A meta-ethnography of patients' experience of chronic non-malignant pain

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Aims and objectives

The aim of this study is to:

- Increase our understanding of patients’ experiences of chronic non-malignant pain and therefore have an impact on quality of care.
- Utilise existing research knowledge to improve understanding and thus best practice in patient care.
- Contribute to the development of methods for qualitative research synthesis.

These aims meet the HSR programme objectives.

Objectives

1. to produce a conceptual synthesis of qualitative findings related to chronic non-malignant pain using the methods of meta-ethnography proposed by Noblit and Hare [1], and developed for use in health research [2-4].

2. To contribute to the development of methods for qualitative research synthesis and produce a qualitative synthesis that is rigorous, accessible and relevant to academics, practitioners, patients and policy makers.

This research will increase understanding and knowledge of chronic non-malignant pain, and thus directly inform best clinical practice by providing new understandings regarding patient experience and their treatment. We will contribute to a more patient focused research agenda. A qualitative synthesis would enable policy makers to determine whether or not the treatment for chronic non-malignant pain is meeting the needs of quality improvement as defined by the Department of Health’s report – ‘High quality care for all’[5] where patient experience is seen as fundamental to quality of care. A greater understanding of patient experience of care has potential to provide new opportunities to deliver services differently and directly influence patient redesign of health services.

There are methodological issues that need to be addressed if qualitative synthesis is to be effectively used to enhance best practice [2, 6]: A systematic search of the qualitative literature is not straightforward [2, 7]. There is a lack of consensus regarding the most appropriate way to judge what should be included in a qualitative synthesis[8, 9].

Background

Chronic pain has been acknowledged as a condition in its own right [10], and has become the focus of recent government policy in the UK [11-13]. Each year over five million people develop chronic pain [11]. As many as 19% of adults in Europe suffer with moderate to severe
chronic pain [14], and 7% have chronic pain that is severe and disabling[15]. Persistent pain may affect more than 50% of older persons living in the community [16]. Pain has a high impact on the individual’s physical, psychological and social wellbeing [17]. For example, 49% of patients with persistent pain experience depression, 25% lose their jobs and 16% feel their chronic pain is so bad that they sometimes want to die [11]. In terms of cost, musculoskeletal pain may account for 2% of the Gross Domestic Product of Europe[18]

**Rationale** - Qualitative research addresses a central concern of the NHS – patient experience[5]. Patient experience is one of the dimensions of quality integral to the NHS. In 2008, Darzi’s report ‘High Quality Care for All’ stated that the patient’s experience of the NHS is fundamental to the quality of care and is of central concern. ‘Quality of care means quality of caring’ which can only be improved by understanding patients experience [5] Qualitative research aims to understand the experience of illness, and make sense of the complex processes involved. It aims to enrich human discourse and help to generate concepts that allow us to understand behaviour [1]. It can thus lead to substantial improvements in health care and policy decisions by enabling clinicians and policy makers to understand the appropriateness, and meaningfulness of interventions. In particular, by understanding the experience of those with chronic pain clinicians, policy makers and patients can be empowered to make more informed decisions about care. Insights from several meta-ethnographies in health care have contributed to a greater understanding of complex processes such as medicine taking [2], adherence to treatments for diabetes[3] and use of antidepressants[19]. Excluding qualitative research from evidence based practice may mean that we neglect vital information from decisions related to policy and practice [20]. Syntheses of qualitative research should thus be used alongside those of quantitative research, to underpin policy decisions. Concepts generated from qualitative research synthesis will help researchers, policy makers, clinicians and patients to ask questions that will enhance the validity of subsequent research.

Syntheses of the existing body of qualitative research can also help to identify gaps in knowledge and to target these gaps. To date, there has been no synthesis of qualitative research related to chronic non-malignant pain, and thus the proposed research is timely [20].

