Including qualitative research in pain education

AIM OF THIS RESOURCE

This is a resource to help educators include qualitative research findings in pain education. We have identified qualitative evidence syntheses in the field of pain and also provide information on how to find and utilise primary qualitative studies. The resource includes activities that can be used in pain education to stimulate thinking about what it is like to live with pain.

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(on behalf of the team)
OUR TEAM

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AIMS & BACKGROUND

Aim of this resource
To create a resource to help educators to include findings from qualitative research in pain education provision, thus improving healthcare for people in pain.

Specific objectives:
1. Provide resources to support our aims.
2. Identify Qualitative Evidence Syntheses (QES) that explore the experience of living with pain.
3. Provide examples of primary qualitative research (or how to find examples in your chosen area).
4. Provide examples of educational activities to support our aims.

How to use this resource
This resource is divided into 4 sections followed by references and appendices.

SECTION 1: AUDIO-VISUAL RESOURCES – identifies useful audio-visual resources for use in pain education; (1) research based qualitative films, (2) Pain Concern resource (3) Healthtalk.org resources. You can use these resources in varied educational settings. This section is supported by Activities 1, 2, 3 and 4.

SECTION 2: QUALITATIVE EVIDENCE SYNTHESES IN PAIN – describes the largest international review of qualitative evidence syntheses in pain. The findings are summarised and supported by a PowerPoint presentation for use in pain education. This section is supported by Activities 5, 6 & 7.

SECTION 3: PRIMARY QUALITATIVE RESEARCH IN PAIN – describes how to identify and utilise primary qualitative studies in pain education. Use this section to encourage learners to find, appraise and engage in primary studies. This section is supported by Activity 8.

SECTION 4: ACTIVITIES – provides activity sheets with ideas on how you can use qualitative resources in pain education. Use these sheets as suggested, or to stimulate ideas on how to engage learners with a variety of qualitative resources.

APPENDICES –
Appendix 1 - provides a script from a research based film of healthcare professionals’ experience. This is supported by Activity 2.

Appendices 2-10 - provide a series of cards presenting the findings from qualitative evidence syntheses. These findings have been rewritten for this report as if spoken by a research participant. We have found this a useful way to engage learners in the findings from research.
Background - ‘Sickness calls forth stories’[1]

When people are ill or in pain, they make sense of this experience by telling other people stories about what has happened. Through these stories people create a sense of who they are and how they want others to judge them [2]. People tell stories to reinforce a sense of self that is threatened by pain and illness. Our stories aim to persuade or compel people to act on our behalf. Part of the work of a healthcare professional is to listen to people’s accounts, to understand the significance of pain in their life and to ask themselves why a story is being told in this way. Modern biomedicine creates a danger that healthcare professionals are removed from their patients’ personal experiences by stripping away stories and focusing on diagnosis.

‘The impulse to roll up our sleeves and do something is irresistible and . . . attentive listening does not feel enough like clinical action’ [1] page 199

Charon urges us to be vigilant to the hint of a story in patients’ accounts as this information it critical to healing [1].

• Stories help patients to make sense of what is happening,
• Stories allow patients to hold onto a sense of self in the face of illness,
• Stories summon a sense of responsibility and duty to act.

Qualitative research – what does it do?

Personal accounts of experience through storytelling or ‘narrative’ are an important ingredient of qualitative research.

1. Qualitative research provides a strong drive towards patient-centred care and humanistic care by showing others what it is like to live with pain. Qualitative knowledge counteracts the risk of reducing patients to their constituent body parts.
2. Qualitative research ensures that patient voices are heard and can thus influence policy, practice and public opinion.
3. Qualitative research can make an important contribution to shared-decision making in healthcare, and can thus have a direct effect on healthcare outcomes.

There is a wealth of qualitative knowledge published that explores people’s experience of living with pain. This resource has been developed for stakeholders in policy, practice and education who think that it is important that this knowledge forms a key part of a clinicians’ education.
SECTION 1: Audio-visual resources
There are some freely available research based audio-visual resources that allow educators to include qualitative research into different learning environments:

RESEARCH BASED QUALITATIVE FILMS
There are two qualitative research based films that present findings from two large qualitative evidence syntheses (QES) of:

a. Patients’ experiences – ‘Struggling to be me with chronic pain’
   https://www.youtube.com/watch?v=FPpu7dXJFRI
   This is a short film based on a synthesis of 77 qualitative studies exploring the experience of adults with chronic musculoskeletal pain. The script is drawn from peoples’ own words about what it is like to live with chronic pain and is performed by an actor.

ACTIVITY 1: learning about living with pain from research based films
Go to page 17 to find an activity sheet

b. Healthcare professionals’ experiences - ‘Struggling to Support People to Live a Valued Life with Chronic Pain’
   https://www.youtube.com/watch?v=477yTJPg1o
   This is a short film based on a synthesis of 77 qualitative studies exploring healthcare professionals’ experience of treating adults with chronic non-malignant pain. The script is drawn from healthcare professionals’ own words about what it is like to treat people with chronic pain and is performed by actors.

ACTIVITY 2: a film script to learn about the experience of healthcare professionals
Go to page 18 to find an activity sheet
PAIN CONCERN AUDIO AND VISUAL RESOURCES

Pain Concern is a UK based charity working to support and inform people with pain and those who care for them, whether family, friends or healthcare professionals. Its trustees and advisory board are made up of leading healthcare professionals in their fields, patient group representatives, and opinion formers. For more information about Pain Concern, visit www.painconcern.org.uk

Pain Concern produces information on pain using a variety of media platforms:

a. BREAKING BARRIERS: Video resource
   http://painconcern.org.uk/self-management-videos/

Pain Concern produced a series of six 10-minute self-management videos as part of its Breaking Barriers research project. Pain Concern’s Breaking Barriers self-management resources are the result of a two-year research project during which researchers spoke to people living with pain, carers and healthcare professionals about the barriers that might be preventing the adoption of self-management strategies for chronic pain.

1. The project – Breaking the barriers to self-management
   http://painconcern.org.uk/the-project/
3. GP consultations http://painconcern.org.uk/gp-consultations/
5. Medical investigations http://painconcern.org.uk/medical-investigations/

Researcher Katy Gordon explains why Pain Concern recognised an urgent need to carry out the project:

‘Callers to the Pain Concern helpline often spoke of difficult consultations with healthcare professionals that left them feeling unsupported and struggling to manage their pain . . . knowing what barriers might exist would be the first step to bringing about change and ultimately hoped that our report would help more people better to manage their pain.’

What people living with pain say about the Pain Concern’s Breaking Barriers study:

‘Your report encapsulates concisely what chronic pain sufferers are exposed to through the NHS care system.’

**ACTIVITY 3: Pain Concern breaking barriers**

Go to page 19 to find an activity sheet

**b. Airing Pain: Audio Resource**
http://painconcern.org.uk/airing-pain/
Airing Pain is a series of half-hour online audio podcasts, freely distributable via download. It is made by multi-award winning, former BBC senior producer Paul Evans, who lives with a chronic pain condition himself. Approaching its 100th edition, that’s 50 hours of listening, the 2nd January 2018 edition featured an interview with Dr Paul Wilkinson, lead for the international task force for IASP’s Global Year of Excellence in Pain Education. The most recent series covers topics such as: sex and chronic pain, diabetic neuropathy, back pain, dementia, pelvic pain & vulvodynia and sickle cell disease. Previous series cover a wide range of other topics exploring patient experience that would be useful in clinical education.

**c. Information Leaflets.** http://painconcern.org.uk/resources/information-leaflets/
Pain Concern publishes a range of leaflets on self-management and other topics authored by leading healthcare professionals specialising in pain. They are downloadable from Pain Concern’s website and sent out on request.

Current leaflets cover: sex & chronic pain; medicines for long-term pain; foot pain – how to manage and prevent it; managing health-care appointments; sleep; chronic pain after breast cancer surgery; manage your pain; neuropathic pain; chronic pain after surgery; tens for pain relief; managing your medications; not all in the mind; diet and pain; amitriptyline.
HEALTHTALK.ORG

Healthtalk.org is an online resource that provides video, audio and text descriptions of people’s experiences of over 100 health conditions. These descriptions are drawn from robust qualitative research studies. For each condition there is a list of topics and associated videos/text. Many of the condition modules describe the experience of pain and its management. In particular there is a module on experiences of chronic pain based on interviews with 47 people from across the country (link in Table 1).

There are also descriptions of pain associated with specific illnesses (links in Table 1). You can scroll down and see videos and text versions of interviews. You can scroll down the overview page and see all the aspects of the conditions that are covered, including the specific section/s that cover/s aspects of pain. You can also access profiles of the individuals who were interviewed, so that you have some background about them.

Table 1: HealthTalk.org - links

<table>
<thead>
<tr>
<th>Condition</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic pain module</td>
<td><a href="http://www.healthtalk.org/peoples-experiences/long-term-conditions/chronic-pain/topics">http://www.healthtalk.org/peoples-experiences/long-term-conditions/chronic-pain/topics</a></td>
</tr>
<tr>
<td>Cancer prostate</td>
<td><a href="http://www.healthtalk.org/peoples-experiences/cancer/prostate-cancer/pain-relief">http://www.healthtalk.org/peoples-experiences/cancer/prostate-cancer/pain-relief</a></td>
</tr>
</tbody>
</table>
The content on the Healthtalk website is developed by The Health Experiences Research Group, part of the University of Oxford’s Department of Primary Care Health Sciences. The website is managed by the DIPEX charity. To read more, visit: http://www.healthtalk.org/about/overview#ixzz53RQkla8

**Using Healthtalk in clinical education**

Healthtalk is used extensively in teaching healthcare professionals – this is a link to how you can use the site’s content http://www.healthtalk.org/learning-and-teaching/copyright.

There are many clips that you could use across the website to show aspects of what it is like to be a patient with pain. You can choose your own and create a lesson around the aspects of pain that you want your learners to consider.

The **Scrapbooks** featured on the website allows learners and teachers to save relevant videos and pieces of content together in collections or scrapbooks. You can:

- add descriptions, keywords and images,
- share individual scrapbooks with learners and colleagues,
- videos will appear as a playlist to use in presentations/lectures/seminars,
- set scrapbooks as private or public,
- browse and benefit from scrapbooks made by others.

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**ACTIVITY 4: LEARNING FROM HEALTHTALK.ORG**

Go to page 20 to find an activity sheet
SECTION 2: Qualitative Evidence Syntheses (QES’s) exploring the experience of pain

If you want to find, and learn from, qualitative research that has been published in your area, a good start is to look for a qualitative evidence synthesis (QES) [3]. QES is a burgeoning method of research that aims to condense, or develop ideas from, published qualitative findings. There are a growing number of QES that explore the experience of pain and also a review of QES, or mega-ethnography, which brings together findings from 11 QES reviews exploring the experience of living with chronic non-malignant pain [4]. The mega-ethnography draws on stories from more than 6000 people living with chronic pain. The following statements summarise the mega-ethnography findings. We have also included a power-point presentation on the IASP website which illustrates these findings visually for use in an educational setting.

The following statements summarise the findings from Toye and colleagues’ mega-ethnography [4]:

| Life impoverished and confined | Pain is all-pervading. It invades all aspects of my day and night. My life is impoverished. I am confined to the moment & uncertain of the future. |
| Struggling against my body to be me | I struggle to maintain my sense of self. My body is alien and malevolent. I cannot fulfil my normal duties. I am irreparably altered. |
| Quest for the diagnostic ‘holy grail’ | I long for a medical diagnosis. If the doctor can’t find anything then people will not believe me. There must be something wrong with me. I need to find out what is wrong with me so that I can be cured. |
| Lost personal credibility | I have lost my personal credibility. No one believes me because there is nothing to prove that my pain is real. |
| Trying to keep up appearances | I need to keep up appearances. I keep my pain to myself because I don’t want to be judged as weak, and I don’t want to spoil things for everyone else. If I keep quiet about it no one will notice that I am no longer the person that I was. |
| Need to be treated with dignity | I am having a negative experience of healthcare. No one is hearing or seeing me. I need to be treated with dignity. I am being sent around in circles. I feel like a shuttlecock in the system. |
| Deciding to end the quest for the grail is not easy | It is a profound personal challenge to give up the quest for a diagnosis and at times I just cannot accept that there is no cure for my pain. |

**ACTIVITY 5: a PowerPoint of findings from a mega-ethnography of chronic pain [4]**

Go to page 21 to find an activity sheet
We aimed to identify any QES that explored the experience of pain.

**SEARCH STRATEGY.**
We wanted to keep the search broad and to identify any QES that explored the experience of living with pain. We used search terms that were likely to identify QES (figure 1) combined with thesaurus and free text searches to identify studies that explored the experience of pain (exp PAIN or pain.ti,ab). We also included ‘arthritis’ as a search term (exp ARTHRITIS/ or arthritis.ti.ab), as we felt that these conditions, although painful, would be otherwise missed. Arthritic conditions had not been included in the QES of chronic musculoskeletal pain experience by Toye and colleagues[5].

**Figure 1 - SEARCH TERMS for QES:**

- qualitative evidence synthesis” OR "QES"
- metasynthes* OR meta-synthes* OR "meta synthesis"
- metasummar* OR meta-summar* OR "meta summary"
- metastud* OR meta-stud* OR "meta study"
- metaethnog* OR meta-ethnog* OR "meta ethnography"
- metanarrative OR meta-narrative OR "meta narrative"
- "critical interpretive synthesis"
- "realist synthesis"
- "thematic synthesis"
- qualitative ADJ4 systematic*
- qualitative ADJ4 review
- qualitative ADJ4 synthes*
- noblit adj4 hare
FINDINGS:
We identified 371 potential QES from 4 medical databases (Medline, Embase, Cinahl, Psychinfo). We removed 179 duplicates. We included 2 additional QES exploring healthcare professionals’ experience of treating patients with chronic non-malignant pain [6] and prescribing opioids [7]. We considered the remaining 194 full text studies and removed 152 studies because; they were not QES, they were out of scope, or we felt that the ideas were not fully developed [4, 8-158]. Of the studies we excluded, one combined the experience of chronic, acute, malignant and non-malignant [156].

The remaining 42 QES explored:

- chronic non-malignant pain (including fibromyalgia) [5, 159-170]
- rheumatoid arthritis [171-179]
- pelvic pain [180, 181]
- osteoarthritis [182-185]
- juvenile idiopathic arthritis [186]
- older people’s experience of pain [187, 188]
- osteoporosis[189, 190]
- cancer pain and living with cancer after treatment [191, 192]
- Healthcare professionals’ experience of treating people with chronic pain [6, 7, 193-196].
- offspring’s experience of living with a parent with chronic pain [197]

In this report we aimed to present findings from these QES in a way that could engage diverse audiences with different experience and knowledge of qualitative research. A useful way to engage people in qualitative research finding is to:

a. Identify the concepts within a qualitative study, and
b. Rewrite these concepts as if spoken by a participant.

For example, the finding ‘AVERSION TO BEING DIFFERENT’ from a study exploring the experience of living with juvenile idiopathic arthritis [186] described how arthritis had a profound impact on a child’s sense of normality. Children described how they ‘despised’ feeling different and felt frustrated, fearful, and powerless. Rewritten as if spoken, became:

“Arthritis makes me feel that I am no longer normal. I despise feeling different and feel frustrated, afraid and powerless”

These first person statements can powerfully portray findings from QES in an accessible way for education. Appendices 2-10 present a summary of findings from the QES rewritten as if spoken that can be used in educational settings.
1. **QES exploring what it is like to live with chronic non-malignant pain [5, 159-170, 180, 181]**

We identified 15 QES that explored the experience of living with chronic non-malignant pain [5, 159-170, 180, 181], including 2 that focused on chronic pelvic pain [180, 181]. Eleven of these had already been synthesised [4]. We identified 4 additional studies [159, 164, 167, 169] which supported the themes and line of argument developed by Toye and colleagues in their mega-ethnography [4]: The 100 concepts from 15 QES are shown in Appendix 2.

**ACTIVITY 6: LEARNING FROM 100 FINDINGS FROM QUALITATIVE EVIDENCE SYNTHESSES OF CHRONIC PAIN**

Go to page 22 to find an activity sheet

2. **QES exploring what it is like to live with rheumatoid arthritis [171-179]**

We identified 9 QES that explored the experience of Rheumatoid Arthritis [171-179]. One of these studies explored the experience of disease-modifying anti-rheumatic drugs (DMARDS) [174]. The findings (rewritten in first person) are shown in Appendix 3.

