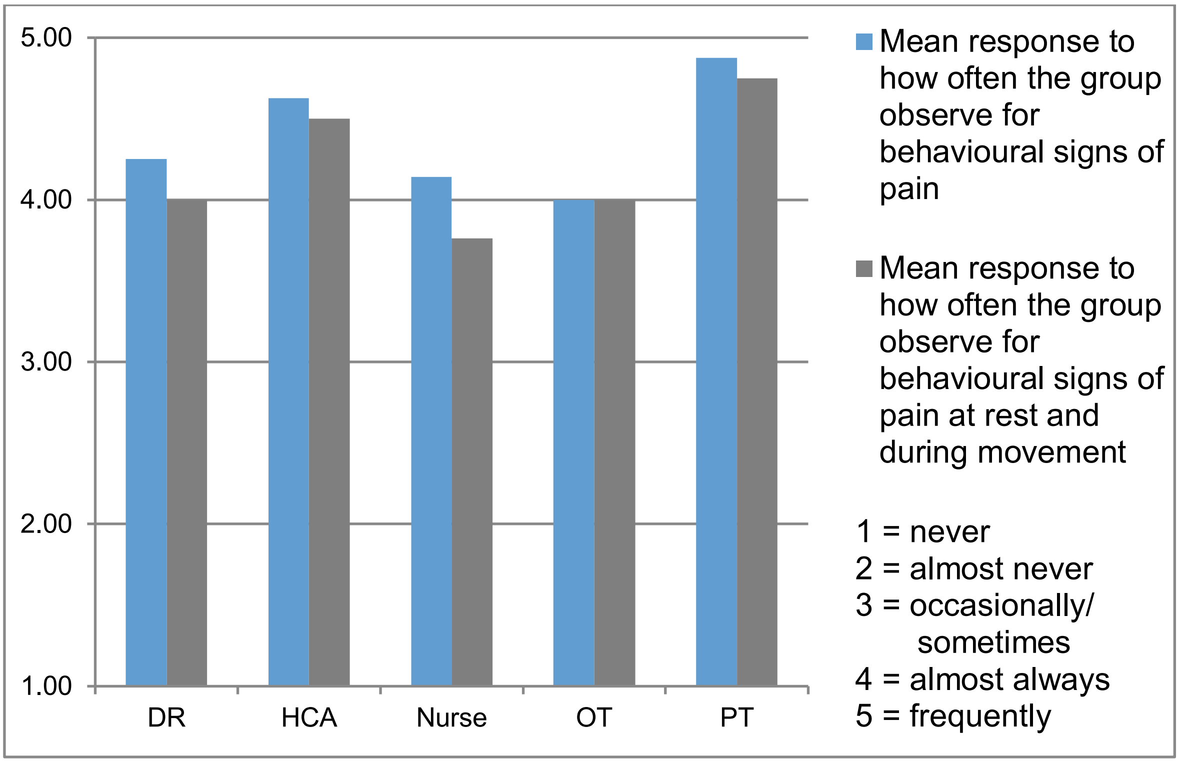


4.1.5 The Frequency of Assessing for Pain through Behavioural Observation

In response to question Q7, 55% of participants reported that they observe for behavioural signs of pain frequently, 34% observe almost every time and 11% observe occasionally/sometimes. A one way ANOVA indicated that there was no significant difference between the frequency of observing for behavioural signs of pain between the professional groups $p \leq 0.05$ [F(4,40) = 1.74, p = 0.16] nor for the groups of years of experience $p \leq 0.05$ [F(2,41) = 0.80, p = 0.46]

In response to question Q8, 50% of participants reported they observe for behavioural signs of movement during movement and during rest frequently (n=21), 36% observe almost every time (n=15) and 14% observe at least occasionally or sometimes. Three participants did not specify if they assess for pain during movement or rest. A one way ANOVA indicated that there were no significant differences between the professional groups $p \leq 0.05$ [F(4,40) = 0.88, p = 0.49] nor between the groups of years of experience $p \leq 0.05$ [F(2,40) = 0.95, p = 0.40]. Despite the difference not being significant, Figure 7 shows that the physiotherapy group tended to report that they assess for pain through behavioural observation and do this during movement and at rest more often than the other groups.

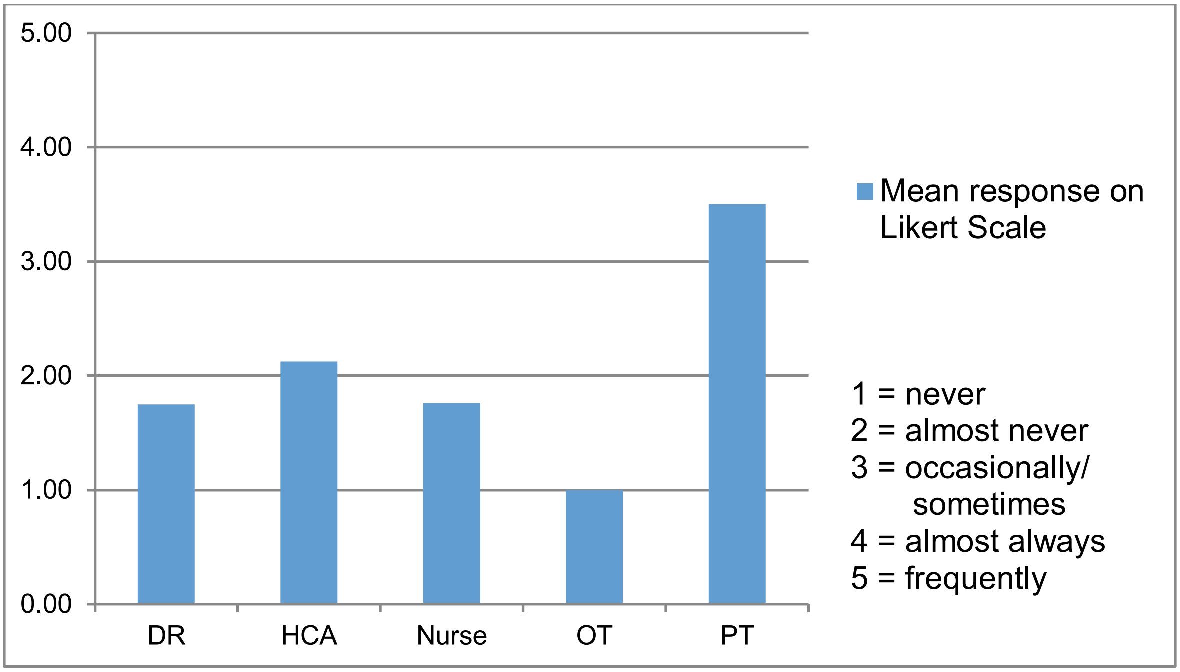
Figure 7: Bar chart of the mean response of the professional groups as to the frequency that they observe for behavioural signs of pain and whether they do this during movement as well as at rest



4.1.6 Frequency of Use of a Standardised Pain Assessment Scale

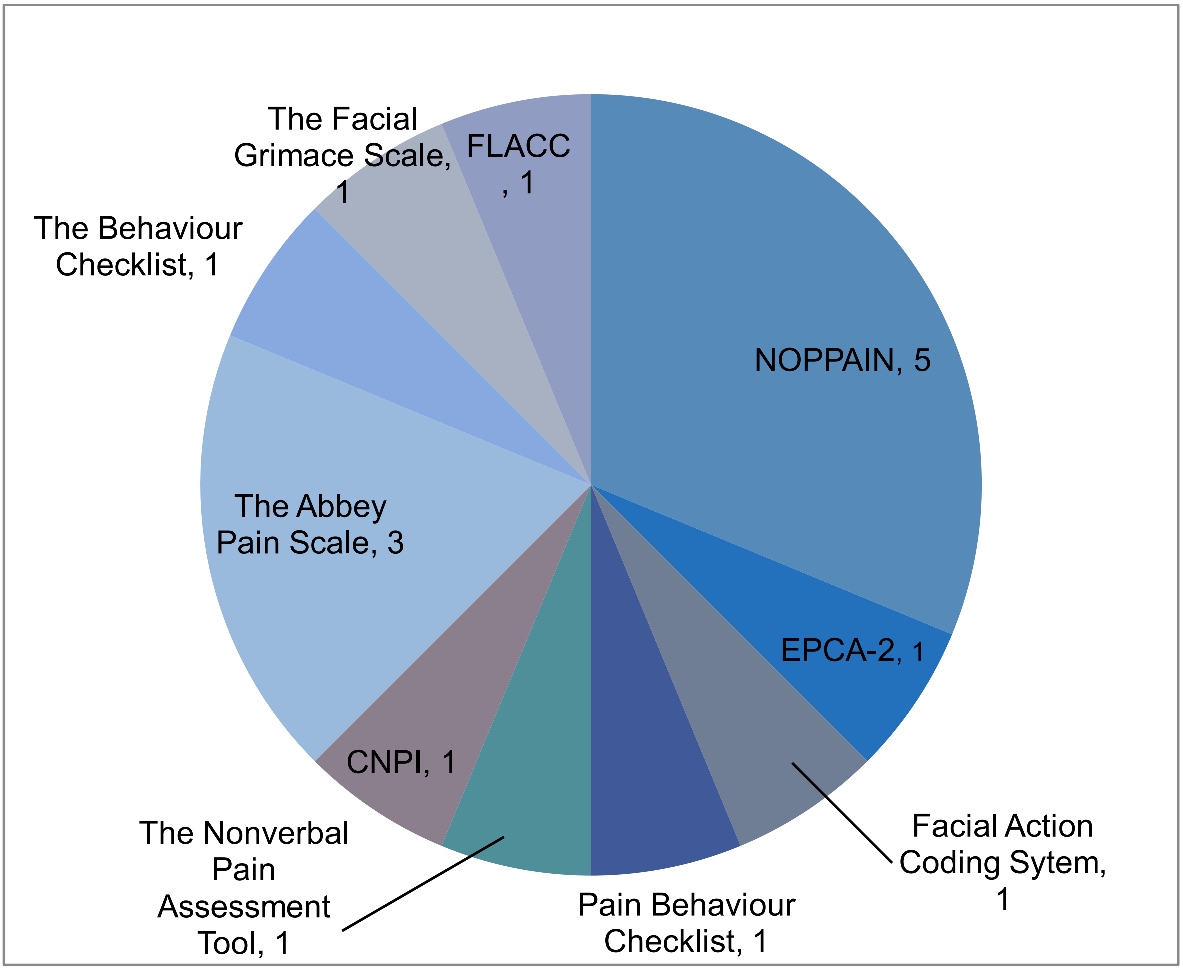
In response to question Q9, 9% of the participants reported they use a pain assessment scale frequently (n=4), 2% use them almost every time (n=1), 27% use them at least occasionally (n=12), 16% almost never use them (n=7) and 46% never use a pain assessment scale (n=20). There was no significant differences between the groups of years of experience $p \leq 0.05$ [F(2, 41) = 0.82, p = 0.45]. There was a significant difference between professional disciplines on the reported frequency of use of assessment scales $p \leq 0.05$ [F(4,39) = 4.32, p = 0.01]. Post hoc comparisons using the Tukey HSD test indicated that the mean score for the nurses group (M = 1.85, SD = 0.93) was significantly different than the physiotherapy group (M = 3.5, SD = 1.51), in that the physiotherapy group were statistically more likely to report more frequent use of assessment scales (see Figure 8).

Figure 8: A bar chart of the mean responses of the professional disciplines as to how often they use pain assessment scales



Question Q10 produced information to suggest that a variety of pain assessment scales are reported to be in use and Figure 9 illustrates the distribution of responses. The NOPPAIN was the most frequently used (n=5) followed by the Abbey (n=3). The raw data indicates that nine participants reported using one scale, two people reported using two scales and one person reported that they use four different scales.

Figure 9: Pie chart to show the proportions of the assessment scales reported to be in use



Key for Pain Assessment Tools in Figure 9

FLACC = The Face, Legs, Activity, Cry and Consolability Pain Assessment Tool

NOPPAIN = The Non-Communicative Patient’s Pain Assessment Instrument

EPCA-2 = Elderly Pain Caring Assessment 2

CNPI = Checklist of Nonverbal Pain Indicators

The text box in Figure 10 comprises the assessment scales that were *not* reported to be in use.

Figure 10: Textbox containing the pain assessment scales that were not identified as being used by the participants

The Discomfort Behaviour Scale

Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

Pain Assessment in Advanced Dementia (PAINAD)

Disability Distress Assessment Tool (DisDAT)

The Discomfort Scale for Patients with Advanced Dementia of the Alzheimer's Type (DS-DAT)

DOLOPLUS-2

Mobilization Observation Behaviour Intensity Dementia Pain Scale (MOBID)

Mobilization Observation Behaviour Intensity Dementia Pain Scale 2 (MOBID-2)

Certified Nursing Assistant Pain Assessment Tool (CPAT)

Pain Assessment for the Dementing Elderly (PADE)

The Assessment of Discomfort in Dementia (ADD) Protocol

The Hospice Approach Discomfort Scale

Davies et al. (2004) pain assessment tool

The Aged Care Pain Chart

The Pain Behaviours for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICIE)

Pain Assessment in the Communicatively Impaired (PACI)

The Pain Assessment Tool in Confused Older Adults (PATCOA)

Amy's Guide

The Simons and Malabar Pain Scale

4.1.7 Frequency of Asking Carers and Loved Ones when Assessing for Pain

In response to question Q11, 38% of participants reported they ask carers and loved ones of people with dementia when assessing for pain frequently (n=16), 48% of participants ask almost every time (n=20) and 14% ask occasionally/sometimes (n=6). A one way ANOVA indicates that there was no significant difference in frequency between the professional groups $p \leq 0.05$ [F(4,37) = 1.71, p = 0.17] nor the groups of years of experience $p \leq 0.05$ [F(2,39) = 0.40, p = 0.67].

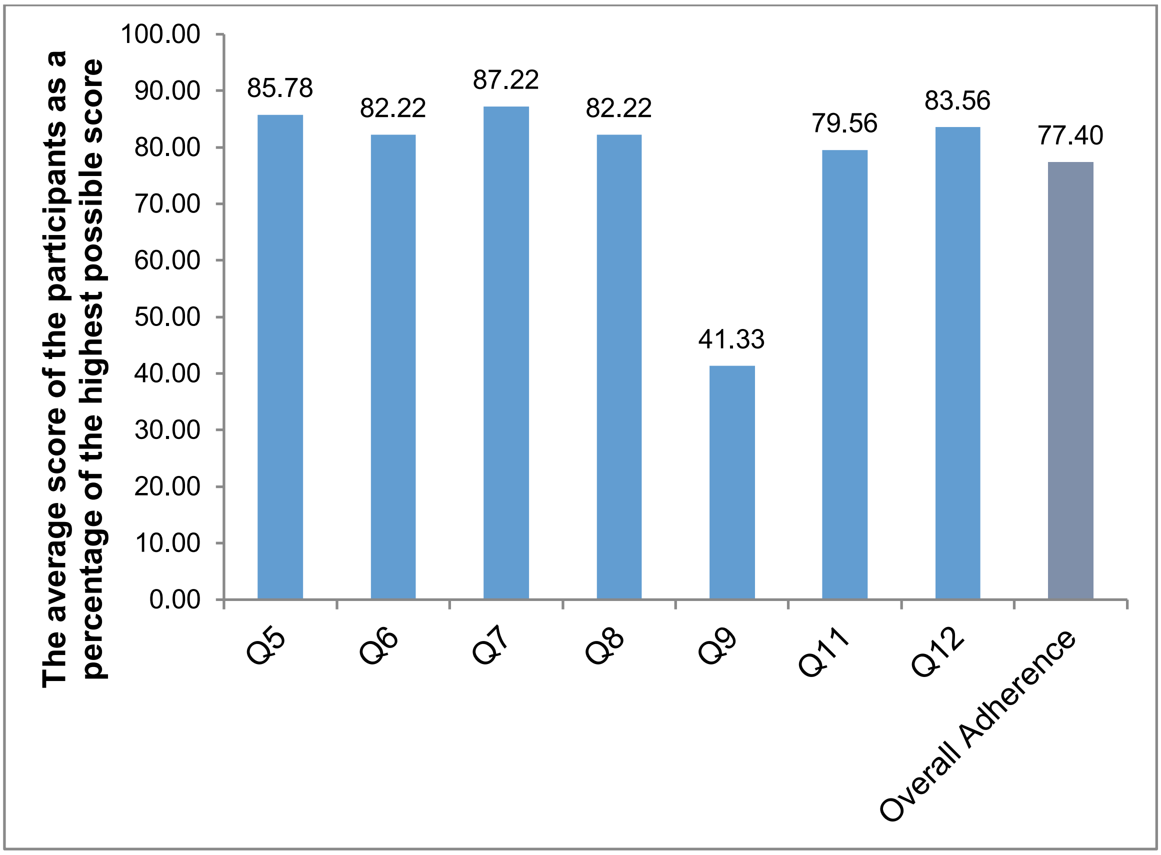
4.1.8 Obtaining Information about Possible Pain-Producing Diagnoses

In response to question Q12, 50% of participants reported they obtained information about possible pain-producing diagnoses frequently (n=21), 45% obtain information almost every time (n=19) and 5% obtain information occasionally/sometimes (n=2). A one way ANOVA indicates that there was no significant between the professional groups $p \leq 0.05$ [F(4,37) = 1.98, p = 0.06] nor between the groups of years of experience $p \leq 0.05$ [F(2,39) = 0.66, p = 0.52].