The aim of qualitative synthesis is to systematically review and integrate the findings of qualitative research in order to increase conceptual understanding. The aim is to make ‘a whole into something more than the parts imply’ [46:28]. This synthesis would be accessible to health professionals, researchers, policy makers and patients, thus having a far reaching impact on the processes of health care. Policy makers and clinicians need to draw on various sources of evidence in order to improve the quality of patient care [21]. Qualitative synthesis can thus add value to evidence on the effectiveness of interventions[6]. Synthesis of qualitative research aims to move beyond narrative description and generate ‘theories that can inform the development of new evidence’ [46:28]. This is the key aim of the qualitative synthesis, and the process of synthesis itself provides opportunities to understand, develop and extend the theories that are generated.
of interventions’ [21], thus informing the implementation of more appropriate and effective patient focused interventions[6, 22].

Need
This research meets the classifications of research need outlined by the NIHR Health Services Research Programme. In particular, a meta-ethnography aims to build on exiting work and generate new knowledge.

1. **Building on existing work.**
   One of the specific aims of this study is to utilise existing research knowledge to improve understanding and thus best practice. Specific to meta-ethnography is the aim of making a whole that is greater than the sum of its parts[1], in order to generate a new conceptual understanding based on the comparison of multiple accounts. A meta-ethnography of chronic non-malignant pain will therefore enhance and add value to the body of existing knowledge in the field of pain.

2. **Capacity to generate new knowledge**
   A qualitative synthesis would offer a greater conceptual understanding of patients experiences and offer insights into effective care. This meta-ethnography would help us to identify gaps in the knowledge that are not addressed by existing research and therefore add to the validity of further research in this area. For example, we have said that certain patients are able to successfully revise their sense of self and others are not [23, 24]. This study is likely to offer conceptual insights into this process[25].

3. **Health need**
   Chronic pain has a huge impact on the quality of life of adults in the UK, [14] [11, 15-17] and this is recognised in recent UK policy documents [11-13]. The research may be used to inform the development of quality of life tools to be used in chronic pain. This research may also contribute to the dialogue with patients about their chronic pain and how policy makers and clinicians can meet their needs. It could thus have a direct impact on quality of care as outlined in ‘High Quality Care for all’[5].

4. **Expressed need**
   A greater conceptual understanding of chronic pain is highly relevant and has been highlighted as important in recent policy documents in the UK. The Chief Medical Officers report in 2009, ‘Pain breaking through the Barrier’ [11] identifies chronic pain as important to NHS policy. In addition to this, an NHS report on ‘getting to GRIPS with chronic pain in Scotland’[12] identified a need to improve knowledge about chronic pain. Chronic non-malignant pain is also recognised as one of they key areas for improvement by the Welsh Assembly Government[13]. Specifically, the Chief Medical Officer recommended that training in chronic pain should be included in the curricula of all healthcare professionals[11]. This meta-ethnography may be used to inform education initiatives related to chronic pain.
5. Sustained interest and intent

Chronic pain has been highlighted as a future priority for NHS policy[11]. If patients with pain are managed more effectively this may reduce unnecessary interventions such as emergency department visits, hospital admissions, secondary and tertiary referrals and inappropriate diagnostic testing. Conceptual understanding may contribute to the development of care pathways for chronic non-malignant pain. Poor quality pain management in the elderly and in care home residents has been highlighted by the Patients Association[26]. This finding is of particular social importance in view of the ageing population in the UK and the potential effect on demand for pain services. Demand for the treatment of chronic pain is likely to increase with increasing age.

6. Organisational focus consistent with HSR mission

This study will inform the organisation of appropriate services for chronic pain. There is currently no synthesis of qualitative evidence available to understand patients’ views of the feasibility and acceptability of interventions for chronic pain. This is fundamental as qualitative research has been highlighted as important in informing health care policy and best practice [6, 8]

7. Generalisable findings and prospects for change

Whilst qualitative research is contextual and therefore can be complex to apply to decision making processes, qualitative synthesis can be used to generate findings that can more clearly inform practice. We have given the example of how findings could be used to inform the development of ‘risk’ tools for assessment of patients with chronic pain. Similarly, we have suggested the findings could be used to inform the development of chronic pain care pathways within the NHS, thus having a direct effect on decision making regarding treatment.

Method

A figure outlining the research process is attached to this application.