3. **QES exploring what it is like to live with osteoarthritis [182-185]**

We identified 4 QES that explored the experience of living with osteoarthritis [182-185]. Dockerty explored patients' adherence to analgesic medication [182]. Smith and colleagues provided a descriptive account of what it is like to live with hip and knee osteoarthritis [183] and attitudes to conservative management [184]. Paskins and colleagues explored peoples' experience of the medical consultation for OA [185]. The findings are shown in Appendix 4.

4. **QES exploring what it is like to live with juvenile idiopathic arthritis [186]**

We identified 1 QES that explored the experience of juvenile idiopathic arthritis [186]. The findings are shown in Appendix 5.

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1 A mega-ethnography of Rheumatoid Arthritis will be submitted for publication in 2018 and will present an interpretive line of argument from these QES findings
5. QES exploring older people’s experience of living with pain [187, 188]
We identified 2 QES that explored older peoples’ experience of chronic non-malignant pain [187] and pain management in nursing homes [188]. The findings are shown in Appendix 6.

6. QES exploring what it is like to live with osteoporosis [189, 190]
We identified 2 QES that explored the experience of living with osteoporosis [189, 190]. The findings are shown in Appendix 7.

7. QES exploring cancer pain and what it is like to live with cancer after treatment [191, 192]
We identified 2 QES that explored pain and cancer. One QES explored the experience of living following cancer treatment [191] and the other QES explored the experience of morphine for cancer related pain [192]. The findings are in Appendix 8.

8. QES exploring offspring’s experience of what it is like to have a parent with chronic pain [197]
We identified 1 QES that explored the experience of living with a parent with chronic pain. The findings are shown in Appendix 9.

9. QES - healthcare professionals’ experiences of treating people with chronic pain [6, 7, 193-196]
We identified 6 QES that explored healthcare professionals’ experience of treating patients with painful conditions. Five of these QES explored the experience of treating patients with chronic non-specific pain [6, 7, 194-196] and one QES explored the management of osteoarthritis [193]. The summary findings are shown in Appendix 10.

**ACTIVITY 7: engaging in findings from qualitative evidence syntheses**
Go to page 24 to find an activity sheet
Limitations of our review

- Although our search was wide, our resources meant that the search was not exhaustive and we may not have identified all QES. This is a rapidly proliferating field of enquiry and QES studies are likely to increase in number.

- We did not include cancer or neoplasm as a specific search term. The search focused on studies that identified pain or arthritis in title or abstract.

- We did not identify a review of children’s pain, chronic pain after surgery or experience of opioid use in non-cancer pain.

- QES provides an interpretation of primary studies and some argue that the process of synthesising studies takes us away from the first-hand experience
SECTION 3: Primary qualitative research exploring the experience of pain

Although we identified more than 40 QES that explored the experience of pain, there is not a QES available for all painful conditions. It may be that the process of synthesising studies takes us a step away from the lived experience. We would therefore encourage clinical educators to include primary qualitative research in clinical education.

In a Cochrane Blog (Evidently Cochrane) Fran Toye asks the question ‘Can qualitative research improve patient care?’ [http://www.evidentlycochrane.net/qualitative-research-patient-care/]. She gives an overview of how to find a study, decide whether or not it is a good one and what to do with it.

How do I find a qualitative study

QUICK VERSION:
Combine qualitative thesaurus terms (e.g. on Medline - QUALITATIVE RESEARCH/; FOCUS GROUPS/; THEORY, GROUNDED/) with condition specific terms.

LONG VERSION:
Include a wider range of terms. For example, some useful thesaurus terms are shown in figure 1.

*Figure 1 – useful search terms for identifying primary qualitative research studies*
How do I know if it is a good study?

Deciding what is good and what is not good can feel like trying to pin down jelly[198].

There are many frameworks and checklists for helping with this. The Critical Appraisal Skills Programme (CASP) qualitative checklist is useful and often used (http://www.casp-uk.net/casp-tools-checklists). However, judging quality is not straightforward so the reader should be prepared to make a judgement call. Fundamentally, do you think that the researcher has challenged their findings, are their ideas clear and have they made you think?

A FEW EXAMPLES of qualitative research.

The QES included in this report provide lists of many qualitative studies that form their review. We also asked various authors from the QES to identify some primary studies that they thought were ‘good’ and that encapsulated patient’s experiences:

- Chronic pain: [199-201] and Fibromyalgia: [202]
- Osteoarthritis [203-205]
- Rheumatoid arthritis[206]
- Pelvic pain[207]

**ACTIVITY 8: finding and learning from primary qualitative research**

Go to page 24 to find an activity sheet
SECTION 4: Activities to engage clinicians with qualitative research

Aim of the activities

To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

The following pages give some suggestions for educational activities that you can use.
ACTIVITY 1: LEARNING ABOUT LIVING WITH PAIN FROM A RESEARCH BASED FILM

LEARNING AIM
To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

MATERIALS: ACCESS TO YOUTUBE FOR FILMS:

https://www.youtube.com/watch?v=FPpu7dXJFRI -
'Struggling to be me with chronic pain' - the experience of adults with chronic musculoskeletal pain

https://www.youtube.com/watch?v=477yTJPs10o -
'Struggling to Support People to Live a Valued Life with Chronic Pain' - healthcare professionals' experience of treating adults with chronic non-malignant pain.

1. Watch one (or both) of the films.
2. Consider, discuss and make notes on the following:
   - What are the main themes of the film?
   - How did it make you feel?
   - Any surprises?
   - How the film resonates with your experience?
   - Describe the impact of the film on you?
   - How could you use what you have learnt to improve healthcare for people in pain?

3. Discuss your ideas in a group.

TEACHING NOTES

- Students can either watch the film before the session or during the session, depending on time available.
- Ask them to write down something about each question.
- Leave plenty of time for discussion in groups.
- Alternatively, you could ask students to write a piece of work that explores these questions.
ACTIVITY 2: USING A FILM SCRIPT TO LEARN ABOUT THE EXPERIENCE OF HEALTHCARE PROFESSIONALS

LEARNING AIM
To understand the experiences of healthcare professionals treating patients with chronic pain and the barriers to a therapeutic partnership.

MATERIALS: FILM SCRIPTS (APPENDIX 1)

1. Ask students to familiarise themselves with the film script before the session.
2. Ask for volunteers to read out the script.
3. Discuss:

   • What are the main themes in the script?
   • How did this experience make you feel as an actor or viewer?
   • How does it resonate with your experience?
   • What changes would you make to your own practice?

TEACHING NOTES

• This film script is drawn from a QES and has been produced as a YouTube film (see activity 1).
• Get several students to share the part of the healthcare professionals.
ACTIVITY 3: PAINCONCERN BREAKING BARRIERS

LEARNING AIM
To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership. This activity focuses on understanding the emotional impact of chronic pain.

MATERIALS: ACCESS TO FILMS:

1. Watch Pain Concern's film – the emotional impact of chronic pain

2. Consider and discuss the following questions:
   - How did it make you feel?
   - Any surprises?
   - How does the film resonate with your experience?
   - Describe the impact of the film on you?
   - What can we do to improve healthcare for people in pain?

3. Discuss your ideas in a group.

TEACHING NOTES

- Leave plenty of time for discussion in groups.
ACTIVITY 4: LEARNING FROM HEALTHTALK

LEARNING AIM
To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

MATERIALS:

You will need access to the following links:

COMMUNICATING WITH HEALTHCARE PROFESSIONALS:
http://www.healthtalk.org/peoples-experiences/long-term-conditions/chronic-pain/communicating-healthcare-professionals

SEARCH FOR A CAUSE AND DIAGNOSIS:

1. Ask the participants to consider what they think is important about communication with patients that have chronic pain. They can discuss this with their neighbours.

2. Play a clip and ask them how they feel about what the patient says.

3. Ask them to consider a similar situation in which they have had to communicate with a patient.

4. Having seen the clips, discuss with them what they might do differently?
ACTIVITY 5: A POWERPOINT OF FINDINGS FROM A MEGA-ETHNOGRAPHY OF CHRONIC PAIN

LEARNING AIM
To familiarise students with findings from a review of QES on the experience of living with pain.

MATERIALS: PowerPoint presentation of mega-ethnography themes (on IASP website)

TEACHING NOTES:
Use this PowerPoint to present the findings from Toye and colleagues review of reviews (mega-ethnography). The review incorporates the experience of more than 6000 people living with pain in 187 qualitative studies [4]

(The slide notes provide an example of one QES finding supporting the review theme. It also shows the source of the image used in the presentation and licensing information)
ACTIVITY 6: LEARNING FROM 100 FINDINGS FROM QES OF CHRONIC PAIN

LEARNING AIM:
To facilitate an empathetic understanding of what it is like to live with painful conditions and thus facilitate a therapeutic partnership.

MATERIALS: THEME CARDS IN APPENDIX 2 (OR ANY APPENDIX FROM 2-10), ENVELOPES:
- Cut and sort the cards into piles with a shared theme.
- Put each pile or ‘theme’ into an envelope.
- Write one sentence on the front of each envelope that describes the theme inside.
- Compare and contrast your ideas with the group.

TEACHING NOTES:
- This activity can be done in groups or as individuals before or during the session depending on the time available.
- Using all 100 cards will take a long time. Give students a limited number to work with, particularly if time is limited during a session. Give each group a random selection of cards (e.g. 20 cards).
- Groups are likely to find common themes to discuss about what it is like to live with pain.
- You could try this activity with any of the QES findings in appendices 2-10.
ACTIVITY 7: ENGAGING IN FINDINGS FROM QES

**Learning Aim**
To facilitate an empathetic understanding of what it is like to live with painful conditions through engagement with QES findings.

**Materials: Choose an Appendix from 2-10**

1. Choose one of the conditions in the appendices 2-10 that provide summary findings from QES rewritten in the first person.
2. Read the findings.
3. Think of an imaginative way to present these findings. For example, write a short script, story or poem.
4. Share and discuss this presentation.
ACTIVITY 8: FINDING AND LEARNING FROM PRIMARY QUALITATIVE RESEARCH

LEARNING AIM
To facilitate an empathetic understanding of what it is like to live with painful conditions through engagement with primary qualitative research findings

MATERIALS: A PRIMARY QUALITATIVE STUDY

1. Ask students to identify a qualitative study that explores the experience of pain.
2. Then, focusing on the findings:

Either - write single sentence that summarises each finding (you could write these summary statements as if you were a participant)

OR - Highlight parts of the narrative that feel important and read aloud in group

OR - Find an image (e.g. from google images) that you feel represents the finding.

3. Present and discuss your summary statements/highlights or images.
4. Consider these findings in light of your own personal or clinical experiences.

TEACHING NOTES:

• Use SECTION 3 (pages 15-16) to help identify a relevant primary study.
• There is not a right answer – the idea is to generate empathetic discussion.
REFERENCES


58. Hoon LS, Mackey S, Hong-Gu H: Elderly patients' experiences of care received in the emergency department: a systematic review. JBI library of systematic reviews 2012, 10(23):1363-1409.


reaction (HCR) in women's medicine wards of Bangladeshi hospitals: a record review and qualitative study. BMC women's health 2012, 12:38.


APPENDIX 1: FILM SCRIPT FOR A QUALITATIVE EVIDENCE SYNTHESIS

Healthcare professionals’ experience of treating patients with chronic pain, by Trevor Hearing, Red Balloon Productions, Bournemouth University, UK

You can watch this film on: https://www.youtube.com/watch?v=477yTJPg10o

SYNOPSIS
This is a drama in the style of an observational documentary, Paul Watson style, handheld, with eavesdropping and comments to off-camera, set in a large GP city practice or medical centre. There are 4 characters, all HCP professionals but their precise roles are ambiguous in the film.

SECTION A

It is early morning – getting up time. We see the cityscape, coming awake, sounds of the city. We home in on the streets and houses. We see the houses where the healthcare professionals live, diverse backgrounds. Their sense of character is identified by home circumstance. They are rushing to get ready for work. Appearing at their front doors, backing out cars, catching the bus, cycling . . . hustle and bustle of the commute, music, traffic news, checking mobile . . .

SECTION B

Arriving at work at the other end of their journeys at the medical centre, We follow them from the car park through the reception, waiting room, corridors to get the geography of the place, greetings, coats off, computers on, a day’s work ahead, they reach their professional spaces though undefined by role. We are never close to or directly involved with a patient, we are focusing on the medical professionals, and we are eavesdropping on the medical centre, camera’s point of view style.

SECTION C

It is the start of the day in the practice, a quiet start, with the waiting room soon filling up, in the background the receptionists are taking calls, making calls . . . we wander around, eavesdropping, point of view camera, moving here, moving there . . . getting the feel of day in the life of the medical centre.

All the action from here on takes place in the consulting rooms and public spaces of the medical centre, and each of the 6 themes becomes a 1-2 minute approx. section spread across these locations with asides, conversations, and turns to camera, as they pass each other, chat over coffee, get frustrated, etc. which we eavesdrop upon. We add in looks, pauses, observation, but all the dialogue is taken from the research data words.
DINUSHA
Some say “This is the worst pain I’ve had in my whole life” without any real sort of physical signs of pain so it’s really tough; we have a complex job in assessing that.

Sometimes I could have a patient sitting there and saying that they are hurting, 10 out of 10, and they are sitting like you and I

JOHN
It is not clear to me why he is the way he is . . . this catastrophic pain and what he is telling himself about it . . . but there is always a little bit . . . of concern - am I being manipulated, is this really real?

You don’t always know how to verify their complaints. You feel somewhat exploited. It is a very unpleasant feeling.

RACHEL
Sometimes we say ‘oh she came in with back pain but I don’t think she’s really in pain’ . . . but really even if somebody is in pain and distress, it doesn’t always have to be in how they present themselves . . . that doesn’t mean she is not in pain.

I hate to say it . . . but I used to be one of the people that used to say, ‘Oh, well, they are probably just wanting attention.’ But I’ve changed in that matter. People are in pain, and it’s not just to get attention.

ROSS
Pain is so subjective and so that’s where the difficulty lies . . . I find it hard to say how someone’s pain can be judged by someone else . . . You have to show a patient you’re empathetic to him. There is a pain. Pain is real.
ACT 2: NAVIGATING JUXTAPOSED MODELS OF MEDICINE

DINUSHA
Being able to track something gives me more comfort than going by what you’re telling me . . . because I like to see proof . . . You want to be convinced that you’re treating something and that what you’re treating is real.

I will listen to their story, I will examine them and I always say you have got to exclude the physical first that is your job . . . I think we have an obligation to exclude the physical first and not jump into psychosocial explanations because it reduces the patient to being an un-necessary complainer and I don’t believe that they really are.

They don’t seem to worry about other health issues like high cholesterol, that might be real . . . he’s not worried. You know? There are some other issues that he needs to attend to, and he’s not worried. His father died when he was 52. He’s not worried about that.

JOHN
The terminology . . . psychiatric and psychological . . . have a stigma attached to them that is not intended . . . we accept that patients with long term pain will have a psychological component to it but actually labeling it as that. It is a subtlety. If you present the explanation for pain as completely airy fairy psychological, it is up to you, then they are going to go away dissatisfied, so you have got to lead them in gently. If you start from the body . . . then it is not threatening, and you can approach things, like, through the body.

RACHEL
Patients tend to do the rounds of doctors looking for a cure, and to have more tests than is good for them . . . Let’s stop doing tests. Let’s stop sending you to lots of different doctors looking
for a cure, let’s accept, if we can, that this is what is going on and now let’s try and make you better . . .

ROSS
The fact that you tell them . . . that there’s something wrong physically . . . Just that gives you a certain sense of relief.

JOHN
I think giving it a label that actually has no justification I think is misleading to the patient and I actually feel quite strongly about that.

If there isn’t a physiological problem, it doesn’t mean that there isn’t an illness, and if the patient is suffering then we should look at the problem and how we can help.

While we talked . . . many losses came up and I began myself to think about what all this was about in fact, what is this pain? . . . There was a lot of disappointment, where there was divorce and . . . yes, it can’t be purely physiological.

Once a person’s life has fallen apart it’s not so much about the pain and the injury anymore. It’s about all these other things in their life and . . . it’s all these other things that need to be addressed in order to get them and get them back on track.