4.1.9 Overall Adherence to the BPS and BGS (2007) Guidelines

The results presented thus far in this chapter were analysed to establish a percentage score of adherence to the national guidelines for pain assessment. The Likert scale was scored one to five, with five indicating the highest possible adherence or “frequently”. If a participant scored five for all seven questions pertaining to the national guidelines, their total score would be thirty-five and they would be considered 100% adherent. Figure 11 shows that the respondents reported least adherence to the guideline of using pain assessment scales and reported most adherence to observing for signs of pain. The overall adherence to the national guidelines for the entire group was 77.40%.

Figure 11: The overall adherence score for each of the guidelines



4.1.10 Barriers to Pain Assessment

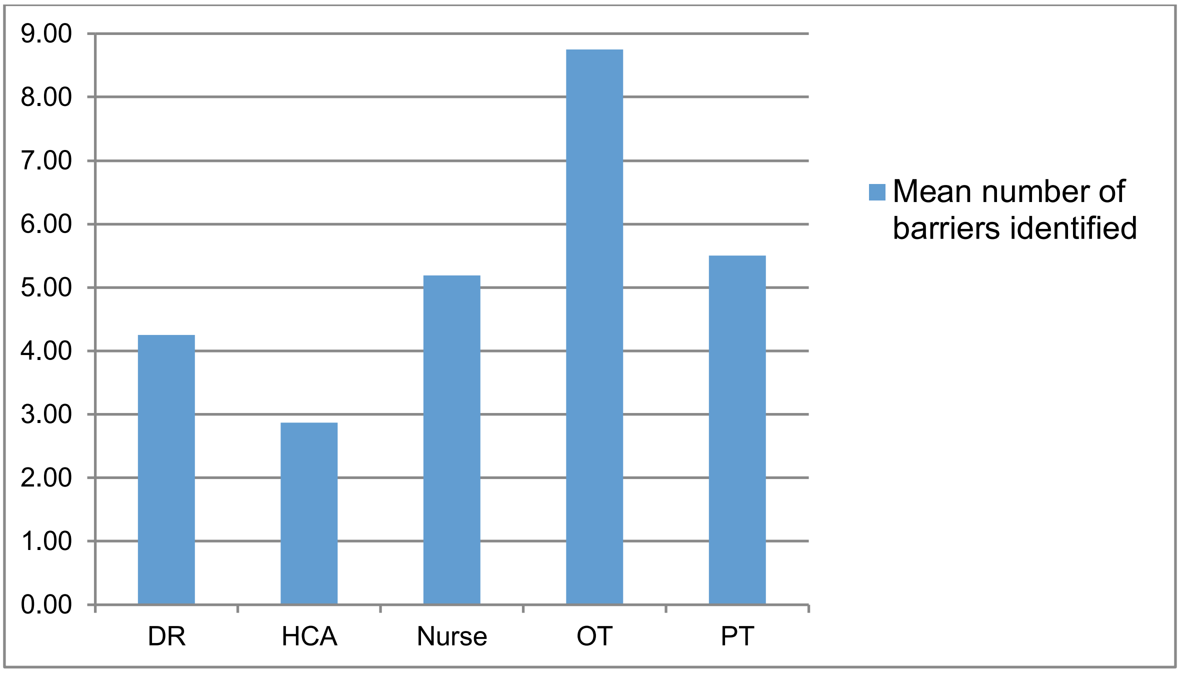
In response to question Q13, the participants identified a number of barriers to pain assessment, the frequency of responses are shown in Table 11 in rank order. All of the predetermined barriers were acknowledged to be relevant barriers and the most frequently reported barrier was “healthcare clinicians are not using pain assessment scales” which was identified by 27 participants.

Table 11: The frequency of barriers identified to be relevant in rank order

Description of Barrier	Number of participants who identified this barrier	Percentage of 41 responding participants who identified this barrier
Health care clinicians are not using pain assessment scales	27	65.85%
The knowledge of pain assessment in carers and loved-ones of people with dementia is insufficient	24	58.54%
There is not enough training about pain assessment techniques	24	58.54%
Pain behaviour is misinterpreted as indicative of other problems related to dementia	23	56.10%
The health care clinicians tend to be reactive to pain rather than proactive	23	56.10%
There is a lack of collaboration between dementia care, palliative care and older adult care	20	48.78%
There is not any training about pain assessment techniques	18	43.90%
Pain assessment is poorly documented in my organisation	17	41.46%
There is a belief that pain is a normal part of ageing	11	26.83%
There is not enough time to learn people's normal behaviours	9	21.95%
In my organisation, dementia is not seen as a terminal illness appropriate for palliative care approach	7	17.07%
There is a belief that someone who is in bed is comfortable	6	14.63%
There is not enough time to assess for pain	5	12.20%
The assessment scales are not appropriate for my place of work	5	12.20%
There is a tendency to treat pain assessment as a paper exercise and information is not interpreted	5	12.20%
There is a belief that some people with dementia do not feel pain	4	9.76%

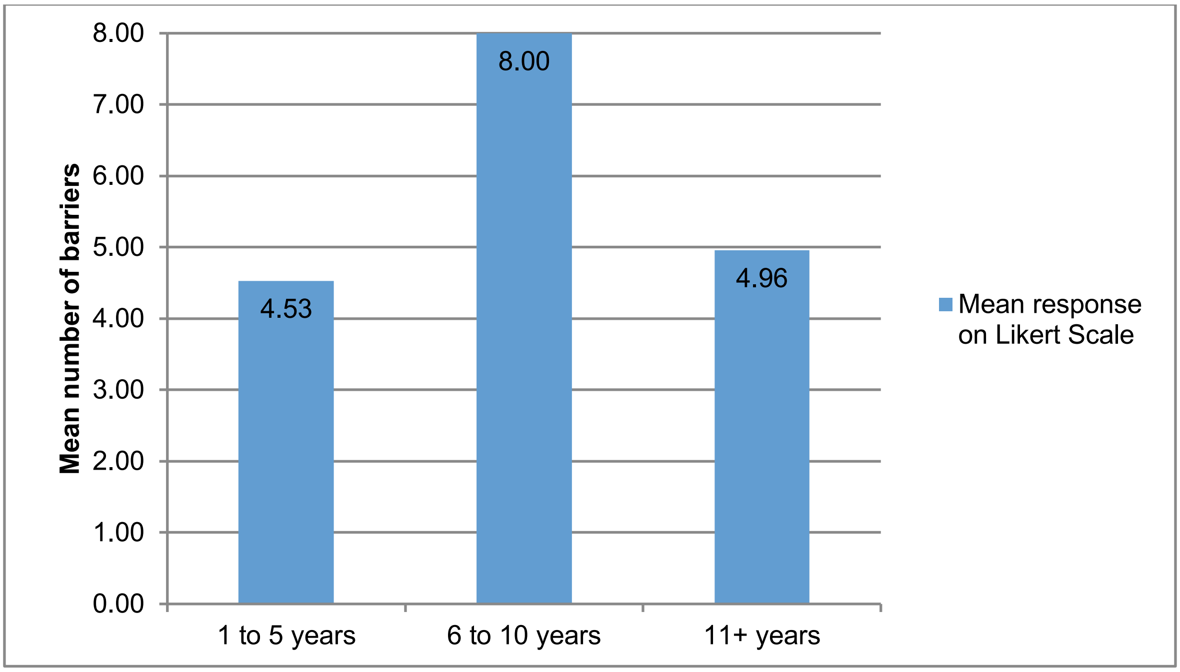
There was a non-significant trend in the mean number of barriers identified between the professional groups with the OT group reporting the most barriers and the HCA group reporting the least *p*≤0.05 [F(4,37) = 2.41, p = 0.07]. Figure 12 presents this trend.

Figure 12: A bar chart of the mean number of barriers identified by the professional discipline groups



There was a non-significant trend in the difference in the mean number of barriers identified between the groups of years of experience and Figure 13 illustrates this *p*≤0.05 [F(2,38) = 1.76, p = 0.19]. The 6 to 10 group reported the most barriers and the 1 to 5 years group reported the least.

Figure 13: A bar chart of the mean number of barriers identified by the groups of years of experience



Two comments were left in the section on barriers and the exact comments are quoted in Figure 14.

Figure 14: Textbox containing the comments written by two participants regarding barriers to pain assessment

I am able to look for verbal/non-verbal ways of communicating re pain; my role does not require me to complete forms for pain.

With regard to dementia not being seen as a terminal illness appropriate for palliative care i would like to add that when we receive a referral for someone with dementia as it's usually the early stages and manageable with support it isn't terminal but obviously in the later stages where admission to 24 hour care or hospital is needed then it is palliative care that is offered by staff in that particular care setting.

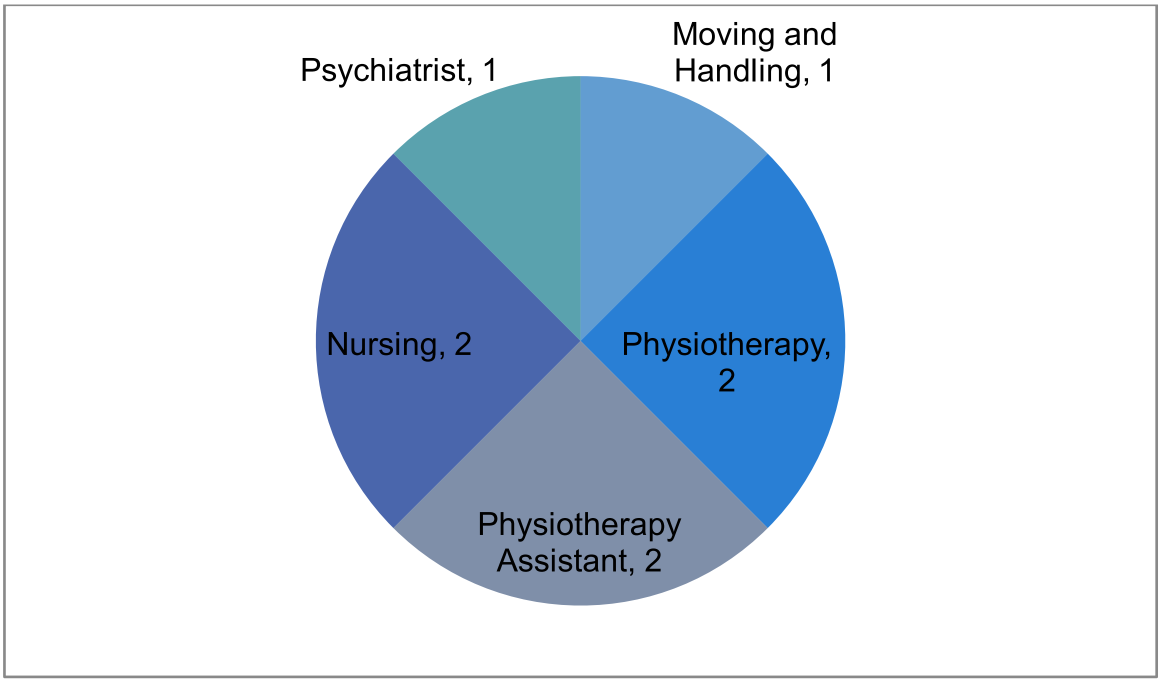
4.2 The Results of the Focus Group

Nine clinicians responded that they wished to attend the focus group and nine attended the focus group. One of these attendees was a nursing student who wished to attend for experience but did not contribute and so this attendee is not included in the analysis. No feedback or corrections were given from the attendees regarding the focus group summary presented in Appendix J.

4.2.1 Demographics

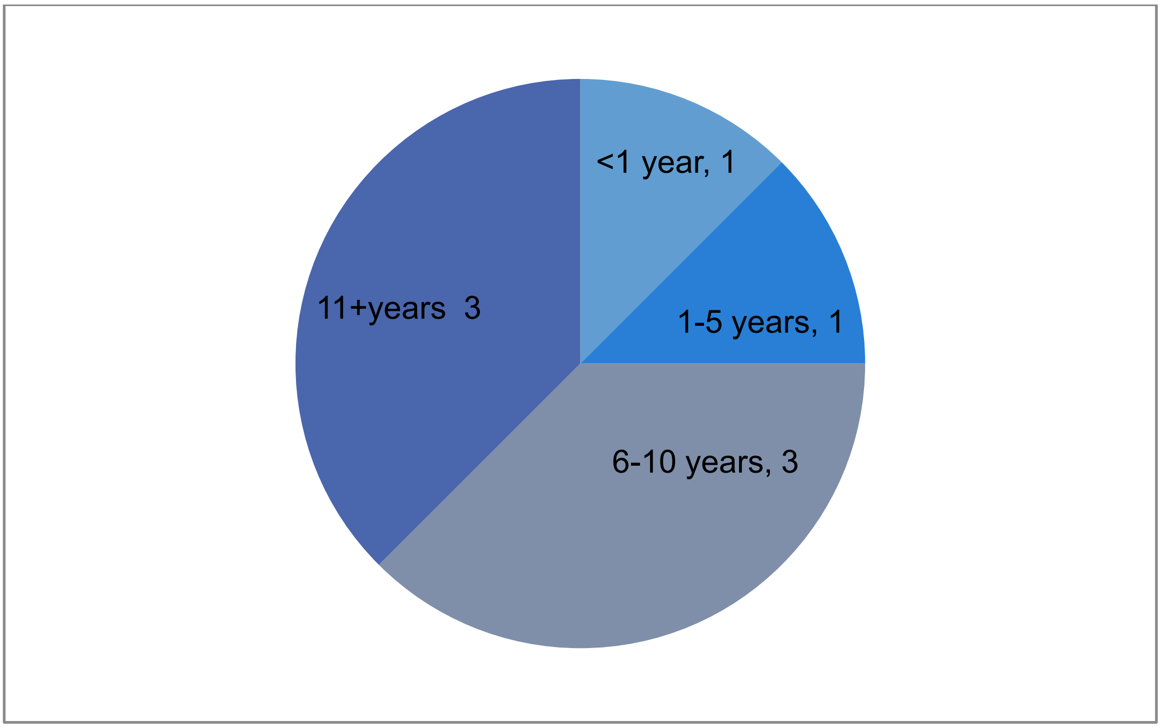
The group comprised five different professions which are depicted in Figure 15. Psychology, occupational therapy and healthcare support worker were not represented in the group.