Search strategy

*Initial scope of literature* - We undertook an initial search of the published literature in order to determine the scope of the meta-ethnography and to refine the research question. Using MEDLINE from 1950 to the present, we used the ‘Clinical Query’ limit to search for articles filtered as using qualitative research methods. We used the widest scope available in this option. Using ‘pain’ as our key word within title or abstract, we identified 1,200 articles in English. One of the research team (FT) read through the titles and identified 206 as qualitative studies pertinent to chronic non-malignant pain. A further 31 were excluded after reading through the abstracts, leaving 175. The number of studies for each condition is shown in Table 1. Searching for qualitative
studies can be problematic [7], and we did not expect to identify all available studies by conducting this search only in MEDLINE. Interestingly, the results for Fibromyalgia (FM) were comparable to a recent meta-synthesis of qualitative findings in FM[27]. However, we know that the search did not identify all studies related to back pain. The search demonstrated that there is a body of knowledge available for a meta-ethnography of patient experience of chronic non-malignant pain.

Table 1 Number of studies identified in initial scoping search listed by condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of studies identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic non-malignant/chronic widespread (mainly musculoskeletal)</td>
<td>39</td>
</tr>
<tr>
<td>Back and neck pain</td>
<td>36</td>
</tr>
<tr>
<td>Hip and knee osteoarthritis (OA)</td>
<td>27</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>20</td>
</tr>
<tr>
<td>Cross cultural studies</td>
<td>12</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>9</td>
</tr>
<tr>
<td>Other*</td>
<td>1-3</td>
</tr>
<tr>
<td>* Included: phantom pain, toothache, orofacial, burns, peripheral vascular disease, pelvic, vulvodynia, urological, menstrual, systemic sclerosis, spinal cord injury, neuropathic, ankylosing spondilitis, chest, headache, osteoarthritis of hand, irritable bowel syndrome, osteoporosis.</td>
<td></td>
</tr>
</tbody>
</table>
depth (e.g. Social Science and Medicine, Qualitative Health Research, Journal of Advanced Nursing) for the previous 10 years. Handsearching journals is an important strategy for comprehensively identifying relevant qualitative studies [7, 29]. A Cochrane Methodology Review found that handsearching is necessary in order to identify relevant studies[30]. A list of journals will be developed at an early research team meeting and refined as the search strategy is developed. We will also search for work by authors identified as having done research in this area.

d. Personal Communication. Each member of the team is familiar with the literature on chronic pain and will use contacts to further widen the search.

e. Grey literature

Once relevant articles have been identified, the process as outlined by Sandelowski and Barroso will be used to exclude articles that do not meet the inclusion criteria [31]. This is shown in Figure 1. A detailed description of the search strategy and reasons for excluding studies will be kept.
Figure 1 Process for excluding articles from search (adapted from Sandelowski & Barrosa[31])

1. Check title
   - INCLUDE
   - UNSURE
   - EXCLUDE

2. Check Abstract
   - INCLUDE
   - UNSURE
   - EXCLUDE

3. Check full article
   - INCLUDE
   - UNSURE
   - EXCLUDE

4. Consensus
   - INCLUDE
   - EXCLUDE
Strategy for determining inclusion of studies

Although methods for determining the quality of qualitative research have been suggested, there is currently no consensus and the use of quality criteria is widely debated [8, 32, 33]. To be utilised within a meta-ethnography, studies must therefore provide sufficient description of concepts to allow translation [1].

To assist with appraisal for inclusion, the team will use questions developed by the critical appraisal skills programme (CASP)[34], that have been adapted and used for appraising quality of studies for meta-ethnography[3, 4, 22]. We will use the initial screening questions used in these studies:

1. ‘Does this paper report on findings from qualitative research in people aged 18 and over and did that work involve both qualitative methods of data collection and analysis?’
2. ‘Is this research relevant to the synthesis?’

This process will be carried out independently by two people, any disagreement will be discussed, and where required will be reviewed by a third person. All members of the team have experience of appraising and conducting qualitative research. If no consensus is reached, the paper will be included. Following quality assessment, data will be extracted and included on a data extraction form developed by the research team.