We are limited by the amount of time with the patient. I know this bad, but talking about pain opens a can of worms.

You focus straightaway on . . . a . . . biological type approach to it. I think some of the psychological feelings get more brushed over perhaps. Very often there is not the space in the consultation.

I think the sort of traditional model of treatment doesn’t allow people to express how pain has affected their whole life, it is very homed in to the particular area of the body and trying to fix it.
**ACT 3: NAVIGATING THE BORDERLAND BETWEEN PATIENT AND CLINICIAN**

ROSS

I recognise that . . . we are trying to promote learning by giving choice and allowing people to get it wrong . . . we learn by doing not by being told what to do. I get that, although it is still hard . . . not to give advice when I see . . . that the advice can be really helpful.

Trying to allow myself to listen objectively and to . . . sit with the fact that actually the patient might want to do something which is wholly unsensible, but allowing that to happen if that truly is what they want.

How do you get them to do what you want?

You want to have a team effort with the patient but you also don’t want to be bullied . . . On days when you are feeling a bit under par they can be the toughest patients to deal with.

I know that this is the correct answer . . . but If we think like this, then you do not allow the patient to participate . . . they become a receiver. But if you share your knowledge . . . really share what you know . . . then you offer the patient an opportunity to think and decide by themselves.

ROSS

If I haven’t grasped what he wants from me, then I’ve missed the problem and I am much less likely to help him. There’s something magical in this. If I’ve understood what the patient wants from me, and he understands what I’m going to do with him, then I have a good chance of succeeding.

Patients have to embrace our suggestion because they are convinced that it is the right one and not because we want them to choose a particular option. If you propose something that is
inconsistent with their experience or knowledge, there is a risk that they will not listen to you.

**DINUSHA**

People feel let down by their doctors . . . The degree of satisfaction is very low . . . basically because we don’t solve their problem . . . They go from one to the other, they find a doctor who gives them hope and they go to him.

I think it’s good to take ownership . . . as soon as someone gets sort of uncomfortable they will shift to a different prescriber . . . And I honestly think it’s like a ship without a rudder and it’s just going round and round in circles.

**RACHEL**

We kept having a difference of opinion: we think that your back isn’t damaged . . . . . He said: I can’t understand that

Sometimes patients refuse to believe that their condition cannot be treated . . . and insistently ask for a series of medical investigations that you, as a doctor, would not perform. In such cases, a medical investigation can work as a therapy because it helps calm the patients and at the same time shows that you listened to them.

There definitely have been times when I have done what they ask me to, just purely because it’s became so antagonistic in a consultation that’s what I’ve done.
**ACT 4: THE CRAFT OF PAIN MANAGEMENT**

**RACHEL**
Everybody is telling me I’m not treating pain well, but nobody is helping me figure out how to treat the pain.

I am not a psychologist . . . I don’t know whether it is fair to expect me to do all of that and I don’t know if anyone is expecting me to. . . Someone bringing out a lot about their past or perhaps a very complex situation . . . we don’t want to say the wrong thing and it be to someone’s detriment ... you don’t want to open this can of worms.

It’s fine saying to a patient yes well you know that is part of the pain . . . you feel depressed with it . . . I don’t really feel I’m at all competent in knowing what to say to try and help them round that.

**DINUSHA**
One becomes more stable as a person over time you no longer believe that you can do everything, that you are able to solve everything . . . Young doctors can have in them, that they believe that they will solve everything. New grads can’t learn all of this, they need a certain number of years, you can’t teach them all of this, there’s so much they’ve got to learn. The way I think about it is If you have a patient who’s not responding the way that you expect, it’s nice to have someone there who can have a look, and see what ideas they come up with......it’s like osmotic learning.

**JOHN**
Treatment has to be tailored to patient’s needs and prescriptive guidelines promoting “one size fits all” is not acceptable.

If you work according to the guidelines, you are constrained in your performance . . . what would be left of your independence,
your own competence, your own practical experience . . . Am I to conclude then that my training was useless.

JOHN
Such a huge heap, such a bundle of paper, such a bundle of characters . . . we have been educated to DO things. So if you give us a pile of papers, who will read them?

Of course, it is not necessary to follow the guidelines exactly; it is more like: this is roughly the approach

In the case of disagreement . . . you can always turn to these national guidelines.
ACT 5: THE CHALLENGE OF DUAL ADVOCACY

JOHN
I mean it's a dual role for us obviously we're responsible for someone's physical health and the second role that we have as a sort of gatekeeper . . . and the two sometimes don't sit very comfortably

It all ends up on our doorstep. It is not only we who face the system – we are mediators of sorts between the patient and the system. Not only must we work with the patient against the system, but with the system as well.

DINUSHA
Every time I send somebody to the hospital they come out with more medication, or injections.

Often I find that they are not accomplishing any more than I was. It’s very frustrating, because if they were easy patients, I wouldn’t have referred them. They wouldn’t have been seeing them.

JOHN
We get a lot of mileage out of slapping each other on the back a little bit. And increasing other members of the team’s confidence by respecting other members of the team, their profile is improved, I think there should be no sort of hierarchy in the team.

If the team sort of echoes the same message and provides richness in terms of their different perspective on it, then I think there’s less confusion for the poor patients and they’re able to follow through on a unified evidence-based recommendation.
ACT 6: PERSONAL COSTS OF TREATING PATIENTS WITH CHRONIC PAIN

DINUSHA
I’m a scientist; at least I like to have objective things, numbers, data, pictures, lab results. . . Unpleasant emotions . . . can cause as much suffering as physical pain. What, then, is pain? And can it be quantified or even identified as a pure sensation?

The problem is that there is no objective test to diagnose these patients. How did we fail them? It’s awful, and I think it’s demoralizing when you leave people in pain. That’s just so disrespectful. I mean you’re supposed to be a doctor, you’re supposed to relieve pain and suffering, and you ignore the pain.

RACHEL
You become a doctor not to tell people I can’t do anything, I can’t find anything, you have this perception of yourself as well that you’re going to sort it out and if you can’t sort it out, it’s frustrating. What’s the point of you being there?

No matter what I do, I can use prescription pad and pen and do sleight-of-hand feats and stand on my knees and perform conjuring tricks! Nothing helps!

ROSS
We forget how much chronic pain affects the patient. They lose their jobs, they have emotional stress and depression.

They need understanding and compassion and you can’t give them that in a pill.

JOHN
I try to listen to the person . . . sort of empathise . . . . trying to see where that person was coming from but not letting it become too personal . . I've used the phrase detached empathy.
JOHN

See the consultation as a journey rather than ‘this is my one chance at this and I have to get it all done in one go’ . . . then you both have a more realistic expectation of where things are going to take you. It's about moving away from that place of stuckness and creating a little bit of momentum . . . you know when you’re pushing a car . . . it's the first movement that is the hardest one, and then it builds.
APPENDIX 2: LIVING WITH CHRONIC PAIN

The following pages include 100 Findings from 15 qualitative evidence syntheses exploring what it is like to live with chronic pain.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with chronic pain.
Activities 6 & 7 will give you some ideas on how to use these cards.
1. **BUNZLI 2013[168]: The Social Construction of chronic low back pain - Participants in the studies held biomedical beliefs about their back pain.**

If my doctor does not give me a medical diagnosis, no one will believe or support me. I won’t be eligible for social welfare. If I don’t have a diagnosis, how can I get better? I am really annoyed with my doctor because he is not telling me what is wrong with me. I need to find someone who will give me a diagnosis so that I know what to do. I am disenchanted with the medical system but I live in hope of a diagnosis and cure in the future.

2. **BUNZLI 2013 [168]: Psychosocial Impact of the Unpredictable, Omnipresent Nature of Pain - The nature of pain.**

The pain is there day and night and disrupts everything that I do. It is unpredictable and I am always uncertain about what I can and can’t do. I am dependent on my family and feel hopeless because I can do nothing in return. I am no longer able to have an intimate relationship with my partner. My role in the family and at work has changed and this can make me angry and short-tempered.


I feel stigmatised because of my pain. The media paint a negative picture and people think that we are frauds and a burden on social welfare. Health professionals think that we are difficult or demanding or that we are just trying to get pain drugs. Employers think that we are lazy and unreliable and don’t want to give us a job. This feeling that we are bad or mad threatens my sense of self.
4. **BUNZLI 2013 [168]: Coping with chronic low back pain (Strategies to control the “assault on the self”)**

At times I avoid social situations because I don’t want to let anyone down. I also know that there is a social stigma about chronic back pain. Social withdrawal protects me from being seen as someone that I am not. However, it also means that I am isolated and this makes me feel low. I try to fight against the pain and sometimes I do too much. However, I have commitments and some things I have to do whether I have pain or not.

5. **BUNZLI 2013 [168]: Coping with chronic low back pain - Strategies to control the omnipresent, unpredictable nature of pain**

Pain is always present and unpredictable. I must be careful what I do and pay careful attention to what my body is telling me. I am very cautious about certain movements and avoid certain activities. Although I will take pain medication, I don’t want to become dependent on pills. I also need to think about the side effects which make me feel like I am not quite myself.

6. **BUNZLI 2013 [168]: Coping with chronic low back pain (Acceptance)**

Despite the “battle” to control my pain and its assault on my sense of self, I know that I need to learn to live with the pain. Although acceptance can fill me with despair, it can also be a turning point to a more hopeful outlook of the future.

7. **BUNZLI 2013 [168]: The Social Construction of chronic low back pain (Strategies to gain credibility)**

Because others doubt my experience, I need to show that I am a trustworthy and credible person who is not to blame for having pain. I need to balance looking too ill with looking ill enough to be credible. This is very difficult because my pain fluctuates unpredictably. Sometimes I just avoid people to avoid their scrutiny. If I compare myself to other people who have pain I can see that my pain is real. Some people just pretend to have pain.
8. **FROUD 2014 [166]: ACTIVITIES**

I can’t do the things that I used to do around the house and have had to give up things that I enjoy.

9. **FROUD 2014 [166]: Changing outlook**

I am afraid that I will lose control of my life and future. I feel overwhelmed by emotions. I want to see what is wrong on an x-ray. It makes me angry when clinicians all tell me different things, particularly if they say it is all in my head. It is confusing. It is much easier for me to move on if I have an official diagnosis. Sometimes I start to doubt the diagnosis they have given me. Since I began to realise that I might not get a diagnosis or a cure, my outlook has begun to change.

10. **FROUD 2014 [166]: RELATIONSHIPS**

I have always been sociable person and want to join in with things. However, my relationships are suffering and I am becoming isolated. Intimate relationships have become difficult. I feel dependent on others but they are not always available. Although I need support, I tend to avoid those close to me when I am in pain. I avoid social events because I don’t want to spoil things for everybody and because I find it physically difficult to keep going. I also don’t want people to see me as I am now. If I join in with things then people won’t believe that I am really in pain.

11. **FROUD 2014 [166]: Stigma**

Family, friends, colleagues and health professionals don’t believe me because I have no proof. If I had a diagnosis people would believe me. Sometimes I even question myself. As there is no explanation for the variability and unpredictability of my pain it makes it even more difficult for people to believe me. At times I make myself look worse so that people believe me. At other times I just avoid people so that I can avoid this.
12. *Froud 2014 [166]: WORK*

I am worried that I will lose my job and this will make things financially difficult. I can’t afford to take time off work or go part time. I don’t tell anyone at work about my pain because I might lose my job. At times I pretend I am taking holiday rather than admitting to being off because of pain. People will think badly of me if I keep taking time off sick. I sometimes carry on and do jobs that I shouldn’t but worry that if I can do things then people won’t believe that there is anything wrong with me. Perhaps I am no longer any good at my job.

**CHRONIC PAIN**

13. *Hopayian 2014 [164]: Necessity of diagnosis*

A diagnosis is important to me even if there is no cure. I want to prove that there is something wrong so people believe me. I want to be certain that there is nothing serious wrong so that I can get on with managing my pain.

**CHRONIC PAIN**

14. *Hopayian 2014 [164]: Recognizing the expert*

My GP does not have the knowledge to treat my pain. I need someone who knows what to do. Medication is not going to make me better.

**CHRONIC PAIN**

15. *Hopayian 2014 [164]: Information*

I need clear and accurate information. I need the clinician to speak clearly and take time to explain things in language that I can understand. Take time to get to know me and encourage me to discuss things.

**CHRONIC PAIN**
17. **HOPAYIAN 2014 [164]: Outcome of care**
When I first had pain I thought that there would be a cure and now I realise I have to learn to live with it. At times I accept that all the clinicians can do is to help me to cope with the situation and to reassure me. Quality of life, rather than cure, is important. At times, I cannot accept that there is no cure and think that the clinician is not committed to helping me find it. There should be cure.

18. **HOPAYIAN 2014 [164]: Personalized care**
I need to be involved in the decisions about my care and my goals. I want the clinician to consider my preferences and plan my care around me as a unique individual with individual needs. I want us to make decisions about me in partnership.

19. **HOPAYIAN 2014 [164]: Process and content of care**
I want a thorough hands-on assessment and this usually will include an x-ray or scan. I think they think it is all in my head or that I am making it up. I want to be treated as an individual.

20. **HOPAYIAN 2014 [164]: Patient-practitioner relationship and interpersonal skills**
I need the clinician to listen and understand the effect that this pain is having on my life and self-image. Show an interest in me as a person and treat me as an individual.
21. HOPAYIAN 2014 [164]: Service matters
It is really difficult to access specialists (e.g. physiotherapy). My family doctor is stopping me accessing specialist services. There are long waiting lists and it costs too much to see someone privately.

22. HOPAYIAN 2014 [164]: De-legitimation
I need to feel that I have been taken seriously: seen, heard and believed. I don’t think people believe me because I look normal and this adds to my suffering. I need a diagnosis so that people believe I am telling the truth.

23. MACNEELA 2015 [163]: Learning to live with pain - Attitudes to collaboration
At times I need someone to push me so that I get on with things but I don’t always want to be pushed too hard or far. At times I just want to be told what to do. At times I want to take a more active role.

24. MACNEELA 2015 [163]: The person as patient~unsatisfying relationships with health care - Disappointment with health care
I am frustrated with my medical treatment. My family doctor lacks knowledge and skills in pain management. I don’t think my healthcare is individualised or personal.
25. **MACNEELA 2015 [163]: The undermining influence of pain - Discomfort, distress, and loss**
I am in constant severe pain like someone is pulling me apart. There are good and bad days. Pain threatens every aspect of my life; I can't sleep; I can't move; I can't look after myself; I cannot fulfil my role; I can't do the things I have always been able to do. My life is impoverished and confined.

26. **MACNEELA 2015 [163]: A disempowering impact on all levels - Family strain**
Pain has affected my personal relationships. I have lost the sense of trust and mutual understanding. I feel dependent on help from those close to me and this is causing negative feelings between us even if they are sympathetic. I may lose my partner because of this. Pain is also putting a strain on the family as I can't do the things that I used to do and that my family expect me to do.

27. **MACNEELA 2015 [163]: A disempowering impact on all levels - Hopelessness**
Why me? Why have I got this pain? I feel weak and emotional. At times I feel angry and depressed and just want to end it all.

28. **MACNEELA 2015 [163]: A disempowering impact on all levels - Loss of job and lack of money**
I may lose my job because of pain and will not be able to support myself or family. Work is really important to my sense of self. I can't manage my normal role at work and I might even damage my back further at work. My work colleagues are not supportive.
29. MACNEELA 2015 [163]: the person as patient—unsatisfying relationships with health care—Listening and communication

My clinician is not listening to me. I need them to listen, even if they can’t come up with a cure. I need someone to listen. I need to be involved in my care decisions.

30. MACNEELA 2015 [163]: The person as patient—unsatisfying relationships with health care—Needing confirmation

The label ‘chronic back pain’ is too vague and does not make it seem real to me or others. I need to know a specific cause or no one will believe me.

31. MACNEELA 2015 [163]: Learning to live with pain—Self-management practices

I will just make some adjustments and avoid the doctors. I will try and ignore my pain and continue to fight against it. Others are much worse off than me. I don’t know how long I can continue to ignore my pain. Even if I see a clinician, it is my own responsibility to manage my pain. I know it is important to do exercise and keep active but it is really difficult to stick to daily routines with pain.