Figure 15: A pie chart to show the distribution of professional disciplines in the focus group



There was a distribution in the representation of the categories of number of years of experience and this is illustrated in Figure 16, with most participants having over six years of experience.

Figure 16: The distribution of the categories of number of years of experience



4.2.2 The Process of Analysis

The transcription from the focus group is presented in Appendix L and was analysed using the methods recommended by Corbin and Strauss (2008) which are summarised in Table 9 in the methods chapter. It is beyond the remit of the project to include every memo that was a consequence of the analysis, but two of the stages of the analysis are presented in a conditional/consequential matrix in Figures 17 and 18. Figure 17 illustrates that the issue of pain assessment was considered to be subject to influences close to the clinician (micro) and those that were wider issues and less close to the clinicians (macro). The more external the influence the nearer to the external concentric circle it is presented.

Figure 17: The macro and micro issues in the focus group

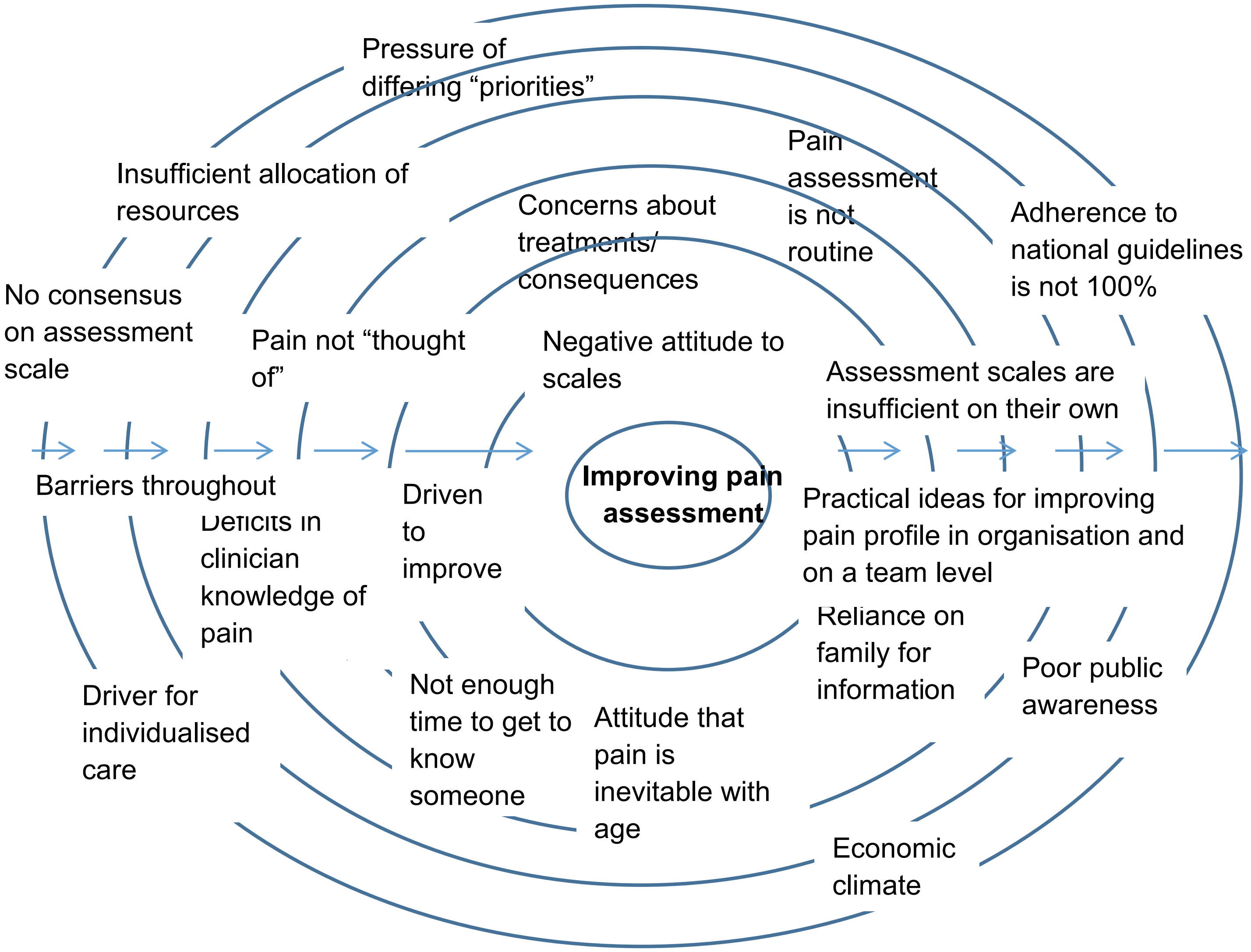
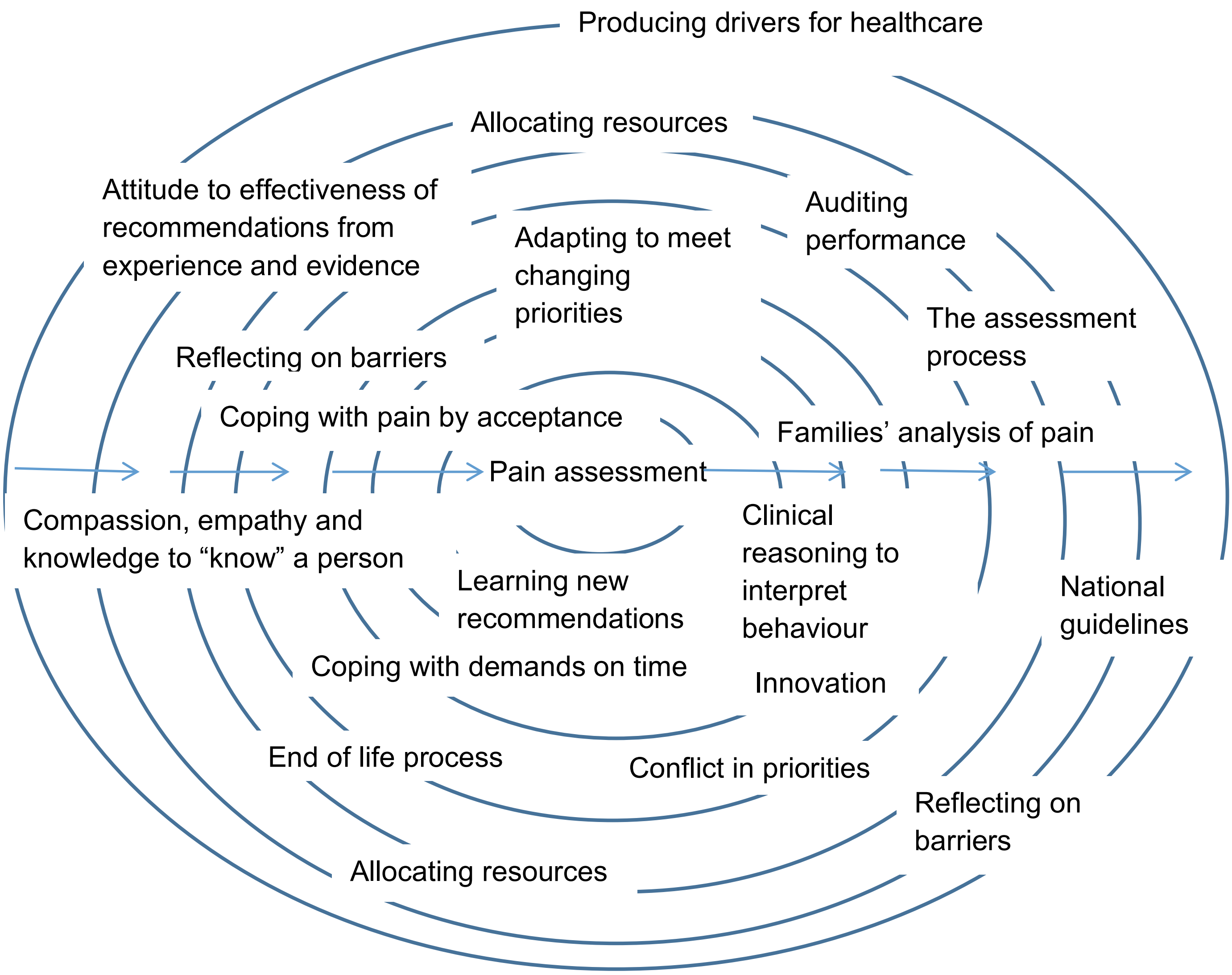


Figure 18 illustrates that there are a number of processes that were considered to be associated with pain assessment and that these ranged from internal processes for the individual clinicians to national processes that were considered to be significant by the group.

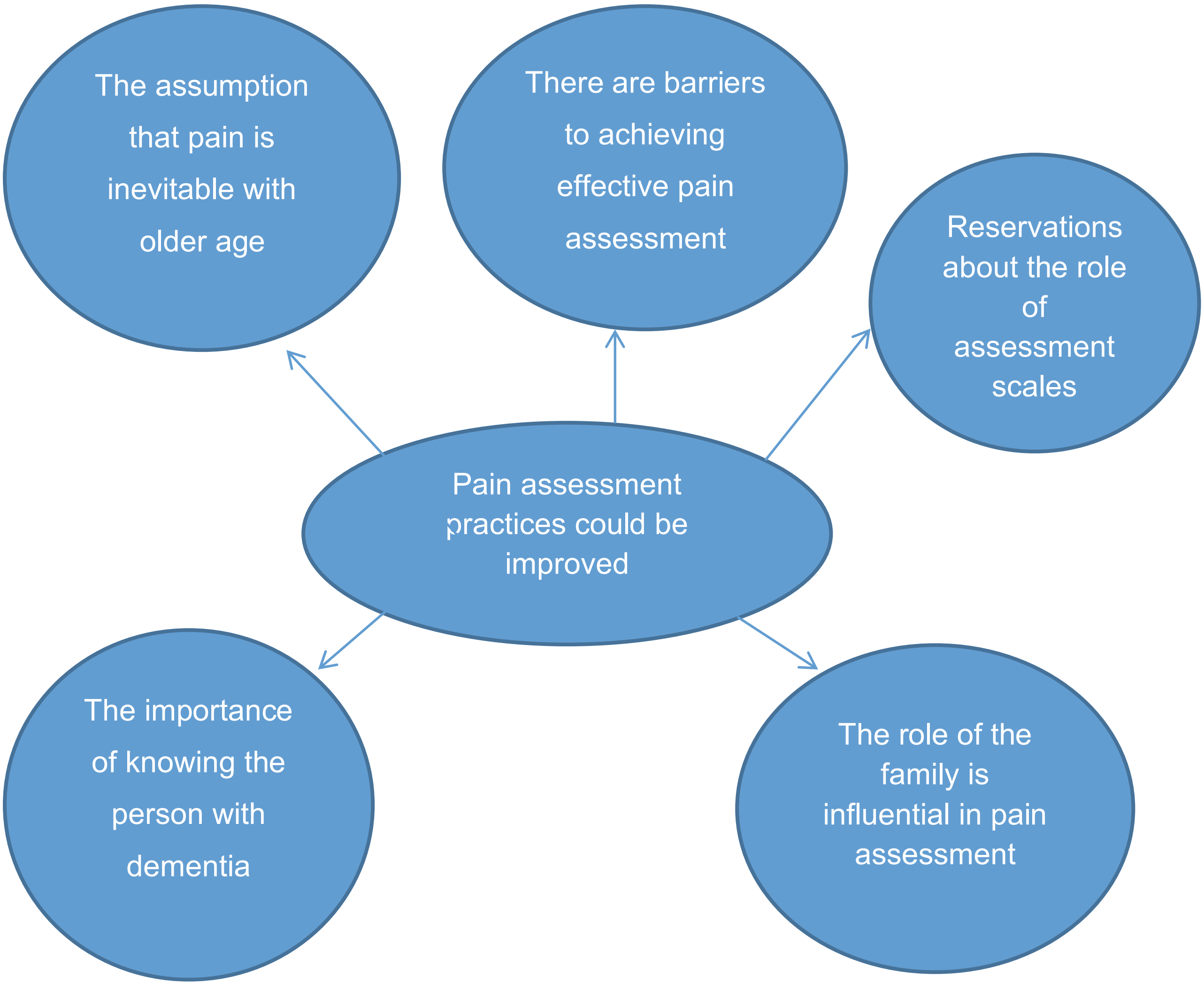
Figure 18: A conditional/consequential matrix of the processes in the focus group data



4.2.3 The Themes

The core theme of the focus group was that pain assessment could be improved in the organisation in question. This drive emerged as a core theme because it acted as a foundation for and permeated all the other themes and because all discussion functioned around the collective belief that improvement was indicated and viable. Figure 19 identifies the other themes identified by the analysis which are depicted around the core theme. The themes were interrelated and a map of the key relationships can be seen in Appendix M.

Figure 19: A map of the themes identified from the analysis of the focus group data



4.2.3.1 The Belief that Pain is Inevitable with Older Age

This theme was identified in Chapter 2 as a possible barrier to effective pain assessment, but was not grouped under the barrier theme in the analysis since it was not consciously asserted as being a barrier by the participants. Table 12 illustrates the evidence for this theme.

Table 12: Evidence for the theme “the assumption that pain is inevitable with older age”

Quotes from the Focus Group Transcript	Comment
“we all have aches and pains” (agreed by all) “(pain is) inevitable”	Evidence of attitude towards pain as an inevitable condition
“well if it’s chronic pain, they get used to it. Don’t notice until it’s gone”	Evidence of the assumption that people can become accustomed to chronic pain.
“there is that expectation that you are getting old and you will have aches and pains”	Assertion that this assumption is common
“they accept that pain is a response that needs to be there as you get older”	Evidence that the person with dementia possesses the assumption that pain is inevitable with age
“they accept it (pain) is part of the condition, the family and the patient”	Evidence that the family might also adopt the assumption
“and the chronic rumbling demoralising pain, which I think does get misconstrued in the ageing process”	Identifies the assumption as erroneous (contradicts the prior assertion that “we all have aches and pains”)
“patients accept that they are going to be fixed in this position”	Eludes to acceptance of the physical postures associated with painful conditions
“it’s not exactly routine either. It’s usually when there is a diagnosis, or as end of life or something, but with old age we should think of it as inevitable, well not inevitable but we don’t use it enough”	Idea that assuming pain is present with age might result in improved pain assessment practices

4.2.3.2 The Importance of Knowing the Person with Dementia

The importance of knowing the person with dementia emerged early in the focus group discussion and then re-emerged throughout the discussion. Table 13 illustrates the evidence for this theme.

Table 13: Evidence for the theme "the importance of knowing the person with dementia"

Quotes from the Focus Group Transcript	Comment
“it’s getting that background isn’t it” “unless we adopt a personalised approach we will treat pain inappropriately or miss pain that does need treatment”	This quote was part of an example where the clinician reported they were only able to effectively assess for pain by knowing the person’s background
“it’s getting used to the person for a length of time and looking at facial expressions and body movements”	Highlights the importance of knowing a person’s facial and bodily behaviours to identify pain
“you have to take into account the other things about the person, whether that’s historical physical health or wellbeing. Things that have happened to them in the past and how they behaved pre-diagnosis, what they were like as a person”	Assertion of the importance of knowing specific aspects of the person with dementia.
“we are not encouraged to think about the mental health and physical health joined together and how one impacts on the other”	Eludes to acknowledging the person as a holistic entity or approaching assessment holistically
“we need to start with the basics of getting to know the person”	Asserts a belief that knowing the person should be a practice foundation
“it’s all individual”	This refers to pain assessment differing for each person

4.2.3.3 There are Barriers to Achieving Effective Pain Assessment

The theme of barriers was formulated in response to a plethora of barriers identified in the focus group. Table 14 identifies these barriers. Reservations about the role of assessment scales and the influence of the family were linked as possible barriers to pain assessment in Appendix M, but were categorised as separate themes since they were multifaceted issues.