Each team member will also categorise papers as suggested by Dixon-Woods[9]. Is this paper:

1. A ‘key paper’ (KP) – ‘conceptually rich and could potentially make an important contribution to the synthesis’
2. A ‘satisfactory paper’ (SAT)
3. A paper that is irrelevant to the synthesis (IRR)
4. A paper that is methodologically fatally flawed (FF)

This method of determining inclusion has been used in a recent meta-ethnography [19], and will allow us to compare two methods of appraisal for inclusion into meta-ethnography.

Design and theoretical/conceptual framework

This study will use the methods of meta-ethnography as proposed by Noblit and Hare[1]. Various methods for synthesizing the results of qualitative research have been suggested [31, 35, 36]. Meta-ethnography is an interpretive form of knowledge synthesis, as opposed to the aggregate form more commonly used in the meta-synthesis of quantitative research[35]. It thus aims to develop new conceptual understandings. Meta-ethnography [1] is currently the most frequently used method of qualitative synthesis used in health care research [20], and provides one of the most explicit methods of synthesising qualitative studies[36].
Analysis involves translating the concepts of qualitative research findings, and exploring how these translations are related to each other, thus 'translating qualitative studies into one another'[1]. The process of translation involves reading and re-reading accounts and constantly comparing the concepts of the original texts in order to ensure that the translations are grounded in the original studies. This is comparable to the constant comparative method of Grounded Theory[37]. Constant comparison allows us to see the similarities and differences and thus generate new concepts. Through comparing and translation, the synthesis aims to provide further conceptual understanding of a particular phenomenon. Once formulated, translations can be, reciprocal (in agreement), refutational (disagree), or brought together to form a line of argument [1] Translations are integrated into a conceptual interpretation that deepens understanding of the phenomenon. It may be more useful to think of translation and integration as ongoing and simultaneous processes, rather than sequential acts. As in other qualitative research methods, data collection does not precede analysis but informs it [37]. The process of meta-ethnography involves continually returning to the ‘data’ in order to ensure that the translations are recognisable and convey the meaning of the source research.

Contribution to collective research effort and research utilisation

Outputs
We anticipate the following outputs from this research:

1. Publication in high impact journals related to:
   a. Chronic pain
   b. Research methodology.
2. A conceptual framework for chronic non-malignant pain. This would help ensure that domains important to the patients are addressed in the complex management of chronic non-malignant pain.
3. A summary of the research for practitioners, policy makers and patients.
4. Identification of research questions not currently addressed by body of qualitative knowledge.
5. Dissemination of research utilising technology such as Podcasts.

Methods of dissemination

The Steering Group will include members with access to practice, policy and patient arenas to advise on appropriate dissemination. The research team have wide experience of research dissemination and are active in the field of chronic pain.

We would expect research findings to be disseminated through

1. 1. PODCAST/DVD production. The Centre for Qualitative Research at Bournemouth University has a strand of ‘Performative Science’ which works with qualitative researchers to produce visual outputs.
It is powerful in the ‘promotion of knowledge’ beyond traditional outputs.

2. Key high impact journals.
3. International conferences e.g. International Association for the Study of Pain (IASP), European Federation of IASP Chapters (EFIC).
4. Patient groups, including the British Pain Society Patient Liaison.
5. Special interest groups (British Pain Society and IASP).
6. NHS Evidence.
7. Electronic open source publication via BioMed Central.
8. Linking a summary of report into key patient websites.

Plan of investigation and timetable
A plan of the study with monthly schedule has been drawn up and is attached with this application.

Ethics
This meta-ethnography would not involve patient participants and does not require ethical approval

Project management
There will be a clear project documentation system, with careful version control. This will be developed by the PI and agreed by the project team at their first meeting. It will include a detailed Gantt chart; roles and responsibilities of each project team member; a risk register; a brief communication strategy setting out principles for communication, updating and discussion within the project team; a dissemination strategy and reference management plan using Endnote. The PI will be responsible for the day to day running of the study, and the project team will meet monthly using a combination of face to face meetings, teleconferencing and Skype. Progress against agreed objectives and budget monitoring will be part of each meeting. A steering group will be established and meet three times during this study to offer advice to the project team.