32. MACNEELA 2015 [163]: A disempowering impact on all levels—Social withdrawal

Back pain has a stigma attached to it and people don’t believe us. I avoid social situations for fear of being judged badly or being accused of malingering. I can’t really afford to join in with things socially anymore. I am irritable because of my pain and no one would want me around anyway.
33. MACNEELA 2015 [163]: The undermining influence of pain - Worry and fear for the future

My future looks bleak and things may even get worse. Pain has taken over my future. I am worried that I will become dependent on others. I alternate between hope and despair.

34. MACNEELA 2015 [163]: Learning to live with pain - Coming to terms with pain

They have done all that they can for me and I have to keep going in spite of pain. I may feel better at times but there is not real cure. There is no medication that will get rid of my pain completely. I need to rely on myself. It is really difficult to come to terms with the thought of living with pain and keep a sense of purpose.

35. MACNEELA 2015 [163]: A disempowering impact on all levels - An oppressive intrusion on the self

Pain assaults my sense of self. It is an intruder. The good side of me is constantly struggling against the bad side. My body is unreliable. I am embarrassed about being the type to have back pain. I also feel that I am to blame in some way.

36. MONSIVAIS 2011 [161]: Pain-Related Behaviours Patients May Exhibit

If clinicians are not taking my problem seriously I have to make sure that I look ill, but I worry about complaining too much. I don’t tell my clinician everything because I want to stay on good terms with them. I can’t stay in a healthcare system that does not acknowledge me or my problem.
37. MONSIVAIS 2011 [161]: Beliefs and Expectations about Appropriate Treatment

I expect the clinician to give me a diagnosis, treatment and a cure for my pain. My family doctor needs to refer me on to a specialist because they are not a specialist in pain. If I do not have a diagnosis how can they treat and cure my pain?

38. MONSIVAIS 2011: Appropriate Treatment Expectations Generally Not Met

I am trapped in the health system that is not doing anything effective to help me. I don’t feel understood or believed. I need clinicians to confirm that my pain is real. I need a diagnosis so that people take me seriously. I can’t get help or benefits unless they prove that I have ‘something’ and I will need to keep going back into healthcare system in order to prove this.

39. MONSIVAIS 2011 [161]: Specifically Requested Needs

I expected to be told more about what is wrong with me. I expect my clinician to be caring and treat me with dignity and respect, not like I am weak or crazy. It helps me to know that they believe me and makes me feel stronger and more confident. I am frustrated to have an invisible illness and I don’t seem to be able to talk to anyone who cares.

40. PARSON 2007[160]: Beliefs About Pain Causation and Influences on These Beliefs

My family doctor seems to focus on my pathology and not on me as a person.
41. **PARSON 2007[160]: patient education**

I am not being given clear or practical advice to follow

42. **PARSON 2007[160]: Gaining Trust through Diagnosis and Referral**

I want to be believed not treated like a malingering. A diagnosis is important to my credibility. I know the doctor is taking me seriously if he sends me for a test.

43. **SIM 2008[159]: Searching for a diagnosis - Receiving a diagnosis of fibromyalgia**

It was a relief when I got a diagnosis of Fibromyalgia as people believed me and I knew it wasn’t life threatening. However, I now realise that this diagnosis does not bring effective treatment or cure.

44. **SIM 2008[159]: Experience of symptoms - describing pain**

There are no words to express my pain to others. The pain is invisible. No one understands what I am going through. This makes it really difficult for me to cope with it.
45. **SIM 2008[159]: Experience of symptoms - Fatigue**

The fatigue is worse than the pain. I am constantly weary. It is impossible to maintain relationships and to do the things I have to because I am so tired.

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46. **SIM 2008[159]: Legitimacy**

Because I look healthy people don’t believe me, particularly if I remain active. I have loads of negative test results and people question my credibility because of this. I keep my diagnosis a secret and try to appear 'normal' because of the stigma of having an illegitimate illness. Doctors lose interest in me, or don’t believe me, because I don’t have a diagnosis.

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47. **SIM 2008[159]: Experience of symptoms - pain**

I cannot explain or get to grips with my pain. It remains ambiguous: it seems very specific at times yet hard to pin down; constant yet varying; when I am active and also when I rest; effecting mundane activities yet globally devastating; I am well yet ill; it affects my body and mind; it is worrying yet nothing to worry about; elusive yet powerfully felt; predictable yet unpredictable; pain affects body and mind yet creates a chasm between my body and self.

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48. **SIM 2008[159]: Searching for a diagnosis - Post diagnosis**

I tried all sorts of interventions after my diagnosis of Fibromyalgia but not relief or understanding has come. I will keep looking for something that will work.
49. SIM 2008[159]: Searching for a diagnosis - Pre-diagnosis

I have gone to so many clinicians looking for a diagnosis. What if it is life-threatening and someone has missed it? Do they think it is all in my mind if they can’t find anything? I resent being told that there is nothing wrong with me or that it is all in my head. I want a diagnosis

50. SIM 2008[159]: Experience of symptoms - Psychological problems

I am depressed, my sleep disturbed and I cannot think straight. I am losing control of what I was. I will never get or keep a job.

51. SIM 2008[159]: COPING (RE-EVALUATION OF LIFE)

My life has really changed because of pain. I try to maintain my normal role but his has put a strain on my relationships. I can’t do all the things I used to do. I feel isolated, lonely and bereft. I have lost who I was. In some ways this has made me discover what is truly important to me. However, I try not to think about what the future holds and live one day at a time.

52. SNELGROVE: Relationships with significant others (Relationships with family and friends)

Although my family and friends can support me, it is difficult to maintain a normal family life. I cannot fulfil my role. I feel guilty and angry about this. I feel like a burden and that I am holding people back. People lose sympathy because there seems to be nothing physical wrong with me. Friends, family and health professionals are judgemental and I am not being treated fairly.
53. SNELGROVE 2013 [158]: Relationships with significant others (Health Professionals and the organisation of care)

A want a mutual partnership with my HCP where I feel safe. I need to be recognised as an individual. It does not help when professionals think that I am crazy or lazy, or that I am trying to get benefits. I don’t think they believe me as they are not doing anything. I feel stigmatised. I try to look like I am in pain so that they believe me. I need to pass a medical test. I am struggling to be taken seriously. I will continue to search for a diagnosis to support my legitimacy.

54. SNELGROVE 2013 [158]: The impact of CHRONIC LOW BACK PAIN on self

My pain is debilitating and I have undermined my positive and valued sense of self. It is persistent, disruptive and distressing. I have lost my previous life and I am a different person. I don’t like what I have become and I feel negative towards myself and other people. I am old before my time and have lost my dignity. I feel ashamed and helpful. I have low self-esteem and I am socially isolated. I can no longer fulfil my usual social, family and work roles. My body has become like an alien, separate from my self. Other people judge me and are unsympathetic.

55. SNELGROVE 2013 [158]: Coping with CHRONIC LOW BACK PAIN:

My pain is not going away but I am trying different strategies to try and cope with it. Staying in bed or lying down all the time is not helping. Drinking too much alcohol does not help. It is having an impact on my self-esteem. I avoid things and people so that I don’t lose face. I am becoming isolated and depressed, although I try and be stoical and appear normal.

56. SOUZA 2011 [179]: Expectations regarding the doctor-patient relationship

I am frustrated with my doctor and the healthcare system. I need to know what is wrong with me. The doctor downplays my problems. They focus on the physical symptoms and not on me as a person. I find it difficult to describe my pain and I don’t understand what they are telling me. I don’t think they believe me.
57. **SOUZA 2011 [179]: The importance of determining the cause of the pain**

I really need to know what is causing this pain and I will continue to look for a diagnosis. Otherwise people think it is in my head. Also they may have missed something serious. I don’t need to know the risks of this diagnostic test (laparoscopy); I just want to find out.

58. **SOUZA 2011 [179]: gender issues**

If the doctor can’t find anything they think that there is nothing wrong with me, and that this is normal. This pain must be normal and I should just put up with it. It’s just my hormones and is normal for women.

59. **TOYE 2013 [5]: affirm self**

It is a struggle to be me. My body has become alien and malevolent. I am struggling to hold onto a sense of self, although I know that I am irreparably altered. I cannot fulfil my normal roles and I feel guilty. My self-esteem is low. I don’t want to be a burden on others and therefore hide my pain. This can be a problem because if people can’t see my pain then they don’t believe me.

60. **TOYE 2013 [5]: Moving forward alongside my pain (Becoming an expert)**

I am the expert and am becoming less reliant on healthcare. I know my body and I am confident to make my own decisions.
61. **TOYE 2013 [5]: Moving forward alongside my pain (Being part of a community of others)**

I feel like part of a community of other people with pain, where I am valued and treated with dignity. However, I am not like all people with chronic pain.

62. **TOYE 2013 [5]: Construct an explanation for suffering**

Pain does not fit into a medical category or diagnosis. I need a diagnosis or no one believes me. I feel worthless and ashamed. Doubt pervades my experience of pain.

63. **TOYE 2013 [5]: Prove legitimacy**

I need to behave the right way in order to show that my pain is real. I struggle to find the right balance between looking too ill and not looking ill enough. I hide my pain so that I can appear normal but then people don’t believe me. I try and make people think that I am a good person who is not to blame for this pain.

64. **TOYE 2013 [5]: Moving forward alongside my pain (Listening to and integrating my painful body)**

I am listening to my body and doing what it tells me to do. It is my body and I am working with it.
65. TOYE 2013 [5]: Negotiate the healthcare system
I feel like a shuttlecock in the healthcare system as I am referred back and forth. I don’t want to keep going to the doctor because they don’t seem to do anything but I am trapped in the system. There may be some hope of a cure. I need to feel valued and treated with dignity in the system. I want a medical diagnosis but I also need to be treated like more than just a body.

66. TOYE 2013 [5]: Moving forward alongside my pain (Realising that there is no cure)
I am no longer looking for a diagnosis as this has stopped me from moving on. I am gaining a new sense of who I am rather than thinking about who I used to be.

67. TOYE 2013 [5]: Reconstruct self in time (construction of time altered — unpredictable now and future)
My sense of self now and in the future has been altered by pain. My pain is so unpredictable that I can only live in the moment. My life is dominated by caution and I can no longer be spontaneous. My plans and dreams are irreparably altered and my life focused inwards.

68. TOYE 2013 [5]: Moving forward alongside my pain - Redefining normal
I am redefining my sense of me. I am different but still me. I can still enjoy life even though I feel a sense of loss for my old self.
I know that I don’t have to hide my pain from others. I need to let people know my limitations. I don’t need anyone’s approval. I will limit the demands placed on me.

Health professionals do not validate my experience. They tell me it is just normal and that other women cope with it. They won’t refer me to a specialist. Some say it will be OK if I get pregnant. They are not hearing my story.

I need a medical explanation so that I can be sure there is nothing serious and so that people believe me. I knew that there was something wrong when they finally found it (endometriosis). I am cross they took so long to find it. However, even though I have a diagnosis this doesn’t mean there is a cure.

I know this is real because I know my own body and there are other people like me. I am not alone with this. I have talked to other women about this shared experience.
73. **TOYE 2013 [5]: Elevation of experiential knowledge**

I am the expert because I am the one with the experience. I am not going to do what the doctor says. My doctor doesn’t know what my experience is like.

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74. **TOYE 2013 [5]: Social construction of ‘pathology’ vs. normal**

I am struggling to know what is normal and what is pathological. They tell me it is normal. Other people just seem to get on with it.

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75. **TOYE 2013 [5]: Relentless and overwhelming pain**

My pain is horrific and overwhelming. I am crippled by it. I am on an emotional rollercoaster. I feel angry, depressed, guilty, bereft, anxious, frustrated, afraid and full of dread.

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76. **TOYE 2013 [5]: A culture of secrecy – managing the disclosure of pain**

Everyone thinks this is a woman’s problem. I keep it private. No one talks about menstruation. Is it just normal? I have no one to talk to and compare with. I am isolated by my pain. Because I don’t have a diagnosis no one believes me. It is difficult to balance the tension between hiding and showing pain. People will just think I can’t cope like other women can. I am embarrassed and ashamed and this makes me feel depressed and isolated. I don’t want people to get fed up with me. I will just put up with it.
77. TOYE 2013 [5]: Threat to self
My whole life and future as I know it has been disrupted. I am struggling to lead a normal life and fulfil my expected roles. I always wanted to have a family. I am no longer me. I am not what I used to be. I used to be healthy. My body has become a threat to myself.

78. TOYE 2013 [5]: Unpredictability and future
My symptoms are random and uncertain. I can’t make plans for the future. I am powerless. I might not be able to have a family.

79. FU 2016 [165]: Effective communication
I need to be listened to, understood and encouraged. I need to know why I have this pain. Effective listening is important to understanding experience and desired outcomes. Listening indicates mutual respect and enabling partnership.

80. FU 2016 [165]: Healthcare service
I want easy and quick access to health services, and follow-up contact or review sessions. I need enough time to get the support that I need.
81. FU 2016 [165]: Individualised care

I want individualised care and care delivery. Some self-management strategies that are recommended are not achievable. I can’t afford to go to the gym.

82. FU 2016 [165]: Information delivery

I expect to be given information about pain, including diagnosis and prognosis, treatment processes and self-management strategies. Even though this information will not make my pain better, it is good to understand what was wrong in my body.

83. FU 2016 [165]: Patient involvement

I know that I must live with the pain and that there is no cure was available; I will want to be involved in my treatment. I want to learn new skills to manage the pain myself and work in partnership with my HCP. I am usually happy to agree with my HCPs decisions and follow their lead. I prefer an individualised, communicative decision-making approach in partnership with my HCP. There are times that I prefer to make my own decision.

84. FU 2016 [165]: Mutual understanding

I need my HCP to understand my pain and life situation. I need the HCP to give me an explanation and teach me how to manage my pain. I feel understood if the HCP listens and believes me and lets me participate in discussion and decisions about my treatment. Mutual understanding and communication is central to building partnerships and trust.
My health professional's should help me find a way to cope with my pain and provide emotional support. Being friendly, empathic and sensitive to my needs is important. I value a good professional manner. Listening to my concerns and understanding my situation, giving information and seeking solutions for me are all important. At times my HCP does not act like this and I am sad that I am being treated as a number but not an individual person.

The unpredictability, relentlessness and fear that pain will progress make me feel that I cannot continue at work. The struggle to be seen as a good worker and to maintain my commitments is taking its toll. I am struggling to balance work commitments with other essential roles, leisure and social activities. I am going to have to leave work because I can’t find this balance. Some people have more flexible working arrangements. I can’t rely too much on my colleagues in this harsh financial climate.

Work is a place, where I have felt respected and valued; it makes me what I am. I struggle to maintain a positive image. I don’t want to be seen as a “bad worker”. I struggle on and rely on my colleagues. I use annual leave rather than be off sick. I may be too risky to keep on. I am treated like a number and feel let down and betrayed by my employer. I no longer feel that I am integral to the work place. I may have to leave work if I don’t have flexible working arrangements.

Relationships with colleagues are becoming hostile. They don’t understand me and think that I am “work shy”. There is a culture of scepticism and mistrust regarding chronic pain that is promoted by media stereotypes and benefits agencies.
89. TOYE (2016) [157]: The battle for legitimacy

I am in a battle to prove that I can no longer work because of my pain and that I need sickness benefits. Critical decisions about my life are outside of my control. Choosing to leave benefits and return to work is risky because it is so difficult to gain benefits in the first place. I wouldn’t risk leaving benefits for some jobs. Benefits officers lack the skills and understanding to help me get back to the right job. Because of my pain I am stuck in a low income job with no opportunity for retraining.

90. TOYE (2016) [157] the system does not facilitate RTW

The system is against my return to work. I have to go to the doctor to get a diagnosis for time off work. This may affect my future employment or alienate me from work colleagues who have to shoulder the work load. A compensation claim would also alienate me from colleagues. I take holiday rather than be certified sick. There is no dialogue between employers, occupational health and health services and this makes it difficult to get back to work. My doctor just issues a sick note.

91. MENGSHOEL 2017 [162]: personal credibility & dignity

I live with invisible pain in the face of negative attitudes. I struggle to maintain credibility and hide my FM. I struggle to convince my doctor that FM is was not imaginary. I feel blamed and accused of being 'lazy or work-shy'. If I don’t get better people question my character and motivation. I feel like a 'difficult patient'. I feel humiliated. FM is stigmatised and people think that it is: hypochondria, ‘women’s disorder’, or hysteria. Sometimes I begin to question the reality of my own experience.