Table 14: Evidence for the theme "there are barriers to effective pain assessment"

Quote from Focus Group Transcript	Associated Barrier
“I don’t think we do always think about pain as routine” “it is not routinely done” “it’s not exactly routine either”	Pain assessment is not routine
“once people have a mental health problem, physical health problems get forgotten” “It seems to be that there have been attempts to look at this, but it has gone into that black hole” “priorities change. Locally and nationally” “you ask them if they have thought of pain, often this is something they have not thought of” “even if a family member knows they have pain they don’t see that they need to tell the CPN or support worker because it’s not something they need to bother with”	Pain assessment is not a priority
“it’s a few lines so it does not necessarily trigger people to do the assessment tools or do this or do that” “so pain is on the assessment tool we use but it’s what you do with it”	The pain indicators are not always interpreted and acted on
“is there also a question about whose place it is to do that” “then you are going to signpost someone to elsewhere”	Lack of clarity about whose responsibility it is to assess pain

Table 14 Continued:

Quote from Focus Group Transcript	Associated Barrier
“GP’s are the most difficult for getting a two way conversation going at times” “I think some GP’s you have a good working relationship with” “do you have time to do the battling and following up” “how do we get it (a truly multidisciplinary approach) from the beginning. I don’t know if we can” “we don’t know each other’s literature or expertise in sufficient detail” “we don’t step over into somebody else’s silence…I don’t try to invade a doctors meeting…we rarely step into somebody else’s pond” “but do we meet outside of our professions…only when there is a crisis”	There are barriers to communication between the professional disciplines
“they might look distressed but it’s hard to know if that’s because they are in pain or possibly its associated with the dementia” “it was thought to be challenging behaviour” “the difficulties or the lack of corporation that a person might display is usually put down to mental health”	There are difficulties in correctly interpreting a person’s behaviour
“it is such a quick turn around” “we only have 37.5 hours a week, we have to do all those bits and bobs” “it’s making time to do this, but all of us only have 37.5 hours a week”. “we, as clinicians, have a 35 to 40 minute window to understand the whole thing, which I don’t think is viable” “staff change very quickly” “the other thing is resources, the thing is there are so few of you when you consider all the teams that there are… you would never actually have any time to see patients”	There are barriers in the organisational structures

Table 14 continued:

Quote from Focus Group Transcript	Associated Barrier
“I think they were also worried about the constipation, and they are more worried about that than the pain” “all I will get is another wretched pill and I’m already on a truck load” “I don’t feel very confident about non-pharmacological treatments for pain” “if doctors felt more confident about advising and pointing people towards non-pharmacological approaches they might feel more enthusiastic about identifying pain rather than burdening the patient with another pill”	Treatment for pain and side effects of pain medication can be a deterrent to acknowledging pain

4.2.3.4 The Role of the Family is Influential in Pain Assessment

The role of the family emerged in the data at a number of points in the narrative of the focus group. Table 15 illustrates the evidence for this theme.

Table 15: The evidence from the focus group transcript for the theme "the role of the family is influential in pain assessment"

Quote from Focus Group	Comment
“I think that a lack of communication between families and carers especially and their lack of understanding about pain” “they never get the chance to find out more about the problem or communicate with other professionals” “even if a family member knows they have pain they don’t see that they need to tell the CPN (community psychiatric nurse) or support worker because it’s not something they need to bother with”	There are issues in the communication of pain related information between the family and the professionals
“I also think they are worried about constipation, and they are more worried about that than the pain” “to the families pain is something that will go if you take a pain killer whereas dementia will not go anywhere”	The family of the person with dementia may have different care priorities than the clinicians
“going into the community, you only see a snapshot on that visit and its getting the broader picture, and you need to get that from the family” “family are a phenomenal resource for getting to know the person”	Family can provide information to help the clinician get to know the person with dementia
“sometimes the spouse is equally as confused as the person you are going to see” “there is so much information that the son or daughter don’t know because mum or dad have not wanted to worry them”	Counter-argument to the above – families are not always able to provide information about the person with dementia
“when somebody has a spouse that has a diagnosis of dementia, and you are trying to educate them about the dementia, so they are grieving about the lost person or the changes in abilities” “they accept pain is a response that needs to be there as you get older”	The family have their own issues and perspectives that can impact on the person with dementia

4.2.3.5 Reservations about the Role of Assessment Scales

Reservations about standardised pain assessment scales were identified early in the focus group and the group collectively shared reservations. Table 16 illustrates the evidence for this theme. Assessment scales are often referred to as tools in this group.

Table 16: Evidence from the focus group for the theme "reservations about the role of assessment scales"

Quote from the Focus Group	Comment
"sometimes it is easier to use the tool when we don't know the person and don't have enough time to get to know and understand them better" "I think that tools can be useful, as subjective as they are, as a baseline, but you have to take into account the other things about the person" "tools on their own are insufficient"	Evidence for the belief that assessment scales are insufficient on their own for detecting pain
"the family .... are well placed to use the tools" "there is also a question of whose place it is to do that"	There is uncertainty about who should be completing the assessment scales
"the tools are not as reliable as I would want them to be"	Concerns about reliability
"there is an inability to localise the pain" "it can be difficult to work out the intensity of pain" "I think that even with them it's still a bit subjective" "I think people often use a tool because it's quick to do rather than being the most appropriate"	Concerns about the clinical suitability of the assessment scales
"I have not actually come across them" "I am used to some tools but not aware of locally what everyone does"	Clinicians may not be aware of the variety of pain assessment scales
"and so pain is on the assessment tool we use but it's what you do with it…" "it's a few lines so it does not necessarily trigger people to do the assessment tools"	Queries raised about whether the assessment scales trigger appropriate actions to address the pain

5 Chapter 5 – Discussion

5.1 Introduction

The aim of this project was to evaluate the methods being used by community mental health clinicians to assess for pain in people with dementia living at home. The methods comprised a questionnaire and a focus group obtaining both quantitative and qualitative data. This chapter aims to interpret this data and discuss the findings in relation to their clinical contexts. The chapter is organised under the BPS and BPS (2007) guidelines so that the findings from both the quantitative and qualitative data can be synthesised.

5.2 The Frequency of Pain Assessment

The BPS and BGS guidelines state that "*any* health assessment of older people should include asking whether they experience pain" (2007, p.7) and the findings of the questionnaire indicate that only 46.7% of clinicians report they frequently assess for pain which compares lower to the 69.2% found by Herr et al. (2004). This project found that 20% of clinicians report they sometimes assess for pain and this also compares lower to the 30.8% found in Herr et al.'s study (2004). The difference in these results may be due to the clinical setting of the studies, for example, Herr et al. (2004) undertook their research on a medical ward for people who had experienced a hip fracture and therefore pain would be a likely expectation whereas this project looked at a group of people with a primary mental health diagnosis and so will not necessarily have coexisting physical ailments. The limitation of not having any published results from similar settings for comparison to this project is that it is difficult to benchmark the practice behaviours occurring within the organisation. The other difference is that Herr et al. (2004) obtained their data around frequency of pain assessment from medical documentation and then compared this to results from a questionnaire, finding that the two did not directly correlate and they proposed that it was likely that pain was being assessed for more frequently than was being documented. The aim of this project was to establish practice behaviours rather than the accuracy of documented practice behaviours, but this does pose a potential management issue that might warrant further exploration. The focus group did not answer the question of why some clinicians assess for pain at some visits and not others, but the findings of both the questionnaire and the focus group identified a considerable number of barriers to pain assessment, which might be contributing to this issue. The barriers are discussed under the heading of barriers to pain assessment.

5.3 Asking the Person if They Have Any Pain

The BPS and BGS guidelines state that "any health assessment of an older person… should include asking whether he/she experiences pain" (2007, p.8) and the findings of the questionnaire indicate that this was not consistently being undertaken. A barrier identified in the focus group suggested that mental health clinicians might neglect to ask about physical health because of their focus on mental health and it is possible that a question about pain is not on the typical repertoire for a mental health assessment. Other research has cited that communication difficulties experienced by people with dementia can act as a barrier to asking about pain, (Frampton, 2003; Sachs et al., 2004; Bachino et al., 2001) but it needs further enquiry to establish whether this was the reason for the mental health clinicians to not always be asking in the context of this project. The findings of this project do not indicate why clinicians sometimes ask about pain and not at other times and further evaluation is indicated to understand this finding.

5.4 The Use of Behavioural Observation to Assess for Pain

The BPS and BGS guidelines state that "in people with difficulty in communicating including cognitive impairment…an observational assessment is additionally required" (2007, p.11). The findings of the questionnaire indicate that only 54.5% of the clinicians are frequently using behavioural observation to assess for pain in people with dementia which compares lower to the 69.2% found by Herr et al. (2004).

The BPS and BGS (2007) acknowledge studies illustrating that many people with dementia can report pain verbally and an example of this is seen in Herr et al.'s (2004) study where the clinicians were able to use a verbal pain intensity scale with 13.6% of people with dementia. Consequently it might be considered that if a person can talk about their pain a formal observation of their behaviour might not be indicated and this would explain why clinicians are not always using behavioural observation to assess for pain in people with dementia.

A second interpretation for this finding might be that there is disparity in opinion in what constitutes a valid behavioural sign (Bachino et al., 2001). Herr et al. (2004) and Stolee et al. (2007) identified 16 and 37 pain behaviours respectively whereas the BPS and BGS (2007) only identify six behavioural signs. The focus group identified two behavioural signs of pain that were considered valid and this lack of clarity in valid pain behaviours is likely to be a deterrent to clinicians following this guideline.

5.5 Assessing for Pain during Movement as Well as at Rest

The national guidelines state that "observing patients during physical activity can help identify pain" (BPS and BGS, 2007, p.9) and the findings of the questionnaire indicate that this was not consistently being adopted. If a person with dementia has been assessed as requiring two people to help them to move then, in accordance with the organisations manual handling policy, the mental health clinician is not permitted facilitate movement since community visits are usually attended by one clinician. The physiotherapy and HCA group reported they look for pain during movement and at rest more often than the other professional groups, and although this was not a significant relationship, it could be said that the role of these two groups comprises more physical activities than might be expected from a psychiatrist, mental health occupational therapist or psychiatric nurse undertaking a mental health assessment. The implications of these findings is that the person with dementia who requires two people to help them move may be at higher risk of not having their pain identified, if their pain is elicited by movement. From a management perspective, it implies that all staff need to have training to help someone move safely and also that an additional staff member may be needed to undertake this aspect of pain assessment, which would increase the demand on services.

5.6 Use of Pain Assessment Scales

The national guidelines describe a number of assessment scales the clinician can use to detect pain (BPS and BGS, 2007). The use of assessment scales received the lowest reported adherence score of all the recommendations, with 45% of clinicians reporting they never use an assessment scale. This frequency of never using assessment scales was lower than that found in Allcock et al.'s (2002) study which found that 75% of the staff in 121 nursing homes did not use an assessment scale. On the other hand, this project found that only 9% of clinicians always used an assessment scales compared to the 41.9% in Herr et al.'s study (2004). The difference in these findings might be due to the different settings of the pain assessment and whether they had management procedures in place for using pain assessment scales, although without an assessment scale being recommended by the BPS and BGS (2007) it might be difficult for an organisation to implement a protocol for this.

In the questionnaire, 12.2% of the clinicians reported that assessment scales were not appropriate for their place of work and a number of reservations about the effectiveness of assessment scales were raised in the focus group, which might explain some of the reluctance to use them. Stolee et al. (2007) also found that staff considered assessment scales to be insufficient since they are perceived to be ineffective in capturing changes in normal behaviours and routines. Consistent with the project's focus group findings, the focus groups in Kaasalainen et al.'s study (2007) also produced a major theme of uncertainty about the accuracy of pain assessments. The inconsistent finding in this project was that, although 45% of clinicians reported they never used assessment scales, 65.85% rated "staff not using pain assessment scales" as a barrier to effective pain assessment. This inconsistency may be linked to the discussion in the focus group where it was questioned which professional group is responsible for undertaking the pain assessments, suggesting that clinicians may believe that completing assessment scales will improve the effectiveness of pain assessment, but that they do not think it is their role to do this. The discussion in the focus group did not identify who they thought should be completing the pain assessments. Nurses were statistically less likely to use assessment scales than physiotherapists and this may link to the aforementioned finding that there is uncertainty as to whose role it is to undertake pain assessment.

This project identified that the NOPPAIN was the most commonly used assessment scale which is dissimilar to the findings of the publications in the literature review (Zwakhalen et al., 2006; Herr et al., 2010; Abbey, 2007; Smith and Kennerley, 2012). These studies were undertaken in different countries, including America and Australia and although this may explain some differences in health care practices, the NOPPAIN was developed in America and so the origins of an assessment scale does not present as influential to its use in other countries. The author notes that several years previously the NOPPAIN scale was introduced into the organisation in question in a short training course for inpatient staff by a consultant nurse and this might explain how it had percolated into the most common practice choice, though there had not been recent training to this effect and none had been offered to community clinicians. The findings in this project do not provide any information about why the NOPPAIN scale is preferred.

5.7 Asking Carers and Loved Ones when Assessing for Pain

The national guidelines assert that “families can be a useful additional source of information” (BPS and BGS, 2007, p.12). The project findings offer a number of possible reasons why clinicians might not be asking family and carers more often when assessing for pain. One frequent explanation was that “the knowledge of pain assessment in carers and loved-ones of people with dementia is insufficient” was the second most frequently ranked barrier to pain assessment. This issue also emerged as a theme from the focus group and reservations were made about the usefulness of asking family due to their possible lack of knowledge about their relative’s past pain, their contrary health priorities and poor awareness of signs of pain. The latter reservation has been highlighted in other research (Thun-Boyle et al., 2010). The BPS and BGS acknowledge that reports of pain by family caregivers do not always correlate with those assessments by professional caregivers, but it is still recommended that they are consulted as a “useful additional source of information” (2007, p.12).

5.8 Awareness of Possible Pain Producing Diagnosis

The BPS and BGS guidelines state that “a full medical history should be taken” (2007, p.12) and the results of the questionnaire indicate that only 50% of the clinicians in this project frequently undertake this. A response in the focus group revealed that “on the initial assessment we have the physical health page that we have to do, and it is part of the standard audit document that we have to do that” and, in addition, the organisation has a policy which states that all clinical documentation should include “history of physical/mental illness and other health problems” (not referenced for anonymity). It is only the nursing, medical and occupational therapy clinicians who complete the initial assessment paperwork but since there was a lack of statistical significance between the professional groups, this refutes this as a possible explanation. An alternative interpretation might be that the wording of “possible pain-producing diagnosis” is considered to be separate to obtaining a medical history. The source of physical health history would be the General Practitioner and this was reported to be an area where communication was difficult. An operational issue is that mental health clinicians do not have access to the general practitioners’ electronic records. In conclusion, further investigation would be required to establish whether this finding was a result of methodological influences of the wording of the questionnaire or whether the roles of operational management systems are influential.

