

# An Ecosystem of Accepting Life with Chronic Pain: A Meta-ethnography



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#### **Background**

Acceptance of chronic pain is recognised as an important concept in successful long term management. However, current conceptualisation within health literature is insufficient to ground further healthcare developments with divergence between psychology literature and primary qualitative studies on lived experience. Furthermore, questionnaires purporting to measure the concept have been found problematic by two systematic reviews.

#### Methodology

Inductive, qualitative research using Meta-ethnography (Noblit & Hare 1988). Constructionist lens (Rees et al., 2020)

#### Aim

To develop a (re)conceptualisation of the lived experience of acceptance of chronic pain in adults.

#### **Inclusion:**

- Chronic pain as the primary condition
- Adults
- 'Collected Definition' developed of 'Acceptance of Chronic Pain' for study
- Primary qualitative studies with an aim to research acceptance
- Sufficiently relevant and rich data (purposeful sampling)

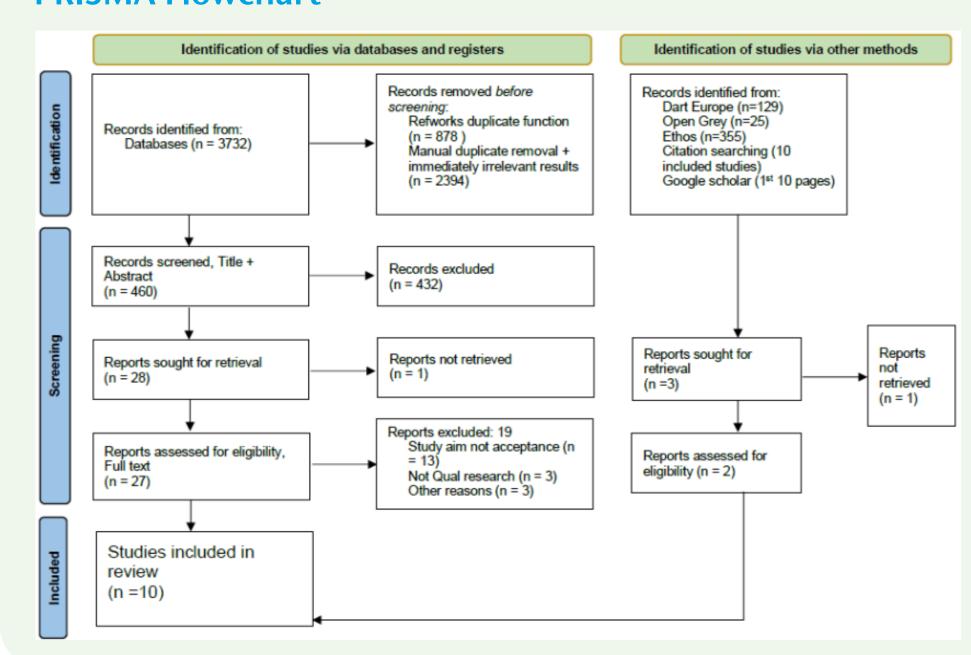
PROSPERO protocol: CRD4202125350

# Method: Interpretive Synthesis, phases 3 to 6

- Reading, developing familiarity with the studies
- Conceptual and contextual data extraction, critical appraisal
- Summarising/ distilling the meaning and concepts
- Developing into themes as per studies
- Juxtaposing study context on to meaning
- Translation of concepts and studies
- Line of argument synthesis

Reflexivity was used throughout. Conducted with co-researchers incl: people with lived experience of chronic pain; backgrounds in clinical practice and academia; physiotherapy, medicine and sociology. Involved in data extraction, providing checks and feedback.