92. MENGSHOEL 2017 [162]: Questioning the FMS diagnosis and medical authority

At first, I accepted my fibromyalgia diagnosis as it validated my pain. Now the diagnosis seems ‘empty’ and doesn’t help me understand or treat my pain. I have become sceptical. My Dr explains away all my symptoms, even without an examination; it is 'a waste-basket' diagnosis to keep me quiet. I have started to question my doctors’ competence. My faith is in medicine is being replaced by faith in my own expertise and judgement.
The diagnosis legitimises my illness to those around me and counters scepticism and negative attitudes. It allows me entry to ‘the sick role’. At times I hide my diagnosis for fear of losing my job, or because of negative attitudes from colleagues. I also face scepticism at home. The diagnosis does not convey a clear meaning to others, nor help to make others understand what is wrong. You can’t look so well and be sick. Fibromyalgia is invisible.

I need to make sense of my pain and fatigue. I went to the doctor when I could no longer cope. I have been through a merry-go-round of consultations. Hope has been replaced by disappointment. HCPs think it’s psychological. At first I was relieved that I did not have an organic disease and that I wouldn’t end up in a wheelchair, and that I was not mentally ill. I was given a name to explain my suffering and tell others.

My initial relief of getting a diagnosis is fading as I sadly realise that it does not mean a cure. My search for a diagnosis has been replaced by a trial-and-error process to find an effective treatment. My Dr has lost interest in me and trivialises my pain as a normal part of life. They think it psychological. They are sceptical that it is ‘real’. This makes me confused and means I have lost faith in medicine. I have to actively resist being viewed as a malingeringer.

Pain is a bodily experience, either local or all over. My body is an impediment that had to be overcome. My body does not work and is incapacitating. My body is an obstacle and confines me. I have to persuade my body to do what I want; it is unwilling.
**97. CROWE 2017 [167]: Keeping going**

I try to keep going despite the struggle with pain. This means I have to accept pain as part of my life. I have found ways to live differently and to accommodate my pain. It is a balancing act between: hope/resignation, dependency/withdrawal, past/present self, suicide/fight, normal/different. However there are others who are worse off than me. I am finding some meaning in my experience.

**CHRONIC PAIN**

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**98. CROWE 2017 [167]: Invisible but real**

I am being disabled by invisible pain. I keep it to myself because I don’t want to bore others and they won’t believe me. Health care professionals don’t believe me. People don’t believe me because my pain cannot be seen or measured. Even though it is invisible, my pain is real.

**CHRONIC PAIN**

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**99. CROWE 2017 [167]: Disrupted sense of self**

I have become a different person and have to redefine what is normal. My body and my self have become separate.

**CHRONIC PAIN**

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**100. CROWE 2017 [167]: Unpredictability**

I cannot control my pain or predict when it will occur. I need to be ever vigilant, be prepared and always calculate the risk of engaging in certain activities. My pain seemed illogical, incomprehensible and overwhelming.
APPENDIX 3: RHEUMATOID ARTHRITIS

The following pages include 76 themes from 9 qualitative evidence syntheses of what it is like to live with Rheumatoid Arthritis.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with Rheumatoid Arthritis. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **STACK 2013 [169]: emotional impact**

I feel depressed and think about killing myself. I am angry. I am afraid. I don’t know what to do because symptoms are insidious and fluctuating and vague. This is very upsetting. Perhaps it is even more frightening when it comes on quickly. RA diagnosis was a relief and validated what I was feeling. “I was relieved to know that it was not in my mind [laugh], that I was not going crazy”.

2. **STACK 2013 [169]: fatigue and weakness.**

I feel weak, weary and “flu-like”. Fatigue overwhelms me. I cannot lift a tray. This is made worse because I cannot sleep.

3. **STACK 2013 [169]: pain and tenderness.**

My symptoms were vague; just “everyday aches and pains”. It came on gradually but has become severe and I can no longer do things. For some, pain comes on rapidly and severely and people will go to the doctor straight away. Sometimes pain can go away or migrate to other areas.

4. **STACK 2013 [169]: joint stiffness**

My joints feel stiff.
5. **STACK 2013 [169]: swelling.**

My joints are “puffed out”. I have pain. It has crept up on me. It started as trivial and is now severe and has a significant impact on my function.

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6. **STACK 2011 [170]: The early RA symptom experience**

At the beginning I sought help when my symptoms (pain, stiffness, swelling and fatigue) got very severe. I was worried because they came on very suddenly and everyday tasks were dramatically affected so I went to the doctor very quickly. For some, the symptoms come on slowly and can be vague or transitory so it is difficult to pinpoint when it started. A change in symptoms can help people to know when to seek help; or when it just goes on too long.

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7. **STACK 2011 [170]: Accessing health services and attitudes towards healthcare professionals**

I don’t have confidence in my HCPs competence and knowledge so I don’t want to go. They might blame me for my illness because of my lifestyle. I am a bit overweight and like a drink. They might dismiss my symptoms OR make me feel guilty or like I am a ‘hypochondriac’. Also I don’t want to waste their time. Some people go quickly to the doctor when they have symptoms; they may have had better experiences.

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8. **STACK 2011 [170]: Making sense of early symptom experience and prototypes of RA**

I didn’t know anything about RA before I got it. I might have gone to the doctor sooner. Everyone knows about cancer & heart disease. They don’t think joint problems are serious. Is RA actually an illness; what do I do; can anything be done; Is it just old people that get it; is it caused by ‘wear and tear’? It has been creeping up for ages. I don’t need help. Is it caused by stress in my life; work; injury; childbirth; ‘overdoing it’? It might just be temporary. Is it related to other illness or osteoarthritis? I didn’t think it was RA. I have no family history so it can’t be that.
9. STACK 2011 [170]: Minimising the impact of symptoms

It is normal ‘aches and pains’ for someone like me (age, gender, life circumstance, etc.). I will ignore it and get on with my normal daily activities. Other life events get in the way of going to the doctor. I am healthy and there is nothing wrong with me. I can’t possibly deal with anything else on top of what I have to deal with already. I am not going to admit that this could get worse or be permanent, and I don’t want to have treatment. However, if it disrupts my daily activity I cannot ignore it. At first I will make adaptations but I may need to seek help.

10. STACK 2011 [170]: Speaking to others, gathering information and seeking alternative treatments

It has come on very slowly so I don’t need to rush to the doctor. I ask my family and friends before I go to the doctor. My partner insisted that I seek help. My friend said that I might have RA. My friends have suggested different remedies so I haven’t gone to the doctor yet. I feel a bit isolated because people are not taking it seriously. I hide it from family and friends because they will think I am a ‘moaner’. People are not very empathetic. My RA is invisible so I don’t have to tell people.

11. LIN 2011 [171]: Bolstering Courage

Finding some energy will help me have the courage to face life challenges.

12. LIN 2011 [171]: Bolstering Courage - 1. Having confidence and optimism in the face of uncertainty

I face the future with the optimism and self-confidence that I have gained from past experience. This is integral to my feeling of well-being. Nothing gets me down because there is always so much more to be thankful for.

Being responsible for looking after my family gives me inner courage and strength. I am determined. I never admit defeat, and have the courage to adapt to my RA.


Keeping hope that I will recover and having faith in medical research helps me to be positive.

15. LIN 2011[171]: Bolstering Courage - 4. Strengthening the will to live

I identify with, and am inspired by, the bravery and accomplishments of others with RA. Caring for each other encourages us to listen and be empathetic to others. My family and partner are an important support. HCPs can also support my well-being. My faith is a source of strength.

16. LIN 2011[171]: Reframing the Situation

I can help my pain by changing the way that I think.
It helps to think differently about my self-worth: don’t think that you are a failure because you can’t do the things you used to do; think about the positive changes in your life; focus on personal growth through adversity; think positively about yourself and your body; don’t worry about what others think; focus on your personal needs.

Be altruistic and make a contribution that will help other people who are suffering. This will give a sense of meaning and purpose.

Things aren’t as bad as they are for some others. Think positive. Recognise negative feelings and do something about them. Focus on positive changes in your life. Transform the meaning of RA.

I want to have the choice about taking DMARDs, “Let me have the choice that I want to be treated aggressively . . . Don’t take that away from me.”
21. *Kelly 2017* [172]: Maintaining control - 1. Minimizing lifestyle intrusion:

I want to have the choice to take DMARDs so that I can minimise the impact of symptoms on my life. I need information to help me make the decision. I want to be involved in decision on how to administer DMARDs.

**Rheumatoid Arthritis**

22. *Kelly 2017* [172]: Maintaining control - 2. Complete ownership of decision:

I have the right to make the final decision about taking biologic and conventional DMARDs and want comprehensive information. The doctor needs to be explicit about the potential effects of DMARDs.

**Rheumatoid Arthritis**

23. *Kelly 2017* [172]: Maintaining control - 3. Taking extreme risks:

I want to keep in control of RA and am willing to accept the risks of complications such as organ damage or low platelet counts. I am going to continue taking them even though I have been told not to. I would “kill for” DMARDs.

**Rheumatoid Arthritis**

24. *Kelly 2017* [172]: Distressing uncertainties and consequences

I am worried that DMARDs are not safe and don’t know if they work. “My orthopaedist said: “arthritis patients actually have 2 diseases, that is arthritis and methotrexate”; I have always remembered that.”

**Rheumatoid Arthritis**
25. KELLY 2017 [172]: Distressing uncertainties and consequences

Doubting efficacy: I feel a bit vulnerable. Like a guinea pig trying out different medications. I don’t know if it is the medication working or if it is just getting better on its own.

26. KELLY 2017 [172]: Distressing uncertainties and consequences

Conflicting and confusing advice: I don’t trust what I am being told, or am confused, because I have not been given enough information or am get conflicting advice about DMARDs. This worries me.

27. KELLY 2017 [172]: Distressing uncertainties and consequences

Prognostic uncertainty with changing treatment regimens: I am worried about getting worse or going “back to square one” if I stop or change DMARDs.

28. KELLY 2017 [172]: Distressing uncertainties and consequences

Poisoning the body: DMARDs are very powerful drugs. . . they are even used to treat cancer. They might cause damage, cancer or even kill me because they supress my immune system.
29. KELLY 2017 [172]: Intensifying disease identity 1. Severity of sudden pharmacotherapy

I was really shocked that I had to take such strong medication. They might have serious side effects. It must mean I am seriously ill. I may not take them.

30. KELLY 2017 [172]: Intensifying disease identity 2. Signifying deteriorating health

I must be getting worse because they are increasing my medication. I am worried about medication interacting. I forgot to take my medication because I felt well. It must be a good sign.

31. KELLY 2017 [172]: Intensifying disease identity 3. Daunting lifelong therapy

I despair at the thought of lifelong medication. It reminds me that RA is incurable. If I stop medication, symptoms can come back. I feel dependent on medication and this worries me because of long-term side effects.

32. KELLY 2017 [172]: Negotiating treatment expectations

Emotional response to DMARDs hinged on expectations of impact.
I have failed multiple DMARD treatments and this is having a profound effect on my mood. I feel very emotional and increasingly desperate. Biologic DMARDs are my last resort and is my last hope.

DMARDs have helped a bit but I still have symptoms and flare ups. I hope for future medical advances. I was disappointed as I was expecting an immediate and pronounced response.

I was delighted that DMARDs exceeded my expectations. I am the “healthiest I’ve been in years”. I forget that I have RA. It has lifted my spirits, improved my self-esteem and my relationships.

My family, friends, doctors and nurses can have a strong influence on my experience and decision to take DMARDS. “I feel I have a good doctor and I feel that he was doing what was best for me personally. If it wasn’t for the trust I have in my doctor, then no, I wouldn’t have took it.”
37. KELLY 2017 [172]: Powerful social influences - 1. Partnering with physicians:

My HCP influences my attitudes towards DMARDs. I have confidence if my HCP is knowledgeable, optimistic, and acknowledges my fears and needs. I will believe the information I get if it is consistent. I want to be involved in the decision and given options. Other people prefer the HCP to make the decision.

38. KELLY 2017 [172]: Powerful social influences - 2. Maintaining roles

I will keep taking DMARDS if they allow me to function independently. If not I might stop.

39. KELLY 2017 [172]: Powerful social influences - 3. Confidence in comprehensive and ongoing care

I have had a positive experience of healthcare.

40. KELLY 2017 [172]: Powerful social influences - 4. Valuing peer support

I would like the opportunity to share experiences with others with RA taking intravenous biologic therapy. I have made some good friends during treatment.
41. **KELLY 2017 [172]: Powerful social influences - 5. Swayed by others’ experiences**

I am influenced by other people’s experience of DMARDs.

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42. **KELLY 2017 [172]: Privilege and right of access to biologics - 1. Expensive medications must be better**

It is a privilege to get biologic DMARDs as they are “horribly expensive”. I am really careful I don’t waste any when doing my injections.

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43. **KELLY 2017 [172]: Privilege and right of access to biologics - 2. Right to receive a biologic**

I feel a bit guilty that I have been given biologic DMARDs and others can’t have them. Everyone has the right to biologic DMARDs and it must make people angry if they don’t meet the clinical requirements. We all pay national insurance. It must be cheaper in the long-term as it reduces surgery and time in hospital.

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44. **KELLY 2017 [172]: Privilege and right of access to biologics - 3. Fearing dispossession**

I am not going to tell anyone about the side effects of biologic DMARDs in case they are taken away. They are valued possessions and I worried that they will be taken from me.
45. HULEN 2016 [173]: social connectedness and support

Social support, connectedness and participation are important to me. People don’t know about RA. I want my expertise as a patient to be acknowledged. I need my healthcare professionals to actively listen to me. I want empathy, mutual respect and kindness. I want to make decisions about my own care.

46. HULEN 2016 [173]: Interpersonal and healthcare system interactions

I am in and out of healthcare and health care professional are an important part of my life now. I need this experience to be a positive one.

47. HULEN 2016 [173]: Achieving normalcy and maintaining wellness

Going to work and joining in socially is integral to who I am. It is important to my sense of well-being to find a way to live normally & appear normal to others. I want to ‘forget’ about having RA and enjoy life. I want to do the things that I want and stay in control. I want to be confident and motivated. I want to accept and find meaning in illness. I want to cope with its emotional impact, improve my mood and reduce stress or depression.

48. HOVING 2013 [174]: Meaning of work

Work is important to my self-identity. It keeps me in touch with people. It keeps my mind of my RA. It gives me independence. It is stimulating. It makes me feel good. I also need the money. Work is not so important to some people.
49. **HOVING 2013 [174]: Disease symptoms and effects on work**

I am tired and lack energy. I am in pain. My joints are stiff and I am physically limited. I can’t concentrate or solve problems. Fatigue is particularly difficult for me and other people don’t acknowledge it. RA is invisible and that makes it worse. My symptoms fluctuate and this makes it difficult to plan.

50. **HOVING 2013 [174]: Societal and economic factors**

Losing my job or benefits has financial consequences. I have to pay for treatments. I feel stressed, afraid, guilty and also uncertain that I can keep at work. My financial concerns affect job choices and career prospects.

51. **HOVING 2013 [174]: Emotional challenges**

RA is an emotional challenge. I am afraid, afraid, anxious and uncertain about the future. I feel sad about my limitations. I feel dependent and helpless. I feel guilty if I take time off work. I feel uneasy about asking for help. I am a burden to the organization. My aspirations are not being fulfilled. I will no longer take risks. I find it difficult to set boundaries. My frustration and low mood can make it difficult to deal with colleagues and create a pleasant disposition at work.

52. **HOVING 2013 [174]: Interpersonal issues and choices affecting work and family life**

I need to my colleagues to know and understand about my RA. If you don’t tell other people it is difficult for others to understand and give the necessary support. Communication is vital to understanding and support. Difficulties at work can spill over into home life. Trying to stay at work can be detrimental to my personal life.
53. **FEDDERSON 2017 [175]: social interactions in the performance of three interdependent sub-identities**

It is a challenge to balance work, motherhood and RA. If there is too much pressure in one area it affects the others. If pressure is off in one area, I feel some relief in the other areas. I need flexibility in these areas to stay in control.