5.9 Barriers to Pain Assessment

The questionnaire and the focus group findings both produced a large number of perceived organisational barriers to pain assessment. Four participants skipped this question in the questionnaire which might indicate they did not consider there to be any barriers or that they did not want to report any barriers; this is a limitation of this question since the views of the four participants that skipped the question are not represented. Two barriers featured in the findings of this project that did not feature in the literature review. Firstly, poor multidisciplinary communication featured as a common barrier discussed in the focus group, but this did not feature in the questionnaire since the literature review did not produce any publications that identified this. It might be that, since the literature did not specify that poor multidisciplinary communication was a barrier, this might be a problem specific to the organisation in the project, and in support of this explanation Herr et al. (2004) conversely found that the nurses in their study did not feel that lack of consultation with peers was a barrier. Poor multidisciplinary communication has been cited as a contributory factor in cases of poor healthcare and has led to upheld complaints (Parliamentary and Health Service Ombudsman, 2011) although these complaints comprised more than just poor pain assessment. This issue warrants further investigation to understand its role in facilitating effective pain assessment. As previously described, the general practitioners' electronic medical methods are inaccessible for mental health staff and so the clinicians rely on telephone communication occurring between clinics coinciding with times when the mental health clinicians are not undertaking community visits.

The second identified barrier that was unique to this project was that mental health needs are perceived to be prioritised at the expense of physical needs. It is likely that this is a barrier specific to mental health settings, but there was only one other study that investigated pain assessment practices among mental health clinicians and this barrier was not identified (Stolee et al., 2007). The difference between Stolee et al.'s (2007) study and this project was that it was undertaken in mental health inpatient services and so the implication is the this problem might be unique to mental health community settings. There was no further evidence about which clinicians might be prioritising mental health needs and neglecting physical needs and the difficulty is that this group of clinicians are unlikely to have completed the questionnaire or attended the focus group as they do not view the topic of physical pain as their priority.

A perturbing finding was that four participants said that there is a belief in their place of work that people with dementia do not feel pain. McAuliffe et al. (2009) also found evidence of this belief in their review of pain assessment literature for people with dementia. These authors referred to two case studies where the person did not display any pain behaviours to noxious stimuli, but strongly refuted that these case studies should be applied to the wider population (McAuliffe et al., 2009). It is a possible that clinicians who are not aware of the signs of pain have cognitively made sense of this by assuming that people with dementia do not feel pain, though this psychology is an unlikely explanation for a person who works in healthcare where pain is reported to be present in 47% to 66% of their service users (Zwakhalen et al., 2009; Ferrell et al., 1995; Feldt et al., 1998). It also is unlikely that the results of two case studies from 1997 would have been sufficient to manipulate an organisational attitude. It should be noted that this is a perceived organisational barrier and further investigation could establish the origins of why this is thought to be a problem.

The belief that “pain is a normal part of ageing” was identified by 26.8% of the clinicians as a barrier to effective pain assessment, which has also been identified by McAuliffe et al., (2009). The focus group provided possible evidence that this belief might be pervasive among the attendees of the focus group themselves, as evidenced by the statement “we all have aches and pains”, in the wider organisation as evidenced by the statement “there is that expectation that you are getting old and you will have aches and pains” and in the person with dementia as evidenced by the statement “they accept that pain is a response that needs to be there as you get older”. The belief that people with dementia assume pain is inevitable with age features in the focus groups in Kaasalainen et al. (2007) study. The literature refutes that pain is inevitable with age, (Zwakhalen et al., 2009; Ferrell et al., 1995; Feldt et al., 1998) indicating that this belief is inaccurate. The results of this project do not explain the origins of this belief but the finding contributes to the issue by identifying that, although the clinicians perceive the belief to be a barrier, they are not critically self-reflecting that since they also hold this belief. If healthcare clinicians do believe that pain is inevitable with age, it is likely to impact upon the person with dementia as they are likely to consider the clinician an expert on pain. The other issue might be that if the expectation is that pain will be present, there is less motivation to assess for it and act on the assessment.

5.10 Models of Care for Pain Assessment

Chapter 2 identified that management systems and individual clinicians can employ a number of different models for pain assessment, including person-centred and standardised approaches. The assertions in the focus group alluded to a collective belief that knowing the person is important and to the extent where “unless we adopt a personalised approach we will treat pain inappropriately or miss pain that does need treatment”. This finding concurs with existing literature that familiarity with a person’s usual patterns of behaviour will improve the ability to identify pain (Smith, 2007; Stolee et al., 2007; BPS and BGS, 2007). The focus group raised the issue of knowing the person in the context of barriers suggesting that this was not being achieved to a satisfactory extent. In addition, both the literature and the outcomes of the focus group suggest that lack of time is a fundamental barrier to getting to know the person (McAuliffe et al., 2009). The service specification for the community mental health teams stipulates for four and a half hours to undertake an initial assessment and one and a half hours to review a person with dementia living at home and the length of time a person has contact with the service can vary from weeks to years. In light of this, knowing the person may not be possible initially and a person will only be referred to the service if they are acutely mentally unwell or in a crisis and so debatably might not be “themselves” at that time. Both the use of time and establishing a person’s normal behaviours might be achieved if there was the appropriate skills and training to achieve this and so the issue around getting to know the person with dementia might be aided by training rather than providing longer mental health assessment times. This implication suggests that the service would benefit from investing in training staff in strategies to get to know the person with dementia because the short-term loss of clinical time will provide long term gains in clinical time since the assessments that require knowing the person with dementia can be undertaken more quickly.

6 Chapter 6 – Conclusion

6.1 Introduction

This chapter aims to draw conclusions from the key findings and evaluate whether they met the aims and objectives of the project. A reflection of the methodological strengths and limitations will be presented and any influences these may have had. My personal reflections of undertaking this project are included together with any changes that might be made if were project were to be repeated.

6.2 Aims and Objectives

The aims of this project were to collect and analyse data about the approaches being used by community mental health clinicians to assess for pain in people with dementia who live at home. The objectives subsidiary to the aim are:

- To complete a literature search to inform the project and guide the methodology
- To identify which approaches community mental health clinicians are using to assess for pain in people with dementia
- To establish adherence to national pain assessment guidelines published by the BPS and BGS (2007)
- To collect information from clinicians regarding any organisational barriers they may be experiencing that are impeding pain assessment practices
- To produce clinical recommendations

This project has been successful in gathering data on pain assessment approaches used for people with dementia and has employed both quantitative and qualitative methods so more than one process of analysis can be undertaken and synthesised for interpretation in the discussion. The literature search objective was achieved and it produced a large amount of varied publications to help with the comparison of findings to the wider areas of healthcare, but future searches should include the term “tool” and well as “scale” and “measure”. In accordance with the objectives, information was successfully obtained about the approaches clinicians are using to assess for pain and it was possible to compare these to each of the extracted BPS and BGS (2007) guidelines to establish adherence scores. Information about organisational barriers to effective pain assessment was also obtained. The objective of establishing the models being adopted for pain assessment was achieved from the focus group analysis and statistical analysis was undertaken to establish any differences between professional disciplines and years of experience. Clinical recommendations are outlined in the next chapter.

6.3 Evaluation of the Methods

The advantage of the mixed methods approach for this project was that it produced data that was both subjective and objective. Previous pain evaluation questionnaires had an average response rate of 71% (Stolee et al., 2007; Herr et al., 2004; Titler et al., 2009; Allcock et al., 2002) and the project’s response rate of 42.86% is notably lower. The methods that were used in the other studies that could be implemented, if the project were to be repeated, comprised having a six week follow up, telephone follow up and monetary reimbursement. The primary shortcoming of the questionnaire methodology was that it only requisitioned 45 responses, which was sufficient to present patterns in practice behaviours but when the respondents were analysed by profession and years of experience, caution needs to be applied in the interpretation since the effect size is small. The questionnaire methodology relies on the clinicians accurately reporting their practice behaviours and research has noted that reported practice behaviours do not always correlate with documented practice behaviours (Herr et al., 2004).

The methodology of the questionnaire embodies a number of positive features. The use of the electronic questionnaire illuminated any order effects in the questionnaire, although the “no-skipping” function could be employed in the future to ensure there is no missing data. An advantage of this project was that it included more barriers than other research and the inclusion method was systematic. The questionnaire achieved a high test re-test reliability score for each of the ordinal questions, except the question asking if participants assess for pain during movement and at rest, so if there was any reporting bias it was largely consistent. The questionnaire also had the advantage of being piloted by a diverse group of eight experts in the field of pain, dementia and research which was a larger group than had been employed elsewhere in the literature.

The primary limitation of the focus group was that the volunteer number was small and so only one group could be held which resulted in no opportunity to further develop themes. Nine clinicians attended the focus group, which presents a low when compared to the 57 in the focus group in Kaasalainen et al.'s study (2007). The methods of analysis were recorded, systematic and referenced for reliability (Strauss and Corbin, 1994), though a second moderator would have been advantageous. There was no feedback to correct the accuracy of the focus group summary which implies it was accurately interpreted.

A disadvantage of the project was also a disadvantage of the existing literature in that it did not differentiate between individual differences; different types of dementia, different causes of pain or different home situations. The generalisability of the findings is also limited to community mental health staff in the organisation. The issue did not feature in this project, but the community mental health team service often see people with dementia and depression or another coexisting psychiatric diagnosis and studies have noted that it is still unclear as to whether a coexisting psychiatric illness has a role in the expression of pain (Stolee et al., 2007). These individual differences might suggest that the guidelines may not be suitable for every circumstance and so it should be questioned whether management should expect 100% adherence to the BPS and BGS (2007) guidelines.

6.4 Personal Reflection

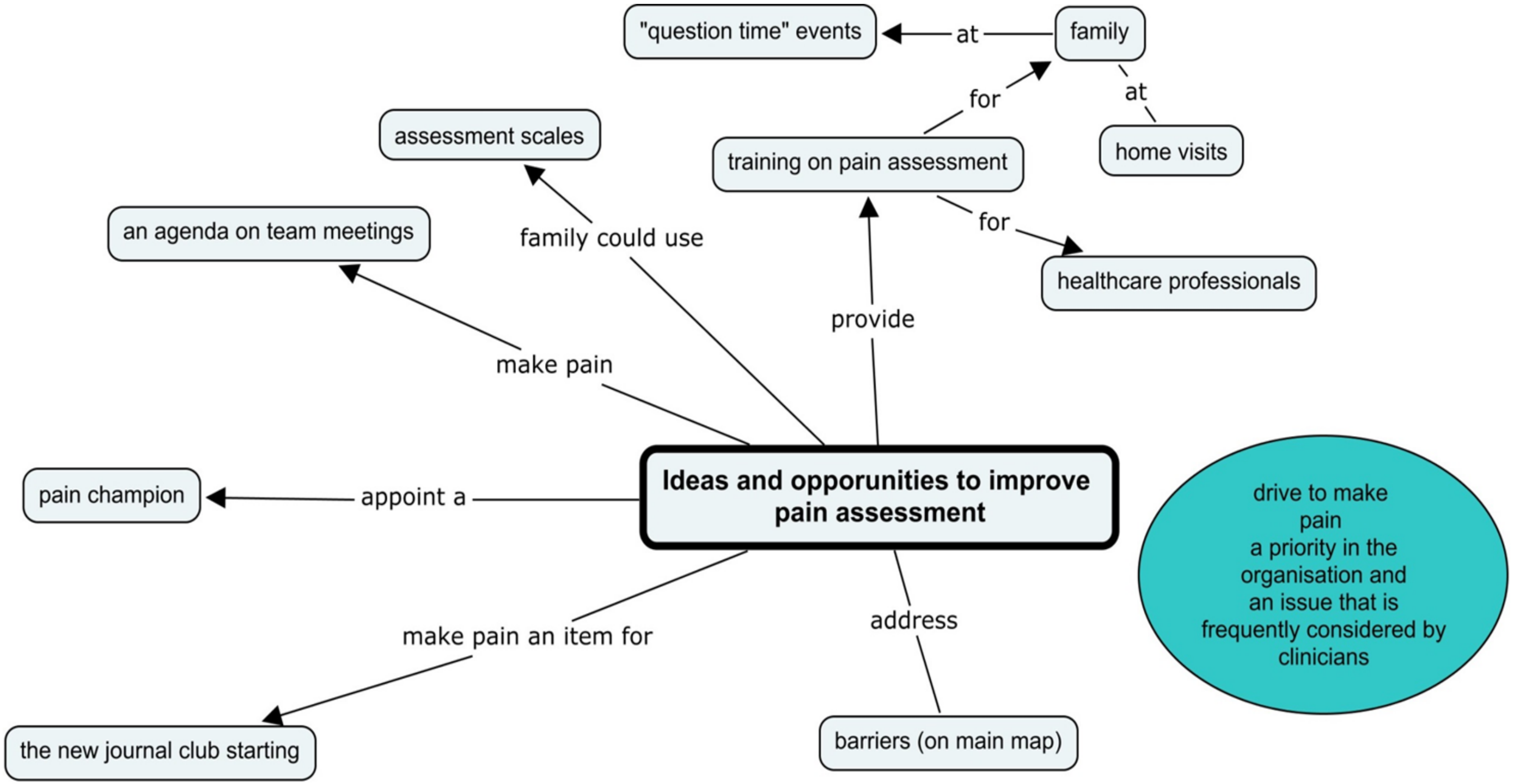
This project has been an important step in my ambition to improve care of pain problems in people with dementia and the literature search has improved my awareness of the existing knowledge in this area. The support I have received from Bradford University has allowed me to develop systematic approaches to developing a methodology specific to answering aims and objectives. This was my first opportunity to analyse qualitative data and, previous to commencing work with Bradford University, I had possessed an attitude that only quantitative data could be useful for evaluating clinical practice. Now I have learnt to value qualitative data for its ability to offer insight into healthcare practice behaviours because it is the clinicians themselves that initiate what is important information rather than the predetermined agenda of the researcher, which is often decided based on the previous research.

The data produced by this project has provided a foundation in which to initiate positive changes in a field of work where I believe there is much improvement to be gained. In my clinical experience, I have witnessed pain take possession of people's lives and cause intense misery. I have also observed that efforts to improve mental wellbeing are fruitless if there is a background of pain and this project provides me with tangible information about where to direct future efforts to prevent this occurring in a population outside my immediate clinical caseload. The project has also prompted communication with other clinicians and researchers with an interest in this field and my network of contacts has significantly increased. I now receive more information about developments, initiatives and projects in the area of pain and dementia and much interest has been shown in the findings of my project.

7 Chapter 7 – Recommendations

The findings of this project suggest that improvements could be made in the approaches used to assess for pain in people with dementia. A positive finding of the project was that mental health clinicians adopt a person-centred approach to pain assessment and this is the recommended model to provide a strong foundation for which improvements can be built upon (BPS and BGS. 2007). The recommendations being made in response to the findings are both for the management of the organisation and for the individual. A number of practical ideas for improvement were asserted in the focus group which percolated all the identified themes (see Figure 20) and the first recommendation is that the feasibility of these ideas is considered by the relevant management bodies.

Figure 20: A map of the practical ideas for improvement that arose during the focus group



The frequency of pain assessments could be improved by both managerial and individual clinician changes. The organisation already has a policy for addressing physical health and although it stipulates obtaining a medical history, it is not explicit about pain. There is a section in the policy for physical health considerations specific to certain groups of people and there is an opportunity to add a prompt about pain and pain behaviours in the section for people with dementia. Additionally, there is the opportunity to clarify whose role it is to undertake pain assessment and resolve the emerging uncertainty seen in the focus group. This project would also recommend adding a prompt about pain on the assessment paperwork where it asks the clinicians to ask about medical history.

In the questionnaire, 58.54% of respondents reported that there was not enough training on pain assessment for people with dementia and so a program could be developed. This program could promote the BPS and BGS (2007) guidelines and address the pervasive attitude that pain was inevitable with older age. Education would also have a role in addressing the possible barrier raised in the questionnaire that some people might consider that people with dementia do not feel pain. A repeat of the project would indicate how effective the training program is to ensure the content and method of delivery are meeting the objectives and whether the information is being translated into actual practice behaviours.