Service Users
Steering group membership

1. A member of the Nuffield Orthopaedic Centre, Patient Research Engagement Forum (PREF) who has recent experience of treatment for non-malignant pain.

2. A patient with an interest in research will be recruited from UNTRAP based at Warwick University (www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/untrap/). UNTRAP is a partnership between users of health and social care services and carers, the University of Warwick and the NHS. UNTRAP aims to support the involvement of service users and carers in teaching and research.
3. Beverly Collett [past Pain Society President], Assistant Medical Director, Consultant in Pain Management & Anaesthesia, Leicester Royal Infirmary NHS Trust, who has been actively involved in policy decisions for chronic pain, has agreed to be part of the steering group.

4. Department of Health representative with an interest in patient and public involvement.

5. Two members of NHS staff working in chronic non-malignant pain.

The steering group will meet a minimum of 3 times spread throughout the study (see study timetable) and aims to provide advice from a broad perspective.

2. Involvement in Analysis - The UNTRAP user will also be active in the synthesis stage of the research (see study timetable). This person will attend 3 key analysis meeting and contribute to the conceptual development of this study. This person will paid at the agreed UNTRAP rate.

Expertise and justification of support required

The main costs for this proposal will be to support the research team. Full details of costing are given in the application form. We realise the likely number of papers will be challenging and so have constructed this team taking this into account. We will allocate each paper to two members of the research team in a rotational system, so that each researcher has the opportunity to work with every member of the team. This will allow a broader perspective on appraisal and interpretation of each paper. We know that meta-ethnography is feasible for studies incorporating smaller numbers of studies [2-4] A meta-synthesis incorporating a large number of studies will contribute to the understanding of the feasibility of meta-ethnography for use in areas of healthcare where a large body of qualitative knowledge exists.

Research Team

Dr Francine Toye (FT) FT will be responsible for overall project management and coordination of the team. She will work closely with the research fellow and information scientist to develop the search strategy and data collection methods. She will be financed to work on the project 1.5 days per week (0.3FTE) for the duration of the trial, and will support the research fellow during this time. She will work jointly with the other team members to translate and synthesise the studies and to disseminate findings. FT is familiar with the literature in this field and has experience of qualitative analysis. She has a social science degree (2.1) in Anthropology, awarded by Cambridge University, and has a continued interest in medical anthropology. For her PhD, FT used interpretative phenomenological analysis (IPA) to explore patient’s perceptions of health care need (total knee replacement). During her doctoral and post-doctoral qualitative research FT has developed the skills needed to identify and analyse qualitative data. She uses IPA and grounded theory in her own research and has attended courses in IPA analysis and qualitative
synthesis and meta-ethnography (Pope & Britten, June 2009). She has a recent qualitative publication related to patients’ experience of pain [79] which used grounded theory to explore how patients with persistent unexplained pain interpret and utilise the biopsychosocial model. She also teaches qualitative research methods to research colleagues within her NHS Trust. Her current role also involves consulting with and supervising clinicians involved in qualitative research. FT is currently involved as a qualitative research consultant at the clinical trials unit (University of Warwick).

**Professor Kate Seers (KS)** - KS has extensive qualitative research experience, is supervising seven qualitative PhDs and has supervised eight qualitative PhDs to completion. One of these was a complex meta-ethnography, a publication from which is currently under review. KS’s topic expertise is within pain management where she has a detailed knowledge and has published widely. She has also undertaken and published two quantitative systematic reviews in pain management, and is feedback editor of the Cochrane Pain, Palliative and Supportive Care Group, so is used to extracting data and assimilating large amounts of data. KS also has extensive experience in leading large research teams and working collaboratively. KS will be responsible for contributing to the development of the meta-ethnography, and working with the team to extract themes and translate concepts across studies.