54. **FEDDERSON 2017 [175]: social interactions in the performance of three interdependent sub-identities: Living with RA**

The amount that I focus on RA is linked to how severe my symptoms are at the time. The unpredictability of fatigue, the fluctuating course and progression of RA is the greatest challenge to my role at work and as a mother. I try to plan and prioritise so that I can deal with unpredictability and be prepared for bad days. I have not personal reserve for leisure or fun. At times, I try to ignore it, even though I know that it can make things worse.

55. **FEDDERSON 2017 [175]: social interactions in the performance of three interdependent sub-identities: motherhood**

It was a huge pressure when my children were young. I didn’t think that I should have children because of RA. Being pregnant might have made it worse. I might have had to stop my medication as it may have been harmful. RA might be passed on to the child. Now my partner has had to take over household tasks. I feel like a burden but I am grateful for help. I feel guilty because I can’t do things.

56. **FEDDERSON 2017 [175]: social interactions in the performance of three interdependent sub-identities: paid work**

Work sometimes has priority over being mum. Work pressures invade. I don’t have the reserve to do anything more than work, rest & sleep. I use annual leave/free time for appointments and don’t ask for time off. I hide pain. Work is integral to my identity and helps me feel normal. I need the money. Work gives me independence. I need support and flexibility from my partner, employer & colleagues to stay at work.
I don't want people to see my distorted body. How I look affects how I feel. At times I feel absolutely rubbish because I look awful. I had my body. I avoid going out. However, in many ways RA is an invisible illness and it is frustrating and upsetting because others cannot appreciate my suffering.

My biography has been disrupted. I am struggling to adapt to my hanging circumstances. My life story has three chapters: 1. the normal or past life; 2. my body out of sync; 3. finding a new way to live. Getting used to it, adapting, or mastering RA, takes time. It is a biographical process. RA might bring some positive opportunities, for example it had made me rethink my obligations.

I am trying to cope with an unpredictable and non-compliant body. My symptoms fluctuate. I feel that my RA is in control of me. I try to find a balance: energy and fatigue; controlling symptoms through medication and side-effects. At times, I refuse intervention to keep in control. Sometimes I just have to manage alone. Sometimes I can control my symptoms and at other times I can’t. I can remain independent with a bit of help.

I have been redefined by RA. RA gives me pain. It makes my joints stiff and causes immobility. I suffer with fatigue. However symptoms are fluctuating and unpredictable on a day-to-day basis. My normal roles are changed or lost. I feel like a social outcast. I can become emotional at times. It permeates “every sphere of life”. I have lost some independence and fear dependency.
61. CAMPBELL 2011 [177]: Living with the symptoms of rheumatoid arthritis

Pain dominates. My symptoms are variable and unpredictable. I don’t know from one day to the next whether I will be feeling better, worse or the same. I don’t know which part of my body it will affect. Pain is the only certainty. Pain makes me weary and lowers my personal reserve. I dread becoming dependent on others. There are no signs that verify my suffering to others. Pain and fatigue are ambiguous as they are invisible. On top of this is my swollen and disfigured body that adds to my suffering.

RHEUMATOID ARTHRITIS

62. CAMPBELL 2011 [177]: Responses and coping strategies

[Campbell’s study does not support a ‘career’ where RA is mastered. The studies included describe the lives of chronically disabled people trying to cope with severe and debilitating disease].

RHEUMATOID ARTHRITIS

63. CAMPBELL 2011 [177]: Consequences for identity and problems maintaining taken-for-granted activities

My life has been disrupted. RA assaults my body and social life. I have lost my previous life and role. I can’t take things for granted. RA has challenged the normal reciprocity of life. Uncertainty means that I have to continuously monitor and manage my symptoms. Life is fraught with danger. Even everyday objects and events take on an alarming character and make me feel insecure. I am locked into my house.

RHEUMATOID ARTHRITIS

64. CAMPBELL 2011 [177]: Lay perceptions of the causes of arthritis

I need to understand why this is happening to feel a sense of order from fragmentation and loss of control. Is it the weather, my age an injury, diet, infection, bursitis, my shoes, air pollution. Is it my age; is it my body breaking down?
65. **CAMPBELL 2011 [177]: perceptions and experiences of care**

Having some medical knowledge can be a resource and a constraint. There is a risk that treatment will cause me side effects. It is frustrating because I am not getting a good explanation for RA. They are not doing anything. It was a relief to be referred and get a diagnosis.

66. **CAMPBELL 2011 [177]: GENDER**

Roles in my family have reversed and changed the division of labour. My partner is doing too much to help me and therefore eroding my role. There needs to be some flexibility in role so that I can cope.

67. **HOVING 2013: Work conditions and adaptations**

Adaptations and flexible hours at work would help. It can be difficult to get to work. Acceptance, support and understanding from my employer would help. I want to be able to discuss solutions collaboratively.

68. **LIN 2011: Living With the Disease - 1. Accepting disease restrictions**

I need to accept that there are things that I can’t do. I shouldn’t hide my symptoms and pretend to be normal. I need to accept that I now rely on others for help.
69. LIN 2011: Living With the Disease - 2. Accepting limitations and changes in roles

I have accepted and am now calmer about changes in my work and life roles. At times I have stretched the limits of what I can do, especially at work, so that I can keep my job. I have needed to adjust my expectations and standards. It can be hard to accept limitations and its effect on normal reciprocal relationships.

RHEUMATOID ARTHRITIS

70. LIN 2011: Living With the Disease - 3. Accepting the disease as a part of life

I am not worried but accept the ups and downs of the disease, the pain, and the treatment as part of my daily life.

RHEUMATOID ARTHRITIS

71. LIN 2011: Living With the Disease - 4. Redefining normal life

I have to redefine what is normal and not be unrealistic about expectations and standards.

RHEUMATOID ARTHRITIS

72. LIN 2011: Reclaiming Control - 1. Being flexible

I need to be flexible, creative and develop new skills to compensate for my disability. Being independent means being able to do things on my own without help. I have the courage to face pain and loss. I recognise my limits but do not exaggerate them. I will continue to persevere with the things that I can do.

RHEUMATOID ARTHRITIS
73. LIN 2011: Reclaiming Control - 2. Concentrating on recovery from disease

I will seek every resource that I can to overcome pain.

74. LIN 2011: Reclaiming Control - 4. Reorganizing lifeways

I need to rearrange my life patterns, find ding time to rest and relax and slow down to preserve energy.

75. LIN 2011: Reclaiming Control - 3. Listening to the body

I listen to my body and adjust medication and activity to my needs. This helps me cope with flare ups.

76. LIN 2011: Reclaiming Control - 5. Seeking resources

It is OK to ask for help.
APPENDIX 4: LIVING WITH OSTEOARTHRITIS

The following pages include 16 Findings from 4 qualitative evidence syntheses exploring what it is like to live with osteoarthritis. Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with osteoarthritis.

Activities 6 & 7 will give you some ideas on how to use these cards.
1. **SMITH 2014: experience of symptoms**

OA gives me pain. Pain at night makes me tired and means that I cannot concentrate, or join in with things the next day. Pain makes me feel low or worried. I am worried that it will progress in the future and that I will become dependent on others. My pain tells me how much, and what, I can do. My joints are swollen, stiff and weak. My joints feel unstable and sometimes lock and creak.

2. **SMITH 2014: Self-perceptions towards OA**

I no longer work or do the things that I used to do. I have become isolated. I feel low. I have lost touch with people. This has an impact on those around me. OA is inevitable as you get older; my parents had OA so it is no surprise. I overused my joints when I was young. Some people have OA because of an injury, poor diet and being overweight. The weather can affect your joints. I will not give in and try to stay positive. It is not as bad as other things, like cancer. However, it is difficult to explain to others because you cannot see it.

3. **SMITH 2014: Functional impairment**

OA has a deep impact on my leisure, life and work. I am gradually joining in with less and less. I am too slow and my joints are too painful and too bad to do what I used to do. I am no longer the able-bodied person that I was.

4. **SMITH 2014: Interpretation of the perceptions of other people towards their OA**

I don’t want to advertise my OA. People might think badly of me. There is a stigma about walking sticks. My deformity might affect what people think of me. I don’t want to be a burden on friends & family. I used to provide for my family and now I am a burden. I don’t want to rely on others. I don’t want to be labelled by my OA. I don’t want others to think that I am a complainer. I don’t tell anyone or just say that it is normal.
5. **SMITH 2014 [182]: delayed formal consultation with general practitioner (GP)**
I have been managing on my own and don’t want to bother the doctor unless I need to confirm my suspicions. I ask other people for information and advice. The GP can’t do anything anyway. I will go to the doctor when I can’t manage anymore. I am a bit worried that I am becoming unsafe because I keep falling. I will seek help when I reach critical point. A diagnosis does not really affect the situation, although it may help to explain things and let me know what to expect.

6. **SMITH 2014 [182]: Inevitability of failure of conservative treatment and requirement for surgery**
A joint replacement is inevitable. I don’t know what I think about non-surgical treatment. It might improve my symptoms but it is not a cure. It may stop things getting worse. Surgery is the only solution. Anything else is a waste of time. Other treatment is just a hoop I have to go through before they will consider surgery. Some clinicians trivialise OA. However, if I had faith in my doctor and they wanted me to try conservative treatment, I might try it.

7. **SMITH 2014 [182]: Role of healthcare professional’s interventions**
My Dr says ‘it’s just old age’. I consult other people & the media. I listen to people with OA. Drs don’t know. I only talk about my fatigue to those who are close; others might think badly of me. I worry about side effects of pills. I am not a ‘pill-popper’. I am not weak. Pills don’t help me and may cause tiredness. I take them by trial and error. Perhaps I should discuss this with my doctor? I don’t know if their job is to diagnose or treat OA. I want to learn how to manage myself.

8. **PASKINS 2014 [183]: Diagnosis**
I waited a long time to be diagnosed and it was a relief to have my symptoms legitimised. ‘Wear and tear’ implies it is my age or that nothing can be done, or the Dr has given up on me. However, it means it is normal. You have to use it or lose it. However, using it might cause more wear and tear.
9. **PASKINS 2014 [183]: Explanations and patient information**

People say it is normal and that ‘nothing can be done’. They say I must accept and persevere. I don’t bother telling my doctor as it is normal. Younger people with OA don’t feel this and look for reasons. No one is explaining it to me. They are not interested or don’t know what it is. I need more information so that I can manage it myself. I fear lifelong pain, and becoming disabled.

10. **PASKINS 2014 [183]: Management of condition**

I go to the Dr if I am in pain or can’t manage. I decide about my own medication. Medication may mask symptoms. No one explains medication to me. I don’t know about side effects and I am worried about the effects on other conditions. I am a bit suspicious about medication. I want to know about other options. I want a cure. The Dr says treatment is ‘palliative’; modern medicine is not working for me. Advice about joint replacement is inconsistent. I don’t know enough to make choices about surgery and I am anxious about making the decision for myself. Care is reactive, and not proactive. I don’t know when to go back to my doctor for follow-up.

11. **PASKINS 2014 [183]: OA and the doctor-patient relationship (a)**

I need the doctor to legitimise my symptoms. I am not being taken seriously. People don’t think that OA is a priority. My relationship with the Dr is important and I need it to be patient centred.

12. **PASKINS 2014 [183]: OA and the doctor-patient relationship (b)**

I want to stay in charge of medication. I won’t see my Dr again because he recommended a TKR. There has been a breakdown in communication and shared decision-making and I am not achieving what I expected. This makes it difficult to control my pain. I have other health conditions and am distressed.
13. DOCKERTY 2018 [180]: Perceived effectiveness of medication
I will take my pills if it will reduce my pain and the impact is more than potential side-effects. There is ‘balance’ between the pros-and-cons of taking medications. I need to have clear information about medication.

14. DOCKERTY 2018 [180]: Knowledge and education
I am not very clear about the timing, duration dose and frequency of medications and don’t have enough support on this. I am disillusioned and not motivated to stick to my prescribed medication. I think that my HCP trivialised OA; this makes me think that it is trivial, so what is the point of taking all this medication. If the HCP involved me in the decision on medication and listened to what I have to say, I would be more likely to take this medication.

15. DOCKERTY 2018 [180]: Severity of symptoms
If I have more pain I am more likely to take my prescription. Pills can affect my sleep and lifestyle.

16. DOCKERTY 2018 [180]: Side effects and acceptability
My pills can make me constipated and dozy. Some people even get ulcers or become addicted to them. I am worried that I will become addicted or come to rely on medication. I am also worried that painkillers will mask my symptoms. If I have no pain then people may not believe that I have a problem. Also, there are just so many pills; it just doesn’t fit in with my lifestyle.
APPENDIX 5: LIVING WITH JUVENILE IDIOPATHIC ARTHRITIS

The following pages include 22 findings from 1 qualitative evidence synthesis exploring what it is like to live with juvenile idiopathic arthritis.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with juvenile idiopathic arthritis. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **TONG 2012 [184]: Aversion to being different**

Arthritis makes me feel that I am no longer normal. I despise feeling different and feel frustrated, afraid and powerless.

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2. **TONG 2012 [184]: Aversion to being different - Disablement**

Pain and stiffness mean that I can’t do normal things. I am frustrated because I can’t join in with friends. I think that I am missing out. I feel sad and depressed about this.

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3. **TONG 2012 [184]: Aversion to being different - Internal disfigurement**

Arthritis is a horrible disease. My body is abnormal and grotesque, both inside and out. It is disgusting.

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4. **TONG 2012 [184]: Aversion to being different - Differential treatment**

Other people try to overprotect me or give me preferential treatment. I wanted to be treated like everyone else.
5. **TONG 2012 [184]: Aversion to being different - Forced dependency on others**

I always have to depend on other people for help with ordinary things; even opening the door. This affects my self-confidence. I am frightened to try and do it on my own. I don’t want to refuse help from others because I don’t want to hurt their feelings. Also, I might need their help later on.

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6. **TONG 2012 [184]: Aversion to being different - Unrelenting and unpredictable pain**

I can’t lead my life like my peers because of my pain. It comes and goes and I cannot lead a normal life. It can be mild one day and the next minute it can be so severe that I can’t move. Pain controls and restricts my body. Pain makes me tired, powerless and incapable of doing things.

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7. **TONG 2012 [184]: Managing treatment - Motivation for physical therapy**

Exercises are important to keep me mobile. I will exercise if it is fun. It can be difficult because I have other priorities, such as school. Sometimes I am just too tired, too busy or just bored of the repetition.

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8. **TONG 2012 [184]: Managing treatment - Respect and involvement in health care**

I want to be part of the decisions that are made about my health care. My HCP should explain the tests and procedures. I can trust a good HCP who understands my illness and the effect that pain has on me. I want them to get to know me and to develop a good rapport.
9. **TONG 2012 [184]: Managing treatment - Benefits of taking medicines**

Medication is important for my health and I integrate it into my daily routine. Some find it difficult to take their medicines and worry about blood tests which may mean that you have to increase medication. I worry about becoming dependent on pain medication and am careful about taking it too much.

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10. **TONG 2012 [184]: striving for normality**

I feel very different to everyone else and that I will not reach my potential. I don’t want to be labelled as sick or disabled.

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11. **TONG 2012 [184]: striving for normality - Focus on remission**

I try and focus on times when I am in remission and can move without pain. I am hopeful about a time when I will be free of pain and symptoms.

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12. **TONG 2012 [184]: striving for normality - Sense of community**

I value support from my family and other young people with arthritis. Meeting others with arthritis makes me feel more normal and means that I can share my experiences and feelings. We can also talk about ways to cope better.
13. TONG 2012 [184]: striving for normality – Resourcefulness

Although I cannot join in with some things, I try and find other things that I can join in with. This means that I have to plan things like when to take pain medication. I really want to do things that my peers can do, like shopping. This makes me feel more normal and more confident. I realise that this might have an impact on my career choices.

14. TONG 2012 [184]: striving for normality - Mastery over body

I refuse to let pain limit what I can do and my opportunities. I push myself beyond my physical limitations to do what my friends do. I just have to endure during the day.

15. TONG 2012 [184]: striving for normality - Preserving social identity

I won’t be labelled as sick or disabled and don’t want sympathy. My friends might think that they can catch it and I am afraid that they won’t want to be near me. I keep it a secret.