To support clinical practice there is a new electronic application that is based on the recommendations made by the BPS and BGS (2007). It takes the user through a series of questions, for which the user selects the most appropriate answer from a set of answers displayed on the device screen, and it acts to build a pain profile and offers suggestions on further actions to be taken (Schofield et al., 2013). This application should be reviewed and made accessible to clinicians in conjunction with the current move in the organisation to implement a system for electronic notes where all staff will have an electronic device.

The barrier around multidisciplinary communication that was identified in this project and the prevalent reporting of it suggests that there is a management problem rather than a problem of the individual clinician. At present the electronic patient records of the organisation are not compatible with any other healthcare service outside of mental health and the nature of the work of community based clinicians means that they are rarely in the office to accept calls. This project recommends that the new electronic system being developed is compatible so that if someone has been to their general practitioner with a pain problem the mental health clinicians are aware of this.

The family and carers of people with dementia are integral to providing information about the person with dementia’s normal behaviours and medical history and this project suggests that there could be improvements in their knowledge of pain behaviours and in the frequency of clinicians consulting them. The physiotherapy department currently send a representative to the organisations “question and answer” evenings for carers of people with dementia and the findings of this project should be conveyed to use the opportunity to offer education to the carers and family members. A leaflet was developed in 2011 for carers of people with dementia containing information around pain assessment by this author, but was not printed at the time due to other organisational priorities. The leaflet for carers should then be reviewed and proposed for publishing. In order to make pain assessment a priority, the findings of this project should be printed in the organisations magazine and reports sent to the committees for physical health, research and quality.

One of the barriers for effective pain assessment was identified as clinicians not using pain assessment scales, but the focus group findings suggested that there were reservations around the use of scales in practice. A review is indicated to look at the clinical context of the pain assessments being undertaken by the community mental health clinicians and whether there is an assessment scale that would be evidence-based and practical.

To influence improvements in this area of healthcare on a wider scale it is recommended that this project be sent to the professional bodies for nursing, medical, occupational therapy and physiotherapy to raise the profile of the findings. There are a number of voluntary and charity organisations that work with people with dementia and information could be sent to them with the information leaflets if approved. It is recommended that future projects should adopt the recommendations in the previous section for adapting the methodology and apply it to other services that provide care for people with dementia. A valuable addition to the methodology would be to include the views of people with dementia.

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Appendices

Appendix A: PEST Analysis (political, economical, social, technological) to Identify the Drivers for the Project

Political	**Economical**
Drive to keep people living at home The DOH National Dementia Strategy (2009) asserts the need for better skills for pain detection A failure to manage pain has been cited as surmounting to professional neglect (Alzheimer's Society, 2012; Parliamentary and Health Service Ombudsman, 2011) Inadequate pain management could result litigation (Schofield et al., 2007) Pain management is a fundamental human right (Brennan et al., 2007) BPS and BGS (2007) national guidelines for pain assessment Research suggests that national guidelines are not being followed (Allcock et al., 2002)	Cost of untreated pain Cost of unnecessary admissions Cost of services to support disability caused by untreated pain Cost of increased falls due to untreated pain Cost to the person with dementia – to their quality of life Cost to the person with dementia, if unable to work
Social	**Technological**
More people living at home Dementia is being acknowledged as a terminal condition worthy of specialist palliative care Studies show that pain assessment in clinical practice does not meet national guidelines	Research is using video technology to investigate behaviours associated with pain

Appendix B: Rationale for Selecting Relevant Guidelines from the BPS and BGS (2007) Publication

Guidelines (these are all the guidelines featured in the paper and are directly extracted)	**Rationale**	**Included or excluded**
Any health assessment of older people should include asking whether they experience pain	This is a generic guideline about frequency of assessment	Included
The single assessment process should include a question seeking to identify the presence of pain	The single assessment process is not the system used in the organisation. There is a section on the community assessment documents that requests information about "physical health"	Excluded
Any health assessment of an older person, including the single assessment process, should include asking whether he/she experiences pain (using terms such as pain, ache, hurt)	This recommends that the clinician asks about pain verbally and applies to people with and without dementia	Included
The assessment should recognise that older people use a wide range of words to describe pain	This applies to people without impairments in verbal communication. The focus of the project is on behavioural signs of pain	Excluded

Table B continued:		
Guidelines (these are all the guidelines featured in the paper and are directly extracted)	**Rationale**	**Included or excluded**
The assessment should recognise that older people may be reluctant to acknowledge and report pain	This applies to people without impairments in verbal communication.	Excluded
Past medical history should be detailed in view of comorbidities which may be contributing to pain/ a full medical history should be taken	This is a guideline that indicates clinicians should gather a medical history so that if pain is detected a possible cause can be established	Included
In people with difficulty in communicating including cognitive impairment and in situations where procedures might cause pain, an observational assessment is additionally required.	This is a recommendation specifically for people with dementia	Included
Observations should include facial expressions, body movements, verbalisations, vocalisations, physiology and changes in interpersonal interactions, changes in activity levels and patterns and changes in mental status	This applies to the particular behaviour clinicians look for when assessing for pain. It is beyond the remit of this project to include this variable.	Excluded
Pain behaviours are very individual and clinical judgement and familiarity with the older person is important in interpreting behaviour	This applies to people with and without dementia and is relevant to the project.	Included

Table B continued:

Guidelines (these are all the guidelines featured in the paper and are directly extracted)	**Rationale**	**Included or excluded**
Families can be a useful additional source of information with the older person's consent.	Relevant to people with dementia	Included
Use a simple Verbal Rating or Numerical Rating Scale in routine practice to asses and monitor the intensity of pain and response to treatment.	This applies to people without impairments in verbal communication	Excluded
Choose a standardised intensity scale to suit each individual person and continue to use this for sequential assessment in that individual.	All the assessment scales are included in the project to evaluate if they are being used, some of these have measures of intensity. It is beyond the remit of this project to also explore follow-up assessments.	Partly included
Scales should use large clear letters/numbers, using black and white rather than mid-tones and be presented under good lighting.	This applies to assessment scales that people complete themselves, this does not apply to observational scales.	Excluded
An attempt to locate pain should be made by asking the patients to point to the area on themselves.	This guideline is recommended for people without dementia	Excluded

Table B continued:

Guidelines (these are all the guidelines featured in the paper and are directly extracted)	Rationale	Included or excluded
Pain maps should also be used to help locate the site(s) of pain	This guideline is recommended for people without dementia	Excluded
Consider assessment of mood, sleep, mobility, function.	This project is evaluating only pain assessment	Excluded
All older people in whom pain is detected should have a clinical assessment of the multi-dimensional aspects of pain including: A sensory dimension… an affective/evaluative dimension…and the impact on life including physical, functional and psychosocial effects.	This project is only concerned with the assessment of behavioural signs of pain	Excluded
Health care professionals should familiarise themselves with relevant assessment tools and use them routinely.	This project is evaluating methods of assessment and asks the clinician to identify any assessment scales they use	Included
Assessors should consider the use of one tool or a combination of tools to assess the differing dimensions of pain	This project is only looking at pain assessment, not the secondary dimensions of pain, such as its effect on sleep	Excluded

Table B continued:

Guidelines (these are all the guidelines featured in the paper and are directly extracted)	Rationale	Included or excluded
In older people with cognitive impairment or with difficulty in communication, observational assessment becomes essential for assessing the presence of pain.	This is a guideline specifically for people with dementia	Included
Carers familiar with older people with cognitive impairment should be included in the assessment of their pain.	This is a guideline specifically for people with dementia	Included
For people with dementia, there is a recommendation for an analgesic trial	This guideline is not included in the methodology of the project since it relates to an intervention only practiced by physicians and often in a hospital environment and so is not relevant to the target population of people living at home.	Excluded

Appendix C: An Illustration of how the Methods Meet the Objectives

Objective	Method to achieve the objective
1. To establish adherence to national pain assessment guidelines published by The BPS and BGS (2007) in terms of:	In the questionnaire:
How often are clinicians assessing for pain	Question 6
Are clinicians observing for pain behaviours	Question 7
Are clinicians asking about pain	Question 8
Are clinicians observing for pain behaviours at rest and during movement	Question 9
Are clinicians using pain assessment scales	Question 10
Which pain assessment scales are being used	Question 11
Are clinicians consulting with loved ones and carers	Question 12
Are clinicians aware of pain-producing diagnosis	Question 13
2. To collect information from clinicians regarding any organisational barriers they may be experiencing that are impeding pain assessment practices	Question 14 in the questionnaire Focus group discussion
3. To identify what models of care community mental health clinicians are using to assess for pain in people with dementia	Focus group discussion
Do pain assessment practices and the identification of barriers differ between professional disciplines and years of experience	Question 3 and 4 in the questionnaire

Appendix D: Email of Invitation for the Questionnaire

Dear Colleague,

I am a studying for an MSc in Dementia Studies at The University of Bradford and am conducting a service evaluation of the community mental health teams in (organisation). This project forms the thesis for the course and is approved by the organisation. The objective of this project is to attempt to understand how people are assessing for pain in people with dementia, who are living at home, and who are unable to verbally communicate. Through your participation, I eventually hope to produce clinical recommendations which may provide training opportunities for community staff and aim to improve quality of care for service users.

The link below, in this email, will direct you to an online questionnaire. It is brief (14 questions) and asks about your preferred practice to detect pain and any barriers you are experiencing in your practice. I am asking you to look over the questionnaire and, if you choose to do so, complete the questionnaire.

http://www.surveymonkey.com/s/VLG5DG3

If you choose to participate, do not write your name on the questionnaire. I do not need to know who you are and no one will know whether you participated in this study. Your responses will be anonymous and no one will be able to interpret which community team or professional discipline you belong to.

I hope you will take a few minutes to complete this questionnaire. Without the help of people like you, evaluation with employees could not be conducted. Your participation is voluntary and there is no penalty if you do not participate.

If you have any questions or concerns about completing the questionnaire or about participating in this service evaluation, you may contact me on the details below.

Yours faithfully,

(name)

(contact details)

Appendix E: Invitation to the Focus Group

Dear Colleague,

I am writing further to my previous email asking if you would complete a short questionnaire about methods you use to assess for pain in people with dementia. If you have not yet completed it you still have the opportunity to by clicking on the link as follows: http://www.surveymonkey.com/s/VLG5DG3

I am writing now to invite you to a focus group to discuss issues around pain assessment for people with dementia. Questionnaires are useful for gathering information that is easy to analyse, but the focus group will draw out any complex issues or issues that the questionnaire did not cover.

If you choose to participate, your name will not be recorded anywhere and you will only to known to myself and the other participants. No one else will know whether you participated in this evaluation.

I hope you will be able to attend at least part of the focus group. Without the help of people like you, service evaluation with employees could not be conducted. Your participation is voluntary and there is no penalty if you do not participate.

Focus Group Topic: Methods and barriers for identifying pain in people with dementia

Venue:

Date: Wednesday 17th July 2013

Time: 12-1:30pm

Incentive: an opportunity to be involved in local audit and also *refreshments will be available*

RSVP please to this email

Appendix F: Pain Assessment Practices Questionnaire (Version One)

PAGE 1

This questionnaire asks for information about how you assess for pain - this only relates to how you assess for pain in people with dementia who are living at home and who are unable to verbally report their own pain.

1. Do you work with people who have dementia who live in their own homes AND who have impairments in verbal communication?

○ Yes

○ No

2. How long have you worked with people with dementia for in this organisation?

○ Less than three months

○ More than three months

PAGE 2

3. How long have you worked with people with dementia in any organisation?

○ Less than one year

○ Between one and five years (inclusive of five)

○ Between six and ten years (inclusive of ten)

○ More than eleven years

4. Which of the following best describes your current occupation?

○ Nurse

○ Psychiatrist

○ Occupational Therapist

○ Physiotherapist

○ Health Care Assistant

○ Other

PAGE 3

5. The following questions ask for information about how you assess for pain - this only relates to how you assess for pain in people with dementia who are living at home and who are unable to verbally report their own pain.
Do you assess for pain in people with dementia?

○ Yes

○ No

PAGE 4

6. How often do you assess for pain?

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**
○	○	○	○	○

Other (please specify)

PAGE 5

7. Do you try to ask the person with dementia about their pain (verbally)?

Never	Almost never	Occasionally/sometimes	Almost every time	Frequently
○	○	○	○	○

PAGE 6

8. Do you observe for behavioural signs of pain? (bracing, restlessness, rubbing part of body etc.)

Never	Almost never	Occasionally/sometimes	Almost every time	Frequently
○	○	○	○	○

PAGE 7

9. Do you observe for behavioural signs of pain when the person is moving as well as at rest?

Never	Almost never	Occasionally/sometimes	Almost everytime	Frequently
○	○	○	○	○

PAGE 8

10. Do you use a standardised pain assessment scale? (for example, The Abbey Pain Scale)

Never	Almost never	Occasionally/sometimes	Almost every time	Frequently
○	○	○	○	○

PAGE 9

11. If you DO use pain assessment scales please indicate which ones below

☐ Discomfort Behaviour Scale

☐ Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

☐ Pain Assessment in Advanced Dementia (PAINAD)

☐ Disability Distress Assessment Tool (DisDAT)

☐ DOLOPLUS-2

☐ Mobilization Observation Behaviour Intensity Dementia Pain Scale (MOBID)

☐ Mobilization Observation Behaviour Intensity Dementia Pain Scale 2 (MOBID-2)

☐ Checklist of Nonverbal Pain Indicators (CNPI)

☐ Certified Nursing Assistant Pain Assessment Tool (CPAT)

☐ The Abbey Pain Scale (The Abbey)

☐ The Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)

☐ Pain Assessment for the Dementing Elderly (PADE)

☐ The Assessment of Discomfort in Dementia (ADD) Protocol

☐ The Hospice Approach Discomfort Scale

☐ Davies et al. (2004) pain assessment tool

☐ The Aged Care Pain Chart

☐ The Behaviour Checklist

☐ The Facial Grimace Scale

☐ The Pain Behaviours for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICIE)

☐ The Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (FLACC)

☐ Pain Assessment in the Communicatively Impaired (PACI)

☐ The Pain Assessment Tool in Confused Older Adults (PATCOA)

☐ Amy's Guide

☐ The Simons and Malabar Pain Scale

Other (please specify)

PAGE 10

12. When assessing for pain, do you ask the person with dementia's loved ones or carers for their insight?

Never	**Almost never**	**Occasionally/ sometimes**	**Almost every time**	**Frequently**
○	○	○	○	○

13. Do you obtain information about the person's possible pain-producing diagnosis? (for example, arthritic conditions)

Never	**Almost never**	**Occasionally/ sometimes**	**Almost every time**	**Frequently**
○	○	○	○	○

PAGE 11

14. This question aims to produce information about any barriers you are experiencing in assessing for pain in people with dementia, who live at home and who have difficulties with verbal communication.
Please tick "yes" to any of the following that you perceive to apply to you and your place of work

☐ The evidence for the validity of pain assessment scales is insufficient

☐ Some pain assessment scales are completed at rest and so may miss movement-related pain

☐ Pain assessment scales are not clinically appropriate

☐ Pain assessment scales are not easy to administer

☐ Assessment scales need further testing

☐ Other health care clinicians are not using pain assessment scales

☐ Research into pain assessment has methodological flaws

☐ People with dementia are often excluded from research into pain assessment

☐ There is a disagreement about the relevancy of physiological changes as indicators of pain

☐ I have not received any training about pain assessment techniques

☐ I have not received enough training about pain assessment technques

☐ There is a lack of collaboration between dementia care, palliative care and older adult care

☐ Pain assessment is poorly documented in my organisation

☐ In my organisation, dementia is not seen as a terminal illness appropriate for a palliative care approach

☐ Pain behaviour is misinterpreted as indicative of other problems or as a symptom of dementia

☐ There is a belief that some people with dementia do not experience pain

☐ There is not enough time to learn people’s normal behaviours

☐ There is the belief that pain is a normal part of ageing

☐ The staff in the organisation tend to be reactive to pain rather than proactive

☐ There is a tendency to treat pain assessment strategies as a paper exercise where the information is not interpreted

☐ The person with dementia has difficulties in verbal communication

☐ The knowledge of pain assessment in carer’s and loved-ones of people with dementia is insufficient

☐ I tend not to involve the carers and loved ones in pain assessment

☐ I tend to adopt a distant and objective relationship with the person with dementia

☐ I believe that someone who is in bed is comfortable

☐ I do not have enough knowledge about pain assessment techniques

Note to reader: the questionnaire has a number of programmed features that *automatically* skip questions if the participant provides certain answers as follows:

Question 1: If the participant answers “no” they are directed to the end of the questionnaire and no more questions are provided

Question 2: If the participant answers “less than three months” they are directed to the end of the questionnaire and no more questions are provided

Question 5: If the participant answers “no” they are directed to the end of the questionnaire and no more questions are provided

Question 8: If the participant answers “never” they skip question 9

Question 10: if the participant answers “never” they skip question 11

Additional note to reader: this is a print out of an electronic questionnaire and so the formatting is altered and less attractive

Appendix G: Prompt Email for Participation in the Questionnaire

Dear colleague,

I am writing to inform you that the deadline to complete the pain survey has been extended until this Thursday at 5pm. This is due to the low numbers of responses. Service evaluation needs participants in order to produce useful results and even if you think you do not know much about detecting pain in people with dementia, your views are still very much valid.