**Dr Eloise Carr (EC)** - EC is an experienced pain and mixed methods researcher spanning over twenty years. All her research studies have involved a qualitative element and she would have access to the international ‘Centre for Qualitative Research’ in the School of Health & Social Care at Bournemouth University. She has supervised doctoral students to successful completion (3 in qualitative methods) and currently supervises six students in pain research. Her most recent grant (Health Foundation £456K) has focused on the management of chronic low back pain in primary care and she has considerable subject knowledge of the topic area. EC is experienced in leading complex projects and working collaboratively. EC will work with other team members to translate and synthesise the studies and contribute to dissemination of the outputs. EC recently took up a position at the University of Calgary in Alberta, Canada. Her principle role will be to further develop her programme of pain research and work collaboratively with others in the field.

**Dr Nick Allcock (NA)** is director of the Nottingham Centre for Evidence Based Practice Nursing, Midwifery and Physiotherapy (a collaborating centre of the Joanna Briggs collaboration and has been trained in the process of qualitative research synthesis. Clinically involved in the management of chronic pain, he has planned and completed qualitative studies into patient experiences of chronic pain [38]. NA works in the School of Nursing, Midwifery and Physiotherapy, and is director of the MSc in research methods. He has successfully supervised PhD and Masters Dissertations.

**Michelle Briggs (MB)** MB has broad experience in systematic reviews. She is an author of a Cochrane systematic review [39] and has served as a Cochrane Wounds Group editor from 2003-2008 and is currently a reviewer for The Cochrane Pain, Palliative Care and Supportive Care Collaborative Review Group. She has completed syntheses of qualitative research during her NIHR post doctoral training using Joanna Briggs QARI methodology. The Cochrane Qualitative Methods group recently asked permission to use the
publication of this synthesis [40] as an exemplar of qualitative synthesis in a qualitative workshop at the Singapore Cochrane Colloquium Oct 2009. She also has supervised others in mixed methods reviews of quality of life issues in pressure ulcers using a combined synthesis of qualitative and quantitative research based on Bayesian synthesis methods involving the generation of a prior distribution of likely factors and their relative importance and using content analysis to generate common categories and themes from findings[41].

Dr Karen Barker (KB) is the Clinical Director and research lead for the rehabilitation arm of the NIHR supported Musculoskeletal Biomedical Research Unit a collaboration between the Nuffield Orthopaedic Centre NHS Trust and Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science at University of Oxford. She has experience in conducting research trials with patients with chronic back pain and has participated in a number of systematic reviews. She has supervised PhD and MPhil students to completion and is currently supervising PhD and MPhil students.

Collaborators

Information Scientist (IS) Full time for 6 months. This will allow time to develop and refine the search strategy within the team. The role of the IS would be to work with the team to develop and refine the search strategy, to identify and retrieve all relevant articles. The quality of this type of synthesis relies on optimising retrieval, and this role is important to the quality of output.

Research Fellow (RF) 0.5 FTE post (2.5 days) over the 24 months. The research fellow would work with the team in all stages of the project (quality appraisal, data extraction, analysis).

Other costs

Include travel for team and servicer users to attend meetings, Nvivo to assist analysis and dissemination costs. These are broken down in detail within the application form.

Building Research Capacity

This project will provide FT the opportunity to develop her post doctoral experience to undertake a large synthesis of qualitative research within an experienced team of qualitative researchers. With the proliferation of qualitative research findings, the ability to synthesise findings is likely to become an increasingly important facet informing best clinical practice.

Planned or active research grants

We have not planned, nor are in receipt of any other research grants for this project.

History of past or existing NIHR programme research

Current

KS Principal investigator on NIHR Research for Patient Benefit Grant: PB-PG-0407-12243 - Research for Patient Benefit (Diabetes Urgent Care) September 2008-November 2010. £230,963
**MB** Co-Investigator on NIHR Research for Patient Benefit Grant: October 2009 – October 2012 PI SJ Closs. Towards culturally competent pain management for older people £239,000

**MB** Co-Investigator on NIHR Programme Grant for Applied Research. PURPOSE Pressure UlceR Programme of ReSEarch. Feb 2008 - Feb 2013 PI J Nixon £1,995,549

**MB** Principal Investigator NIHR Post Doctoral Award Jan 2006 – June 2010. Self-management for people with painful leg ulcers: the development of a complex intervention using qualitative synthesis of research, realistic synthesis and grounded theory. £231,000

**Completed**
References


This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSR programme or the Department of Health.