16. TONG 2012 [184]: Suspension in uncertainty - Control versus powerlessness

I cannot predict my pain. I am trapped in a perpetual limbo. At one moment I am in control and next I am overwhelmed by intense pain.
17. TONG 2012 [184]: Suspension in uncertainty - Hope versus disappointment

My mood swings between the extremes of hope and despair. When I feel sick and in pain, I feel depressed, defeated, and sometimes want to give up. When pain is mild, I feel hopeful for remission or recovery.

18. TONG 2012 [184]: Stigma and misunderstanding – Discrimination

My career opportunities may be limited. Potential employers may discriminate against me due to my physical disabilities.

19. TONG 2012 [184]: Stigma and misunderstanding

Others trivialise my arthritis. They do not see how serious it is. They do not understand that it can be unpredictable. They think it is a minor complaint of old people, or that I have caused it by cracking my fingers.

20. TONG 2012 [184]: Stigma and misunderstanding - Invisible pain

I am frustrated and hurt by the lack of empathy from others who cannot see my invisible pain. This is the worst thing about living with arthritis. Because my symptoms fluctuate, people accuse me of faking pain so that I can get out of things at school. I can’t explain what it is like and don’t want to talk about it.
21. **TONG 2012 [184]: Desire for knowledge - Lifestyle management**

I want to know the possible impact of arthritis on school, relationships, family, finances, and daily living. I want to know what I should and shouldn’t do. I wanted to know that I may be rejected or bullied by my peers. This knowledge gives me power to manage my pain. I want to know about possibility of remission and recovery as this can give me hope.

22. **TONG 2012 [184]: Desire for knowledge - Medical treatment and advances**

I want to know how medication works and what the side effects are. I want to know about research and medical advances as it offers me hope.
APPENDIX 6: OLDER PEOPLE LIVING WITH PAIN

The following pages include 10 findings from 2 qualitative evidence syntheses exploring what it is like for older adults to live with pain.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like for older people to live with pain. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **CROWE 2017 [185]: Adjusting to the inevitable**

I must adjust to the inevitability of living with an aging body. My body is frailer and fragile and I need to adjust my lifestyle accordingly. I need to pace myself and establish daily rhythms so that I can make the most of the things that I can do. Pain is an inevitable part of ageing.

2. **CROWE 2017 [185]: Doing it my way without medication**

I don’t want to take medication and have been disappointed with the effects of them. There are side effects, long-term consequences, and possible addiction. I don’t want to take a whole load of medications for different things. Medication is a last resort and may mean I lose my independence. I prefer to cope with pain with my own remedies. My independence is really important to me and I want to stay in control. I am responsible for managing my own pain. I want to manage on my own without assistance. I will keep busy and keep involved in things.

3. **CROWE 2017 [185]: The importance of support in managing the struggle**

Coping with pain is a daily personal struggle. I need to persevere and become confident in managing my own pain so that I can cope. I need support to manage this daily struggle, not necessarily medication. I need information to be able to make decisions. I want to be active in healthcare decisions. My peers are important sources of information.

4. **VAISMORADI 2016 [186]: Care-centred perspective**

Staff members are not validating my pain; I kept telling her about this ugly pain. She’d take no notice of me. At times I hide my pain and don’t tell others; I don’t want them to worry or think I am a complainer.
5. VAISMORADI 2016 [186]: IDENTITY OF PAIN - Life-bounded

Pain is not just physical; it is connected with how I feel. Other things in my life, such as deteriorating health, loss of freedom, the death of loved ones, and the experience of being abandoned increase my pain.

6. VAISMORADI 2016 [186]: Normalizing suffering

My pain is inevitably caused by the physical changes of old age. My pain also brings emotional suffering which increases pain. Emotional distress with age is painful. Physical and emotional pain overlap. This makes it hard to measure pain. I want someone to validate my pain. At times, my pain is undermined by others and my suffering is framed as a 'normal' part of ageing.

7. VAISMORADI 2016 [186]: IDENTITY OF PAIN - Age-bounded

Physical pain accompanies old age. Pain varies in intensity, location and duration. My pain is not always as disturbing but ever present. Moving me around also causes pain; “don’t grab hold of me there, grab me here”

8. VAISMORADI 2016 [186]: Expected pain

Pain is expected and unavoidable as you get older. It is difficult to control it. Pain causes lack of energy, disability, personal loss, loneliness and isolation, and a low quality of life.
9. **VAISMORADI 2016 [186]: imposed pain**

I don’t want this pain and will take measures to avoid it. I will seek help from health care and continue to struggle against the pain.

10. **VAISMORADI 2016 [186]: Person-centred perspective**

Unable to distinguish professional and patient voice in this finding.
APPENDIX 7: LIVING WITH OSTEOPOROSIS

The following pages include 25 findings from 2 qualitative evidence syntheses exploring what it is like to live with osteoporosis (OP).

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with osteoporosis. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **BARKER 2016 [187]: Biographical integrity—osteoporosis is not manifest**

OP has not affected my life.

2. **BARKER 2016 [187]: Biographical integrity—osteoporosis is not manifest: There was nothing fragile about it**

I did not break my bone because they are fragile. It was a traumatic event, nothing fragile about it. The HCP said that anyone would have fractured in these circumstances.

3. **BARKER 2016: Biographical integrity—osteoporosis is not manifest: I know I have got it but I can’t see it**

OP is invisible in my life. I am healthy and have no sign of OP. You must be able to feel something if you have it. I don’t need to keep taking my medication.

4. **BARKER 2016: Biographical integrity—osteoporosis is not manifest: I am not the type to get osteoporosis**

I am not the type to get OP, my results can’t be right. I have lived a healthy life with a good diet and plenty of exercise. This must have protected me from OP. I have a strong genetic makeup, I am too young and I have strong bones.
5. **BARKER 2016 [187]: Biographical integrity—osteoporosis is not manifest: It is not as bad as other condition**

Other health concerns are more important. Other people have more serious conditions such as dementia or cancer. I have broken a bone and am taking medication but my OP is not serious.

6. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest**

OP has had a profound impact on my life and biography.

7. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: OP choreographs my life**

OP choreographs my life even after my bone has healed. It has a profound impact on mobility, work and social life. I am shocked, angry, sad and fearful.

8. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: Living in fear of falls**

I am vigilant of the world around me and see it as dangerous. I am threatened by activities that would not normally pose a threat. I take great care to avoid falls. I am using a stick now. I don’t think that I have to change my diet and exercise level, or take medication. Caution has become my natural habit. I am becoming isolated because I stay at home in a ‘safe’ environment.
9. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: Fear of what is to come**

I am worried about what the future might bring. If the treatment is successful this will give me some hope. I fear the unpredictable consequences of OP. I fear loss of mobility, being wheelchair bound, being dependent on others, further fractures, falls and deformity.

10. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: I am becoming isolated**

Relationships with people I care about underpin my health and quality of life. I have become isolated and depend on family and friends for social contact. Continuing pain affects my relationships with family and friends. I avoid social situations. I feel vulnerable, lonely and abandoned. I would like to be able to talk to other people with OP about this experience and become more confident.

11. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: I am watching my body get old**

The physical changes of OP are synonymous with becoming ‘old’. My loss of height and deformity are hallmark of both OP and ageing. I do not want to accept the diagnosis of OP because it’s seen in our culture as a mark of being old. This threatens my personal identity. I am diminished (shrunken, stooped, bent). I don’t want to be like her...

12. **BARKER 2016 [187]: Biographical fracture—osteoporosis is manifest: I don’t want to rely on other people**

My autonomy and independence are integral to good health & quality of life. Dependency on my family members has profoundly altered my role in the family. Having to accept help (particularly with personal care) is one of the most difficult things to do. At times, relatives can be ‘too’ helpful. Equally, it is not easy to ask for help when I need it. Although I am pleased to get help, it is not always available. This is a frank reminder that I am getting old.
13. BARKER 2016 [187]: The ageing body: osteoporosis synonymous with age and decline

OP is a normal part of ageing that is out of my control. I am no longer steady on my feet so at risk of falls and fractures. I am a bit doddery, not fragile. Older bones are weak, brittle or thin. It is the wear and tear of age, like arthritis. I can see my body getting old and this is a frank reminder of decline with age.

14. BARKER 2016 [187]: The ageing body

I am focusing on life’s possibilities - I focus on enjoying the possibilities of getting older and taking on new challenges. I maintain meaningful and valued occupations. This is integral to good health, quality of life and a positive sense of self. Ageing is natural. Growing wise with age has benefits. A positive approach to life keeps you in good health; negative thinking and worry can have an adverse effect.

15. BARKER 2016 [187]: Gender - osteoporosis is a women’s condition

I am ashamed and embarrassed about having a ‘female disease’. I don’t tell anyone because people might laugh at me; I may even lose my job. Men should be strong and OP means that I am weak. It is not manly to be sick.

16. BOMBAK 2016 [188]: What Does Osteoporosis Mean for Patients and the Public - Clinical Confusion

OP is a natural by-product of aging. It can also be life-altering & catastrophic. I am confused by the connection between bone health and fractures. I get different messages from different people. I don’t see how my bone health leads to broken bones. My fracture was from a traumatic accident. I don’t understand ‘BMD’ tests. I don’t know what osteopenia is; it can’t be that serious. Maybe the results aren’t accurate? If I don’t hear back from my tests it must be OK.
17. BARKER 2016 [187]: overwhelming uncertainty: What are the actual benefits of medication?

It can’t decide whether or not to take medication. The side effects seem to outweigh the benefits. I am afraid and suspicions; will it cause cancer? Have I been fully informed? Is the doctor over-prescribing? What is the agenda of pharmaceutical companies? The whole procedure for taking the medication is very complicated. I don’t like the idea of taking a lot of pills. I prefer to make lifestyle changes. Some feel medication is the only way to stop it getting worse.

OSTEOPOROSIS

18. BARKER 2016 [187]: overwhelming uncertainty: Relationship with healthcare professional

I need a positive relationship with my HCP to help me through this uncertainty and to help me to understand my risk and choices. I need them to listen to me, treat me with respect, keep me informed and to take me seriously. At times the doctor is too busy or ‘not interested’. Some think that the doctor can’t be wrong and you should just follow their instructions. I need to be my own health advocate; to take control and find things out, ask questions and actively seek out specialists or specific medications.

OSTEOPOROSIS

19. BARKER 2016 [187]: overwhelming uncertainty: What is my risk?

I really don’t understand if I am at risk of fracture. Everyone gets a bit of OP. I haven’t discussed my BMD tests. No news is good news. I am confused and worried about inconsistent information. One clinician told me that don’t need testing because I don’t have the body type that is at risk; one told me that medication is preventative. I find out all that I can from written material, friends, family or other people with OP.

OSTEOPOROSIS

20. BARKER 2016: overwhelming uncertainty: What is a ‘BMD’ test all about?

What is a BMD test; I don’t understand it or what it means for my risk of fractures. I thought it was going to be an invasive test and was pleasantly surprised. A good understanding of test results could help participants to evaluate their risk and decide what to do.

OSTEOPOROSIS
21. BOMBAK 2016 [188]: What Does Osteoporosis Mean for Patients and the Public - Metaphors and Cultural Models

OP can have catastrophic effects for some people, and yet not for others. I am confused about how serious this is. I am confused about its prevention and treatment. I don’t trust my body. This is not my normal body. My body is frail. OP is destroying by body. You can SEE from your body changes if you are at risk.

22. BOMBAK 2016 [188]: What Are Patients' and Providers' Views of Programs in Place for Osteoporosis - provider view

Not patient perspective.

23. BOMBAK 2016 [188]: What Are Patients’ and Providers’ Views of Programs in Place for Osteoporosis - Patients’ and Caregivers’ Views

Difficult to distinguish patient and carer voice in this account.

24. BOMBAK 2016 [188]: How Do Patients Live with Osteoporosis? - Medication Adherence

Medication is confusing and I need to be able to trust my doctor. I need reassurance about safety and side-effects. Calcium might be cheaper/safer. I seek information before I make a decision. Some say I should take medication, and some don’t. Fear makes me take it. I feel guilty if I don’t take it. I am not at risk of fracture. OP is not as bad as other things. I will continue to take medication if it helps, but if I feel better I will stop. I try to modify my diet, exercise, take supplements and use walking aids. The most important thing is to not fall.
It is my duty to seek help. However I am at low risk. Screening is not as important as cancer screening. I am worried about being labelled or over-medicalised. I don’t trust my HCP. I prefer to do things for myself. I don’t always take my medication or adapt it. Some prefer the HCP to decide on treatment.
APPENDIX 8: LIVING WITH CANCER PAIN

The following pages include 19 findings from 2 qualitative evidence syntheses exploring what it is like to live with cancer pain.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to live with cancer pain. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **BENNION 2013 [189]: Health services interaction and the need for information**

   Communication

   When my treatment was over my doctor abandoned me. I have to deal with it alone. I am left with symptoms that I didn't expect and struggle to come to terms with it. I don’t want to bother the doctor with things that may not be related to cancer. I am afraid that I will miss something and my cancer is back. The doctor is dismissing my concerns and thinks that I am imagining things. They don’t want to talk about things that they cannot fix. The doctor should ask specific questions, rather than just say 'how are things? so that I know what is normal and what isn’t.

2. **BENNION 2013 [189]: Health services interaction and the need for information - Future fears**

   Cancer makes me uncertain about the future and I am fearful of any new health problem. Cancer brings mortality into focus. I am worried about death and what death will be like.

3. **BENNION 2013 [189]: Changing relationships - Family relationships and friendships**

   I am embarrassed by my symptoms and hide them, or pretend it is normal to my friends and family. I feel more confident with people who know about it. However, it is still embarrassing. I am worried about being stigmatised. I feel misunderstood and alone.

4. **BENNION 2013 [189]: Changing relationships - Sexual relationships**

   Cancer has disrupted my existing relationship. I feel insecure about my body and my partner also has concerns. I struggle to communicate my feelings to my partner. I don’t feel attractive and have lost my sex drive.
5. **BENNION 2013 [189]: Symptom experience**

I can't sleep and have no energy; I am in pain; my mood is low at times; I can't do things; I can't think straight; I don't look the same; I have respiratory symptoms; my menopause came early and intimacy is no longer the same.

6. **BENNION 2013 [189]: Health services interaction and the need for information - Being unprepared**

I was not prepared for symptoms after cancer treatment. I expected to feel sick because of treatment, but no one tells you about the other things. I didn’t expect symptoms to go on for so long. Early menopause was a big shock.

7. **BENNION 2013 [189]: Changing self - Changing bodies**

Cancer has changed my body and how other people see me. I have lost control of my own body. I am frustrated that I can no longer do some very basic things.

8. **BENNION 2013 [189]: Changing self - Changing mind**

I am no longer the person that I once was. I am struggling to be my old self. I have been left with ongoing unexpected symptoms which prevent me from being my old self. However, cancer has made me have new priorities.
9. **BENNION 2013 [189]: Changing self – Coping**

I cope in various ways: sometimes I just give in to it; sometimes I take it as just another health problem to deal with; sometimes I just wait and see what will happen; sometimes I just live from day to day.

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10. **BENNION 2013 [189]: Changing self - Losing independence**

I need to get back my old independence so that I can be me again. Lots of things make this difficult. For example, if I can’t drive I need to rely on others.

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11. **BENNION 2013 [189]: Changing self - Challenges of returning to work**

Returning to work is a major challenging step for me. I need to prove that I am ill when I am at work. My colleagues don’t understand that I still have symptoms after treatment. I returned to work too early to prove that I was ‘well’ and still capable. I tried to do too much too soon and this has caused other problems. My ongoing symptoms meant that I struggle to return to my old job, to find a new job or continue with education.

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12. **FLEMMING 2010 [189]: The inter-subjectivity of pain - The Role of Caregivers.**

[Carer experience]
13. FLEMMING 2010 [190]: CONTROL - Opioids and Opioid Concern.

I am really worried about taking opioids. It means my cancer is worse and death is approaching. Opioids are the last resort; a “death sentence”. There is a social stigma about taking opioids. Once I start, I will have to take more and more; I will be sedated and death will follow. I will resist taking them because I remember what it was like when I had them before. I may become addicted to them or they may lose their effects so won’t work when I really need them.

14. FLEMMING 2010[190]: The Existential Meaning of Cancer and Cancer Pain

Cancer means pain. Increased pain means that my cancer is getting worse. Death will be a relief from pain. Starting morphine means that I am at the end stage. Starting morphine means that I am coming to the end. Pain signals death and relief from pain. Why me?