I apologise to those who have already completed the questionnaire, because it is anonymous I was not able to exclude you from the mailing list. For those of you who still wish to complete the questionnaire you may do so using the link below:

http://www.surveymonkey.com/s/VLG5DG3

If you choose to participate, do not write your name on the questionnaire. I do not need to know who you are and no one will know whether you participated in this study. Your responses will be anonymous and no one will be able to interpret which community team or professional discipline you belong to.

I hope you will take a few minutes to complete this questionnaire. Without the help of people like you, service evaluation with employees could not be conducted. Your participation is voluntary and there is no penalty if you do not participate.

If you have any questions or concerns about completing the questionnaire or about participating in this project, you may contact me on the details below.

Yours faithfully,

[Name]

[Contact details]

Appendix H: The Responses from the Pilot Questionnaire and Actions Taken

Extract of feedback from expert panel	Action taken
Q1. “are you focusing only on people who are unable to verbally report pain?...it is important to look for behavioural signs even in people who can verbalise”	On consideration the rationale for this inclusion criterion is subjective, for example what constitutes impairment in verbal communication and behavioural signs are important regardless. This inclusion criteria was removed.
Q14. “the research has methodological flaws (item) do you think this would be an issue people are aware of”	This was acknowledged to be one of the external barriers that the clinicians and organisation could not control and so was removed.
The questions are very clear	No action needed
Q14. “the last long page of "statements" are a bit more grey than "yes or no" but doing it that way at least gives you a clearly defined outcome, rather than a scale for completely agree, partially agree... etc.”	This approach is intentional. No action needed.
“I certainly didn't object to any specific question”	No action needed.
“some might be cautious about saying/admitting that they or their organisation do not take pain assessment seriously”	This issue is addressed by informing the participants that the questionnaire is anonymous. No further action needed.
“The format is clear and easy to follow”	No action needed

Table H continued:

Extract of feedback from expert panel	**Action taken**
Q14. “some of the barriers may be ‘time’ is it worth asking this?”	This barrier was added to question 14.
“Would it be worth capturing if staff are aware of other healthcare involvement as some may assume that this is being done by another professional i.e. district nurse etc.”	The guidelines state that pain should be assessed for at every visit by every health care professional and so this item was not included
“if Liverpool care pathway / Supportive care pathway is in place this would be incorporated within these assessments?”	The guidelines state that pain should be assessed for at every visit by every health care professional and so it was not felt it required specifying as to the context of the pain assessment
“if I responded in certain ways it just ended”	This indicates the inclusion/exclusion questions are functional, no further action needed.
“survey took about five minutes so quick”	This is the intention, no further action needed
Q6. “I thought the question on how often you assess for pain was a bit difficult as I always consider pain in my assessments but do not formally test with tool unless I felt there was indication, could “consider” pain in assessment process.”	On review, it was also felt that the word “assess” might incite a negative response for people who do not consider that what they do is formal assessment. This question was re-worded.

<table>
<tr><td colspan="2">Table H continued:</td></tr>
<tr><th>Extract of feedback from expert panel</th><th>Action taken</th></tr>
<tr><td>Q14. “difficult to answer and had to read a couple of times may be could put something like tick the comments you agree with or a question around what do you perceive the barriers to pain assessment to be.”</td><td>This question was re-worded.</td></tr>
<tr><td>“The questions were clear and straight forward, layout clear.”</td><td>No action needed.</td></tr>
<tr><td>“The only problem I could see was that the degree of dementia is so wide”</td><td>Chapter two does identify this as a limitation of the research and consequently of this project. To be discussed in chapter five.</td></tr>
<tr><td>Q14. “Do they relate to me or the organisation? My knowledge is good but I consider that other staff have poor knowledge of pain assessment and therefore it is a barrier”</td><td>This question was re-worded for clarity.</td></tr>
<tr><td colspan="2">One of the expert panel sent an unpublished literature review with their responses and this used different search terms and identified 5 further behavioural assessment scales. The following were added to question 11:
The Facial Grimace Scale
Elderly Pain Caring Assessment 2 (EPCA-2)
Facial Action Coding System
Pain Behaviour Checklist
The Nonverbal Pain Assessment Tool</td></tr>
</table>

Appendix I: Amended questionnaire

This questionnaire asks for information about how you look for pain - this only relates to how you look for pain in people with dementia who are living at home.

1. Do you work with people who have dementia who live in their own homes?

○ Yes

○ No

PAGE 2

2. How long have you worked with people with dementia for in this organisation?

○ Less than three months

○ More than three months

3. How long have you worked with people with dementia in any organisation?

○ Less than one year

○ Between one and five years (inclusive of five)

○ Between six and ten years (inclusive of ten)

○ More than eleven years

4. Which of the following best describes your current occupation?

○ Nurse

○ Psychiatrist

○ Occupational Therapist

○ Physiotherapist

○ Health Care Assistant

Other (please specify) ☐

PAGE 4

5. When you are visiting a person with dementia, how often do you consider whether they experience pain?

	Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

Other (please specify)

☐

PAGE 5

6. Do you try to ask the person with dementia about their pain (verbally)?

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

7. Do you observe for behavioural signs of pain? (bracing, restlessness, rubbing part of body etc.)

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

PAGE 7

8. Do you observe for behavioural signs of pain when the person is moving as well as at rest?

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

PAGE 8

9. Do you use a standardised pain assessment scale? (for example, The Abbey Pain Scale)

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

PAGE 9

10. If you DO use pain assessment scales please indicate which ones below

☐ Discomfort Behaviour Scale

☐ Elderly Pain Caring Assessment 2 (EPCA-2)

☐ Facial Action Coding System

☐ Pain Behaviour Checklist (PBC)

☐ The Nonverbal Pain Assessment Tool

☐ Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)

☐ Pain Assessment in Advanced Dementia (PAINAD)

☐ Disability Distress Assessment Tool (DisDAT)

☐ Discomfort Scale for Patients with Dementia of the Alzheimer's Type (DS-DAT)

☐ DOLOPLUS-2

☐ Mobilization Observation Behaviour Intensity Dementia Pain Scale (MOBID)

☐ Mobilization Observation Behaviour Intensity Dementia Pain Scale 2 (MOBID-2)

☐ Checklist of Nonverbal Pain Indicators (CNPI)

☐ Certified Nursing Assistant Pain Assessment Tool (CPAT)

☐ The Abbey Pain Scale (The Abbey)

☐ The Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)

☐ Pain Assessment for the Dementing Elderly (PADE)

☐ The Assessment of Discomfort in Dementia (ADD) Protocol

☐ The Hospice Approach Discomfort Scale

☐ Davies et al. (2004) pain assessment tool

☐ The Aged Care Pain Chart

☐ The Behaviour Checklist

☐ The Facial Grimace Scale

☐ The Pain Behaviours for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICIE)

☐ The Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (FLACC)

☐ Pain Assessment in the Communicatively Impaired (PACI)

☐ The Pain Assessment Tool in Confused Older Adults (PATCOA)

☐ Amy’s Guide

☐ The Simons and Malabar Pain Scale

Other (please specify)

PAGE 10

11. When assessing for pain, do you ask the person with dementia's loved ones or carers for their insight?

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

12. Do you obtain information about the person's possible pain-producing diagnosis? (for example, arthritic conditions)

Never	**Almost never**	**Occasionally/sometimes**	**Almost every time**	**Frequently**

Q13. This question aims to produce information about any organisational barriers to identifying pain in people with dementia who live at home. These are barriers that you perceive apply to your area of work, not necessarily to your personal practice. Please tick any of the following that you perceive apply to your place of work.

☐ There is not enough time to assess for pain

☐ The assessment scales are not appropriate for my place of work

☐ Health care clinicians are not using pain assessment scales

☐ There is a lack of collaboration between dementia care, palliative care and older adult care

☐ Pain assessment is poorly documented in my organisation

☐ In my organisation, dementia is not seen as a terminal illness appropriate for a palliative care approach

☐ Pain behaviour is misinterpreted as indicative of other problems related to dementia

☐ There is a belief that some people with dementia do not feel pain

☐ There is not enough time to learn people's normal behaviours

☐ There is a belief that pain is a normal part of ageing

☐ The health care clinicians tend to be reactive to pain rather than proactive

☐ There is a tendency to treat pain assessment as a paper exercise where the information is not interpreted

☐ The knowledge of pain assessment in carers and loved-ones of people with dementia is insufficient

☐ There is not any training about pain assessment techniques

☐ There is not enough training about pain assessment techniques

☐ There is a belief that someone who is in bed is comfortable

Other (please specify)

Appendix J: Focus Group Summary

The focus group commenced with a discussion about assessment scales and their utility within the community workplace. Reservations about the usefulness of the assessment scales were expressed and the consensus emerged that pain assessment scales were useful, but insufficient on their own. The discussion progressed to avocations of the importance of knowing the person when assessing for pain and examples of where care home staff do not know the person were illustrated with a suggestion for a pain champion.

The topic of focussing on mental health to the detriment of physical health was debated during the focus group and concerns were raised about pain behaviour being misinterpreted and conversely that opiates were being over-prescribed. A significant discussion occurred about the barriers being experienced in relation to difficulties with multidisciplinary communication. Further barriers were identified in the knowledge of the family and the role of the family of the person with dementia was discussed.

The final part of the focus group explored the effectiveness of pain treatments, practical strategies to improve pain assessment in the organisation and the multidisciplinary roles in pain assessment. The focus group explored the issue of people accepting pain with the consensus emerging that pain was deemed an inevitability of older age.

Appendix K: The Interview Schedule for the Focus Group

1. Thank you for coming
2. Introduce myself
3. Outline the goals of the research – to collect information about the methods community mental health staff are using to assess for pain in people with dementia and any barriers they/you are facing.
4. The reasons for recording
5. The format of the focus group: one and a half hours, help yourself to refreshments. There are some guidance questions but I am happy for the discussion to follow its natural course
6. Conventions – one person speaks at a time for recording
7. All data is confidential and anonymous
8. Session is open and all views are important
9. Could we begin by sharing some of our experiences of detecting pain in people with dementia?

Questions if issue does not naturally arise:

- Are person-centred approaches used by community mental health teams to assess for pain?/ how important is knowing the person with dementia when assessing for pain?
- How does pain assessment fit into the standardised processes or pathways in your area of work or if it should fit in somewhere?
- Does anyone use pain assessment scales?
- Are there any barriers you are experiencing to assessing for pain/is there anything in you/your area of work that prevent you assessing for pain?
- Is pain assessment routine?

- Does everyone always obtain information about possible pain producing diagnoses?
- I wonder if anyone has come across any other barriers to detecting pain or do we feel there are no barriers and we are detecting pain well enough? / deterrents
- What are your experiences of working with family in assessing for pain?

End – thank everyone

Explain what will happen with data

Appendix L: Transcription of the Focus Group

Key:

Mod = moderator

M&H = the moving and handling advisor

CN = the consultant nurse

CPN = the community practice nurse

SN = the student nurse

P1= physiotherapist

P2 = physiotherapist

PA1 = physiotherapy assistant

PA2 = physiotherapy assistant

Dr = psychiatrist

Mod: Welcome everyone and a big thank you for your participation in this focus group. The goals of this project are to collect information about the methods mental health clinicians are using to detect pain in people with dementia and any barriers they may be experiencing in their personal practice or in their team or organisation. The format of the group is that everyone must help themselves to refreshments and to have just one person speaking at any one time so that the recording can be transcribed. Recording of the group is so that a systematic analysis of the data can be completed later and no important information will be lost. The data will be anonymous. The session is open and all views are valued, so please say as little or as much as you like. So could we begin by sharing some of our experiences of trying to detect pain in people with dementia?

PA1: Initially, I have been used to working with people for a long time and so it is getting used to the person for a length of time and looking at facial expressions and body movements and so it is different for me coming to this service as it is such a quick turnaround. I've had years and years of getting to know somebody so there difference there is that I have not come across all the different sheets of programs you use and I have not actually come across them and I would be interested in having a look at them and how you use them.

Enter Doctor.

Mod: Welcome, we are just starting the group by sharing some of our experiences of detecting pain in people with dementia so please join, help yourself to refreshments and join in when you are ready.

Dr: Thank you, apologies that I'm late.

Mod: Thank you (PA1), would anyone like to add to this?

CN: I have had some experience of end of life care and I suppose I am used to some tools but not aware of locally what everyone does, I think the tools that were (inaudible and CPN and SN arrive).

Mod: I'm sorry (CN). Welcome CPN and SN, please take a seat. Help yourselves to anything and do join in when you are ready. We have made a bit of a start and are sharing some experiences of trying to detect pain in people with dementia.

(CPN and SN introductions)

Mod: Just to repeat that we are recording for data analysis later and all data will be confidential and one person speaking at a time please for transcription ease. The session is open and all views are really important, and say as much or as little as you want to say. So if we are continue to share our experiences of detecting pain in people with dementia.

PA2: I think with someone with dementia it can be difficult to work out the intensity of pain, they might look distressed but it is hard to know if that's because they are in pain or possibly its associated with the dementia.

CN: I think that sometimes even with the tools it's still a bit subjective. I think people often use a tool because it's quick to do rather than being the most appropriate.

M&H: I think the tools can be useful, as subjective as they are, as a baseline. But you have to take into account the other things about the person, whether that's historical physical health or wellbeing things that have happened to them the past and how they behaved pre-diagnosis, what they were like as a person. And that's where it comes back to yourself, (PA1) where you were used to knowing the person and now you require a faster response. So I think the tools on their own are insufficient, I think you have to use your other skills.

P2: I personally think that sometimes it is easier to use the tool when we don't know the person and don't have enough time to get to know them and understand them better. I think the family, who know them better are well placed to use the tools, and as a professional we can go there and ask them to use it over a period of two weeks. Then we can average it out and see what is going on. Whereas we, as clinicians, have a thirty five to forty minute window to understand the whole thing. Which I don't think is viable and it also depends on what you see that day: if you are in a grumpy mood then everything is painful. The tools that I use are not as reliable as I would want them to be.