15. FLEMMING 2010(190): The intersubjectivity of pain - The Role and Influence of Health Care Professionals in the Management of Pain

(healthcare professional experience)

16. FLEMMING 2010(190): The intersubjectivity of pain - The Management of Pain by the Patient A.

Opioids are a blessing and a curse. I am striving to live but also want to ensure a comfortable death. Taking morphine just isn’t me. I feel guilty and constantly try to justify why I have to take it. I will just take it when I need it. I will use other ways of reducing my pain; I will try and relax; I will try and distract myself. There are others who are less fortunate than me.
I don’t tell everyone when I am in pain. I don’t want to frighten or burden anyone. Pain is private and it is difficult for others to understand if you haven’t had it. I will talk to my HCP about my pain if we have a good relationship and if this helps to choose the right treatment. I won’t tell the HCP if we don’t get on, even if my pain is really bad. At times, I feel abandoned by my HCP when they say that nothing can be done about my pain.

My cancer has given new meaning, strength, potential, and control. It is part of my life now.

There is a trade-off; I want to get rid of pain but also be able to do things. Taking opioids makes me feel that I have lost my dignity, my autonomy, and my sense of self. My life has lost its meaning. When the pain increases I feel that it is in control. Although I continue to take opioids I feel conflicted. At times I choose pain over side effects. There comes a point when you have no choice. At that point I will take opioids because I am worried about others seeing me in pain.
APPENDIX 9: HAVING A PARENT WITH CHRONIC PAIN

The following pages include 6 findings from 1 qualitative evidence synthesis exploring what it is like to have a parent with chronic pain.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to have a parent with chronic pain. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **Higgins 2015 (195): Struggles with communication**

I hide my true thoughts and feelings from my parents. My mum doesn’t know that I am worried about her pain. I keep myself at a distance from my parents and talk about my feelings about my mum’s pain with anyone. It makes me feel closer to my parents if I discuss it. I don’t want to talk to them about their pain as it may cause more suffering.

**HAVING A PARENT WITH CHRONIC PAIN**

2. **Higgins 2015 (195): Development of compassion or empathy for others**

I enjoy helping my mum and understand that chronic pain is very complex. I have learnt life lessons. For example, “it is important to look beneath the surface” and being able to empathize with others.

**HAVING A PARENT WITH CHRONIC PAIN**

3. **Higgins 2015[195]: Development of children’s independence at an early age**

It can be a good or a bad thing. I don’t like being left alone or unsupervised. It can be difficult to take care of my mum, both physically and emotionally; “growing up too fast is not a good thing”.

**HAVING A PARENT WITH CHRONIC PAIN**

4. **Higgins 2015[195]: Effects on participants’ emotional health.**

At times I have suffered emotionally because of my mum’s pain. I felt sad, angry, frustrated and afraid. Partly because it is difficult to have a parent with pain, and partly because I am worried that my mum won’t be around for important events in the future. I am worried that pain is life-threatening. I am worried that I may also get pain in the future. I feel guilty because sometimes I doubt my mum’s pain.

**HAVING A PARENT WITH CHRONIC PAIN**
5. **HIGGINS 2015[195]: Learning about health and coping.**

I have learnt some life lessons because of my mum’s pain.

6. **HIGGINS 2015[195]: Missing out**

I am missing out on social activities because of my mum's pain and sometimes I feel angry about this. Some people feel that they lost out on a normal childhood and don’t know whether or not their parents loved them. I have learned to accept missing out on certain things.
APPENDIX 10: HEALTHCARE PROFESSIONALS' EXPERIENCE

The following pages include 35 findings from 6 qualitative evidence syntheses exploring healthcare professionals’ experience of treating people with chronic pain.

Print out the pages, cut out the cards and use them to stimulate thinking about what it is like to treat patients with chronic pain. Activities 6 & 7 will give you some ideas on how to use these cards.
1. **TOYE 2017 [196]: The challenge of dual advocacy**

I am simultaneously an advocate of the patient and the healthcare system. I am part of a system where it feels that the cogs are not always working together. I can’t always access the services I need for my patient. Sometimes other services don’t provide what I expect. We need to work together to make this work for our patients. We need to be confident in our colleagues and respect each other as fellow professionals.

**HEALTHCARE PROFESSIONALS**

2. **TOYE 2017 [196]: The craft of pain management**

Clinical work is a craft gained from experience not education. At times I feel under-skilled in chronic pain management. Personal experience and maturity, patient mileage and learning from other more skilled professionals underpin craft knowledge. Although guidelines can possibly support a patient-centred approach, they tend to constrain professional knowledge and don’t facilitate individualised care. I use guidelines as I see fit.

**HEALTHCARE PROFESSIONALS**

3. **TOYE 2017[196]: Navigating juxtaposed models of medicine**

It is difficult to navigate between the biomedical and bio-psychosocial model. I am pulled towards the ‘siren song of diagnosis’. I exclude the biomedical before I shift to psychosocial. This shift can threaten the relationship so I try and smooth, or conceal, the shift. A diagnosis can help things to move forward, or give a sense of relief. However, I need to understand this person’s suffering not just their body. I can be rewarding to get to know the patient and be alongside them.

**HEALTHCARE PROFESSIONALS**

4. **TOYE 2017[196]: Navigating patient-clinician borderland**

It is difficult to navigate the patient-clinician relationship. I have not given an expected diagnosis. I make concessions just to keep a good relationship; I prescribe pain killers; I refer for scans. I have to balance long and short term gains. I sometimes feel bullied into clinical decisions. I need to find a balance between imposing my opinion and enabling the patient to make their own decisions; it is difficult to watch them take a ‘wrong’ step. My short circuit is to take control. However, negotiation rather than enforcement is more effective in the long-term.

**HEALTHCARE PROFESSIONALS**
5. **TOYE 2017[196]: Personal costs**

It is an emotional challenge for me to treat patients with chronic pain. First, the biomedical model makes me feel like I am a professional failure because I cannot fix things; ‘how did I fail them?’ If I get to know my patient this can incur a deep sense of personal loss. I have to balance being too close to my patient or too distant.

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6. **TOYE 2017[196]: A sceptical cultural lens**

Society is sceptical about chronic non-malignant pain. At times I have to decide whether the pain is ‘real’ or imagined. What they say and what I see don’t match. I am ‘on guard’ against exploitation from fraudulent claims. There are good and bad patients: easy/difficult patient; explained/not explained, local/diffuse pain; adherent/non-adherent; stoical/weak; motivated/unmotivated; accepting/resisting; non-complaining/complaining; deserving/non-deserving. However sometimes my judgements are wrong.

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7. **GARDNER 2017[192]: Treatment orientation**

I focus on the biomedical (chronic back pain) and lack confidence in my ability to use the biopsychosocial model. I don’t like treating 'difficult patients' and am not confident in my skills, or outcomes from treatments. It is not my job to assess psychosocial factors.

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8. **GARDNER 2017[192]: Patient factors**

I am influenced by patient and their beliefs and expectations when deciding on treatment. I tend to choose an intervention that promotes a good relationship. I make decisions based on my judgement of how 'passive' the patient is and how likely they are to engage in treatment and/or self-management. I individualise my treatment choices for each person.
9. **EGERTON 2017 [191]: ‘Dissonant patient expectations’**

If a patient expects/wants something that I don’t think is appropriate, I will sometimes do it so that I can maintain trust. It is sometimes difficult to talk to patients about their diagnosis if I don’t have a diagnostic test. It is difficult to talk about weight loss. I don’t have the skills for these difficult conversations.

10. **EGERTON 2017 [191]: Osteoarthritis is not that serious**

Osteoarthritis is a normal part of ageing and not as serious as other conditions. Everyone gets it.

11. **EGERTON 2017 [191]: Other reported barriers or enablers**

No central theme in this finding.

12. **EGERTON 2017 [191]: Personal beliefs at odds with providing recommended practice**

I feel pretty negative about the chances of this osteoarthritis getting worse and don’t know if any treatment will work. I don’t think that they will take my advice. Patients don’t think that medications are effective. There is not much that I can do for this.
13. \textit{SLADE 2015 [193]: Barriers to Guideline Implementation - Beliefs That Imaging Will Lead to a Definitive Diagnosis}

There is a risk that I might miss underlying spinal pathology if I don’t refer for imaging. There is also the worry about litigation. It can also facilitate patient engagement in treatment. I am a bit uncomfortable with the term “nonspecific” LBP; you can always identify a definitive, patho-anatomic cause and diagnosis. I always want to give a diagnosis. I don’t need to utilise psychosocial assessment and treatment approaches and it is not my place to use these approaches.

14. \textit{SLADE 2015[193]: Barriers to Guideline Implementation - Beliefs About Knowledge Limitations and Professional Role and Identity}

I am not confident about assessing and treating LBP. Some HCPs are more confident. I think that there is a biomedical diagnosis/cause for pain but the “art of caregiving” is also important. This is underpinned by intuition and creativity.

15. \textit{SLADE 2015 [193]: Maintaining the Patient-Clinician Relationship With Imaging Referrals}

I use imaging results to explain the problem, to relieve anxiety and to encourage optimism. An “unambiguous explanation” can increase trust and help my patient to engage in treatment. At times I order a test if I don’t have time to discuss the options fully.

16. \textit{SLADE 2015 [193]: Maintaining the Patient-Clinician Relationship With Imaging Referrals - Imaging Referrals are Used to Manage Patient Beliefs and Expectations}

I tailor my treatment to my patients expectations and experiences, ways of coping, fears and anxieties, and cultural influences, despite the guidelines. I am more likely to refer a more demanding patient.
17. SLADE 2015 [193]: Guideline Implementation and Adherence Beliefs and Perceptions - Positive Perceptions of the Role of Guidelines

I believe in Evidence-Based Practice and that guidelines are relevant to my practice. However, current recommendations are not practical or realistic to implement; they do not promote patient empowerment or self-management.

18. SLADE 2015 [193]: Maintaining the Patient-Clinician Relationship With Imaging Referrals

I would rather negotiate things and avoid conflict with my patients. They can find it difficult to accept a non-biomechanical diagnosis; patient expectations don’t match the guidelines. They want a specific diagnosis and intervention. They want imaging to identify and legitimise the problem. Patients doubt my clinical ability if I don’t order a test.

19. SLADE 2015 [193]: Barriers to Guideline Implementation - Time Constraints Make it Difficult to Implement the Guidelines

I am facing an information overload. The volume of all the guidelines is overwhelming I can’t read them all and assimilate into clinical practice. The time it takes to implement guidelines exceeds that which is allocated for a standard consultation.

20. SLADE 2015 [193]: Guideline Implementation and Adherence Beliefs and Perceptions - Guidelines Restrict Clinical Judgment

The guidelines are constraining and prescriptive; they control practice and subjugate clinical judgment by reducing medicine to algorithms; they are autocratic in nature; they stifle professional autonomy and clinical reasoning. They don’t represent all the treatment modalities and thus limit choice of treatment. The guidelines cannot possibly reflect the diversity of patient presentations.
21. SLADE 2015 [193]: Guideline Implementation and Adherence Beliefs and Perceptions

I rely on past experience and clinical judgment more than guidelines. Accepted practice, intuition, experience and the ability to understand the patient in context underpins my decision. Social influences, training, colleagues, patients, and the organisation influence my decisions about whether to comply with guidelines.

22. SLADE 2015 [193]: Guideline Implementation and Adherence Beliefs and Perceptions - Clinicians are not familiar With Guideline Content or Development Processes

Guidelines are not supported by research evidence; there is not enough evidence to support the guideline. I don’t know what is in the guideline and how it was decided. Some don’t even know that it exists.

23. EGERTON 201 [191]: clinicians under-prepared

I didn’t know about the clinical practice guidelines for osteoarthritis management. I am not clear about recommendations and feel under-prepared to manage patients with osteoarthritis. I don’t have time to read the volume of information that I am expected to know.

24. SLADE 2015 [193]: Barriers to Guideline Implementation

I don’t have time to read the guidelines. I am overwhelmed with the volume of guidelines for all the disease categories and can’t possibly assimilate them into my clinical practice. I will refer for imaging when I can’t access other options such as physio
25. SYNNOTT 2015 [194]: Some physiotherapists stigmatise patients whose behaviour indicates that cognitive, psychological or social factors are influencing their LBP.

I realise that there are many factors, cognitive, psychological and social, that influence the pain experience. Some LBP patients are poorly motivated, demanding, attention-seeking and, in some cases, self-centred. They are not interested in helping themselves to recover. Some have a financial incentive.

26. SYNNOTT 2015 [194]: Physiotherapists' biomedical preferences

My role is to address the mechanical aspects of back pain even if it is non-specific pain. This is what I have been trained to do. I prefer to find a biomedical reason than explore the psycho-social. It might go horribly wrong if I broach the psychosocial. There may be a financial incentive that means they don’t try and get better. I prefer patients to bring it up themselves. It is easier to do it if you are used to treating this type of patient.

27. SYNNOTT 2015 [194]: Patients' biomedical expectations

My patients’ biomedical treatment expectations influence my treatment choices. I find it difficult to communicate with this type of patient. My default is to give in to expectations. They want you to make them better.

28. SYNNOTT 2015 [194]: Limited role in dealing with the cognitive, psychological and social factors

I don’t want to discuss psychosocial factors. I need to provide a clear and simple explanation for pain and a biomedical diagnosis offers the best framework for this. Psychosocial management is beyond my professional role and scope of practice. I don’t have the knowledge or skills. These patients are challenging and I feel pessimistic about these interactions and expected outcome. This has an effect on my job satisfaction and self-confidence.
29. SYNNOTT 2015 [194]: Limited role in dealing with the cognitive, psychological and social factors - Concerns about training, expertise and exceeding professional scope of practice

I don’t have the skills to influence psychosocial factors. I feel pessimism about the potential for therapy to help. It is beyond my professional role and scope of practice. I am pessimistic about these ‘difficult’ patients and this has an impact on my job satisfaction and confidence.

30. TOYE 2017[197]: Walking a fine line

We walk at a fine line. I have to balance the benefits and adverse effects. If I focus on the adverse it might lead to unnecessary pain; on the other hand, I don’t want to cause harm or contribute to substance abuse. However, pain control is the priority. Misuse is better than pain. In theory a person’s age should not affect my decisions, but in practise, it does. What if they fell down the stairs and died? You have to assess on an individual basis.

31. TOYE 2017[197]: Social guardianship

Our culture is very hostile to opioid use and there is a professional taboo about prescribing opioids. I am worried about being judged by peers. I have a personal responsibility to protect society from the consequences of opioid misuse. I am worried that they will give opioids to others. I am suspicious if someone loses their prescription or requests more opioids. However, this might actually mean that pain is out of control. I have to make the decision whether the pain is real.

32. TOYE 2017[197]: Should I, shouldn’t I?

I am uncertain about when to prescribe opioids and don’t know about the effects. Other doctors seem to make different decisions. Am I wrong? It is even more difficult if I don’t know why they have pain. My clinical education did not prepare me for this. Specialist referrals are restricted or unproductive. I need more support in my decisions.
33. TOYE 2017[197]: Moral boundary work

I have to decide whose pain is ‘real’ before I prescribe. Some patients make demands and won’t take advice. Pain with no biomedical diagnosis, vague symptoms or dissonance between what the patient says and what I see makes me suspicious. If there is an obvious pathology, like cancer, then I know it’s real. I’m constantly asking myself if I am prescribing to the right person. You go by gut feelings. I trusted the wrong patients. You pick it up as you go along. I’m not always a good judge of who to trust. You can’t always judge a book by the cover.

34. TOYE 2017[197]: Pain is pain

Our main aim is to relieve the pain. Addiction should not be a barrier to opioid prescription. There is a stigma against patients with addiction. If someone’s got chronic pain it doesn’t matter if they’re an addict. Your two end points are different.

35. TOYE 2017[197]: Regulations and guidelines

The guidelines can interfere with our professional autonomy. You can’t do your job when you are thinking about these things. It sometimes means that people who are in real pain don’t get the help that they need. However, I am worried about reprimands if something goes wrong. My name is on that bottle. Guidelines strike a blow at the patient-clinician relationship. They can create mistrust and hostility. However, they can also establish boundaries and open up discussion. I can also use them to justify my decision to challenging patients.