P1: Also there is an inability to localise the pain. And also if they have a high pain threshold as well. And even though they have a pain they cannot express where is the pain and as a clinician we are finding it hard to identify where exactly is the pain or discomfort.

CN: It's not exactly routine either. It's usually when there is a diagnosis, or as end of life or something, but with old age we should think of it as inevitable, well not inevitable but we don't use it enough.

CPN: I think that the other thing, that from my perspective when going into residential and nursing homes is that the staff change very quickly so you may do some work with a particular home about thinking about pain as a causative for understanding some of the behavioural symptoms we see in people with dementia, but then the staff change and you have to start over again. It's about trying to teach staff about, not just ticking a box, but about, like you (M&H) said, understanding the person and getting to know them over a period of time. Some homes are pretty good and that and some homes struggle and will find an excuse about why they can't do that, but when you go in and do an assessment you ask them if they have thought of pain, often this is something they have not thought of.

P2: Care homes are a different entity all together; every time you go there you seem to talk to a different person. There is no pain champion in a way, if there was a pain champion you could go and talk to them about something. Care homes are difficult and they interpret things differently too.

CPN: I think the CMHT's now are doing some projects around nursing homes, supporting them in looking at getting staff to understand what dementia is and looking at communication needs and looking at how somebodies behaviour might indicate different things. So one might hope that that will improve some of that.

Dr: I agree it's very basic, we need to start with the basics of getting to know the patient, understanding the dementia, speaking as a doctor, I think there is a lot of publicity coming from drug companies urging us to prescribe particularly opiates medication in pain. That is the end point of a very complex assessment and my worry is that we will end up prescribing opiates rather too freely rather than examining the person's predicament in more detail.

M&H: Is that about managing the pain rather than addressing the reason for the pain?

Dr: It is. It is a lot more complex than the drug adverts would suggest. I think there is one advert going around at the moment with a very angry looking gentleman, it for buprenorphine patch or something, but the idea that angry dementia patient equals buprenorphine patch is way to over simplified.

CN: I think you need to counter balance that with the treatment for pain and the treatment of agitation with the prescribing of antipsychotics. It's so complicated.

Dr: Yes, yes. It's all individual.

CN: We need to treat them all as individual.

Dr: Yes, yes that is the core of it. Unless we adopt a personalised approach we will treat pain inappropriately or miss pain that does need treatment.

Silence

Mod: We seem to be picking up on the theme of processes and I wondered if anyone had seen how pain assessment fits into a process or pathway in their area of work or if it should fit in somewhere.

CN: If you mean a pathway, it is part and parcel of the supported care pathway but it is not routinely done. It's only if it is end of life or if there is already a diagnosis of a pain problem.

Silence

Mod: You said it's not routine, does anyone have any more thoughts about this?

CN: I don't think we do always think about pain as routine and when we do formulations of people who are in much distress it is not at the forefront of our minds, and that's not meant to be detrimental to …(inaudible)

M&H: I think that sometimes, and it's not a criticism, that once people have a mental health problem, physical health problems get forgotten. As though if you have a mental health diagnosis you can't possibly have a physical problem and it's almost as if you have one or the other. It's as though the thought processes of staff is that they prioritise the mental ill health, not wrongly, but then forgot about those other things that might be impacting on the person.

CPN: I actually think that's changed. I actually think that we are encouraged more to think about physical health. Because on the initial assessment we have the physical health page that we have to do, and is part of the standard audit document that we have to do that, but what it does is that the physical health assessment gives you prompts so people should be at initial assessment and on-going review should be asking about pain but I don't know what they do with that information afterwards. So, as you say, we do actually address physical health but, as you say, is for some people is the mental health a priority but I think we are not encouraged to think about the mental and physical health joined together and how one impacts upon the other. So pain is on the assessment tool we use but it's what you do with it.

M&H: What you do with it.

CPN: And you know its pain and then it's a few lines so it does not necessarily trigger people to do the assessment tools or do this or do that.

M&H: Is there also a question about whose place is it to do that. So, on admitting someone to your caseload in the community, you do your physical assessment, you use the tools that you have and then you are going to signpost someone to elsewhere.

CPN: Yes.

M&H: And from my experience of falls prevention and management in the community and assessment that there are so many other services potential to be involved that the communication changes all the time and GP's are the most difficult for getting a two way conversation going with at times and they are going to be a key player in a community dwelling persons wellbeing.

CPN: I think some GP's you have a very good working relationship with, a two way, I think some of the GP's I work with are very good and will do visits and leave a message for me at the persons house, but others there are those barriers. And I think it's about the staff too, I've been around a long time and I probably have a bit more confidence and I will challenge and not let things go, whereas if staff are newly qualified it can be hard to kind of battle with a GP or stand up for somebody.

M&H: I guess as well that in the kind of climate we are in, the economic or business climate, do you have the time to do that battling and following up, with whether it be a GP or, in my case, falls clinics is there the time to invest in that.

Silence.

Mod: I wonder if anyone has come across any other barriers to detecting pain or do we feel there are no barriers and we are detecting pain well enough?

PA1: It wasn't first hand but it was through some training that someone else mentioned a patient who was difficult in the mornings and it was questioned whether it was pain or challenging behaviour, and automatically it was thought to be the challenging behaviour.

CN: I think that was my point that whatever seems to have more precedence and if it was his behaviour then you tend to link it with behaviour as opposed to linking (inaudible, few people speaking in agreement).

M&H: And we do get that quite a lot, that the difficulties or the lack of corporation that a person might display is usually put down to the mental health even though they may have had a long standing arthritis or they may have always had difficulty in the morning, well for years.

PA1: Its addressing the giving the medication half an hour before they get up so they weren't so stiff.

M&H: Because they were prescribed pain relief anyway

P1: And also I think that lack of communication between the families and carers especially and their lack of understanding about pain so they are prescribed medications and they give medications and they never get the chance to find out more about the problem or communicate with other professional.

CN: I think they are also worried about the constipation, and they are more worried about that than the pain, I sometimes pick up on that, and it’s about getting the balance right about the pain and the person getting impacted.

Silence

Mod: Did we want to explore the idea of family a bit more? Does anyone have any experience of that?

CN: You know going into the community, you only see a snapshot on that visit and its getting the broader picture, and you need to get that from family. Or indeed there is no family.

CPN: Or sometimes the spouse is equally as confused as the person you are going to see. You sometimes wonder if it’s the right person you should be going to see. I do think family are a big part of the total assessment and looking at how people have managed in the past, if that have got symptoms of pain and what people pain tolerance has been in the past, is useful from family members. But equally I think that with extended families now, there is so much information that the son or daughter don’t know because mum or dad have not wanted to worry them. Sometimes your history from family is a bit patchy because they are not aware or if they have only visited once a month or.

M&H: Do you think as well, because family are a phenomenal resource for getting to know the person, but when somebody has a spouse that has a diagnosis of dementia, and they may have a little knowledge and you are trying to educate them about the dementia so they are grieving about the lost person or the changes in abilities, do you think they are in a position mentally themselves to talk about those things. Will they recognise this (inaudible, CPN talking).

CPN: I think it depends on the individual carer and part of the assessment also is to support for that carer and we do actually do a carers stress questionnaire and find carers support and we do look at how able they are to look at their situation. But I do think that for some people the focus is on dementia and what they know and have read. And interestingly it doesn't always seem to be the thing that they are worried about, for example at the Question Time Panel Dr "K" was really trying to get people to ask about physical health and was saying "we have a physiotherapist here" and direct questions to you. But it was difficult to get people to ask those questions.

P2: I think people tend to focus on the headline acts and don't look to the subtext what is actually causing those headline acts. To the family's pain is something that will go if you take a pain killer whereas dementia will not go anywhere and so they focus on the big things and not worry about the small things.

M&H: And they don't even think that the small things are bad. Do you think also, I'm being a bit ageist, but I'm not ageist and I'm not meaning to be ageist, but don't you think that older people tend to be a bit more stoic, and do not say they have pain, and don't want to appear needy. And so even if a family member knows they have pain they don't see that they need to tell the CPN or support worker because it's not something they need to bother with.

PA1: It's getting that background isn't it. Someone young just popped into my head, who won't admit if she has had enough or if she is tired or in pain and she is just got that stubborn streak and strong will power. And getting the background from a family member that they have that stubborn streak or you have to look for visual clues that they are tired. They will admit it in the end but not initially.

CPN: There is that expectation that you are getting old and you will have aches and pains.

P2: They accept pain is a response that needs to be there as you get older, we all have aches and pains (agreeing noises from the group), but they do not see the bigger picture what pain is actually causing (inaudible) they accept it is part of the condition, the family and the patient.

DR: So we are talking about chronic pain here. There is a big difference between acute pain that will likely need an acute response and chronic rumbling demoralising pain, which I think does get construed in the ageing process and all I will get is another wretched pill and I'm already on a truck load. I don't feel very confident about non-pharmacological treatments for pain, perhaps if doctors felt more confident about advising and pointing people towards non-pharmacological approaches they might feel more enthusiastic about identifying pain rather than burdening the patient with another pill.

CN: Is that due to lack of knowledge or confidence in use? Do you mean, your perspective the medical model that you don't feel confident in different therapies.

Dr: Different therapies yes.

CN: Is that due to lack of knowledge of from experience.

Dr: I think a lack of familiarity with non-pharmacological interventions.

Mod: Does anyone else have any deterrents in their area of work or disciplines to go looking for pain, acute or chronic.

Dr: Acute pain is less of a problem for doctors, as it suggests a nice identifiable problem that can be fixed, it's the chronic grumbling stuff.

M&H: To be honest with the work that I do, identifying pain can alleviate many problems and I actively seek to assess pain and encourage others to do so. And that means that if we can get a treatment for it, either non-pharmacological or medication treatment, we can alleviate other problems. So I actively seek to assess for it as you can change the way that a person responds with moving and handling interventions and mobility and other things.

Dr: Perhaps if doctors were more familiar with what you do they may be more enthused about saying here is someone with chronic pain, find an intervention that might help.

CN: I think this might be even bigger than that. I think that managing challenging behaviour and talking about formulation, that looks at pain but what we don't see is the biopsychosocial model do we, (inaudible with agreements).

PA2: A low lying grumbling pain can wear you down and you don't realise but it can wear you down and it can be quite depressing.

M&H: It can be worse than acute pain.

Dr: There is a big argument for multidisciplinary education.

P2: I have had a patient who had a chronic pain for quite a while, it was quite easy to fix and I got this referral from one of the CPN's. It was quite straight forward to fix. They had some trigger points in their shoulder which I treated in two or three sessions and it was better. I understand your problem of awareness what we can do and I am trying to figure out in my head what we can do so other professionals can know as physios what we can do. It could be a chronic reason such as a chronic arthritis, or a spondolysis that is painful but it better if it is checked out if there is any reason such as they are not mobile, they are anxious, they are in bed for a long while causing these trigger points not to move and then it could easy be alleviated. And I understand your point as well. Where we would not know if someone has been prescribed medication until they came to us and you wouldn't know when to push the person to physiotherapy. Not just physio but any approaches.

Dr: Its having a vision about what you do so we can enthuse about a referral.

CPN: I think historically there was a drive looking at pain and dementia and "KF" was involved in that and definitely coming round community teams and there was a presentation to think about pain, but that stopped there. I know a colleague that has since retired who was interested in massage and aromatherapy, she was qualified at university but she was then discouraged from actually practicing that, she was discouraged by the Trust at the time. I'm going back a few years now. It seems to be that there has been attempts to look at this, but it has gone into that black hole. I think unless you are kept up to date and things are kept current then something else becomes current and there is suddenly a drive by the organisations for something else so everybody focusses on that. And everything they have learnt and understand beforehand falls by the by.

M&H: Priorities change. Nationally and locally.

P2: I think the drivers are mostly nationally. They'll say "look at this for a two year period" as if it will go after two years. So if a driver changes the whole attitude changes and we only have 37.5 hours in a week, we have to do all those bits and bobs.

M&H: I think that what you were saying about the knowledge and skills that any of us have, you can't always know everything that another professional can do, it reinforces to me that we do work in a multidisciplinary way and I think we call upon those other professionals when you see a need but we might not see the need because you don't know what you don't know.

Dr: No exactly.

M&H: So it's how do we have a truly multidisciplinary approach from the outset rather than waiting for a need to be identified? When I might not be able to identify that need. Because none of us know everything. How do we get it from the beginning? I don't know if we can.

Dr: I am hoping to set up over the coming year a multidisciplinary journal club. We are going to call it the Kitwood club in honour of Tom Kitwood and hope to include both the bio and the psychosocial. We don't know each other's literature or expertise in sufficient detail. I don't think many doctors go trawling through nursing or physiotherapy literature. Whilst I'm sure there are key papers we need to be familiar with in one profession or another.

M&H: It's making time to do this. But all of us only have 37.5 hours a week. And even if you do this in your own time, your home time, is picking up somebody else's literature going to prioritise over your own. So I think using the Kitwood Club is an opportunity to share information and have a purpose for reading it.

Silence

Mod: Does anyone have any other thoughts about practical ideas for this topic for the organisation?

M&H: It could be an agenda item at team meetings but to keep that awareness and priority there, like health and safety.

P2: We could have a prompt sheet I would say, if it is chronic pain to see if there is anything else other professionals. Have a prompt sheet to see which team, to say try this team, there is always the back-up of the medical model.

M&H: Like falls, pain is a question on there and it gives you referral options.

CPN: I mean I think that that is useful, on falls, because it encourages you to think and if you are busy it reminds you of the things you should have asked. And obviously pain is part of that but that is related to falls and people with chronic pain are always falling are they. There are lots of reasons for chronic pain. People initially moan but then they get on with it and find it useful

M&H: Well if its chronic pain they do get used to it. Don't notice until its gone.

Dr: Yeah.

PA1: Patients have accepted that they are going to be fixed in this position and it takes five minutes to relax her and to get her shoulders back and she thought she was stuck like that for ever and a day. It's a miracle. Going back to the literature thing, it would be good if each profession could say that if you have time you should read this this this and this, the top five books or articles.

P2: I think it falls on the individual profession as well, if we find something that needs to be read we need to say please read this. For other professions because it is not fair for a profession to see what's happening in physio then it is our job to highlight what is happening in physio by saying please read this. And it's like this (inaudible) saying please read this. Perhaps when you guys have monthly meetings someone can take responsibility and share the information.

Dr: If a fancy new pill the drug companies will make damn sure (inaudible, laughter).

M&H: But do we ever meet outside of our professions.

P2: Only when there is a crisis.

M&H: We don't step over into somebody else's silence, I meet with myself on a regular basis and I consult with physios often. But I don't try and invade a doctors meeting, or I might try to invade a nurses meeting. We rarely step into somebody else's pond, do we but actually that would be more effective, you verbally sharing because you would have a greater understanding of the articles.

PA1: The biggest overlap is at training sessions, like moving and handling.

P2: That is the only time really.

M&H: Yeah it is.

CPN: The other thing is resources, the thing is there are so few of you when you consider all the teams that there are, ward teams, community teams, you would never actually have any time to see patients.

CN: What if you got a pain champion who had a responsibility to feed back to the team, that might be a way of doing it.

M&H: Yeah.

CPN: Yeah because we have champions and links for other things and they work, we know that they work. They go off to meetings and they come back and feed back to team meetings. So we do know that that system works, that’s a good idea.

Mod: I’m afraid we need to start closing the group now; does anyone have anything they still want to contribute?

Dr: With this Kitwood club we are hoping to have a blog, so that if you can’t attend you can still see what’s happened.

Mod: Thank you to everyone, I think that has been really productive and there is a lot of rich data there to compliment the questionnaire. There is a lot that has been contributed so thank you.

Appendix M: Map of the Connections Made between the Themes Throughout the Narrative of the Focus Group Discussion