#### **PRISMA Flowchart**



#### **Included Studies**

Included Study	Population + recruitment	Pop no. gender	Age (years) Mean, (range)	Pain duration (y) mean, range
Populations attending/ recruited through healthcare or communities not requiring 'acceptance perspective.'				
Viane et al. 2004 Netherlands	34: self-help group for FM (healthcare). 32: pain clinic in a Hospital.	66 M=16	'average'= 47 (20 to 74)	10.5
Biguet et al. 2016 Sweden	'Entering into' a PMP, not previously attended a PMP.	9 6W	38 (24 to 52)	6.5 (2.5 to15)
Brady et al. 2017 Australia	1 <sup>st</sup> gen. Mandaean, Vietnamese and Assyrian communities in Sydney.	41 (83% W)	60 (36 to 74)	≥ 5 y: 46% V, to 93% in Ma
Liersch, 2019 England	People with CP who dropped out/ disengaged from a PMP. (10/55 contacted)	10 5F	47 (34 to 59)	14
Ng, 2020 New Zealand	Community dwelling older adults, recruited via GP, chronic MSK pain as main problem	18 12W	77 (68 to 93)	26 (2 to 56)
Community recruitment (adverts, posters, word of mouth etc.), accepting perspective/ retrospective				
Kinzel, 2008 Canada	Incl: disruption due to CP, living meaningful life, indicated accepted CP.	10 n/s	range = 'late 20s' to 74	Range = 1.5 to 40
LaChapelle et al. 2008, Canada	Had not 'undergone any type of ACT programme'	45 W	51.4 (23 to 75)	15 (0.5 to 39)
Completed a Pain Management Programme (ACT = Acceptance + Commitment Therapy)				
Rodham et al. 2012, England	Post inpatient PMP for Complex Regional Pain Syndrome	21 16W	45 (22 to 65)	1 to 11
Casey et al. 2019, Ireland	Finished an ACT based PMP	26 54% W	52.7 (SD = 8)	8.8 (2 to 25)
Casey et al. 2020, Ireland	Opted in following at least 50% attendance at an ACT PMP	11 7 W	47 (42 to 58)	7 (2 to 20)

## LIMITS OF INDI ACCEPTANCE TIMUOUS JOURNEY CHALLENGE THE PAINFUL DESIRABLE EIST SOCIE CONDITION DENTITY RESIGNED AUTOMATIC , EQUIVOCAL TAL HEALTH MACGREGOR TULLE · BLANE CAMPBELL · BARBER COHERE SEENAN · 2022 RENT SYSTEM The Conceptual Framework

## Caring, supportive, coherent system

includes healthcare, workplaces, adequate finances, and cultural norms. Communication is clear, open and empathetic, helping one feel believed and validated. Sharing with others who have pain helps to normalize the condition like other chronic illness. The painful condition needs to make sense to the person with pain; systems and culture also need to provide a coherent experience in fitting with the nature of chronic pain, limitations, and the necessary adaptations.

# The challenge to identity in a capitalist ableist society:

identity was frequently related to 'capability' and accepting involves change from the 'pre-pain identity'. Acceptance can mean personal failure or surrender if one identifies as an 'active, capable' person and cannot accept the limits pain brings. Accepting chronic pain is an ongoing process with no end; the individual continually engages with capitalist, ableist systems and norms.

## Summary

Accepting life with chronic pain is conceptualised as a fluid and continuous journey interdependent with the social, cultural and political world; an ecosystem. This includes, but is not limited to, the concept of a desirable 'acceptance' state.

The principles of the ecosystem can be used to develop understanding and delivery of healthcare, and also the interfaces and limits of it. In this conceptualisation, 'chronic pain' is a long term health condition which therefore comes with the capacity required for condition management work which may be impacted by health inequalities.

The language and meaning of acceptance of chronic pain is fluid and complex bringing definitional and conceptual challenges to the research topic.

# Language and meaning

goes beyond terminology to ideas represented within culture and society. 'Acceptance' of chronic pain is difficult to articulate and attach meaning to which may lead to difficulty in the use of standardised language and quantification of the concept. Having a diagnosis or name for the symptoms, and how the painful condition was conceptualised influenced the process of accepting the pain, moving forwards, managing, or not.

# The fluid and continuous journey

is fluctuating, evolving and occurs on multiple levels, easier to accept cognitively than emotionally. The direction can be circular, back and forth, with parts revisited repeatedly, with an overall forwards quality. Accepting is likened to learning, growth and grieving. The turning point in the complex journey of smaller moments facilitated a shift in attitude toward living with pain.

#### The fluctuating states of acceptance

have a temporal nature. One might move between them, or one may dominate. These include acceptance conceptualised as:

- A desirable state; an active, adaptive relationship with the pain and its impact.
- A failure of the self and others, non/acceptance, may mean giving up, giving in, one feels overwhelmed.
- Resigned/ begrudged, there is a forced coexistence with the pain which is beyond ones control.
- An automatic way of responding to the pain, aiming to neutralise the impact, not a conscious decision.
- Equivocal: struggle, uncertainty and contradictions.

#### The Limits of Individualism:

Prevailing neoliberal ideology advocates personal responsibility and health improvements targeted at individual risk factors, reliant on the individual's capacity. However, health inequalities impact on the individual's capacity to manage their health (White, 2011). The desirable state of acceptance required space to look forwards, adaptation, resources, and agency over identity, which may require socioeconomic capacity. Healthcare for the individual, can be more effective in the long term, if accompanied by systemic and cultural changes around the person in pain.

#### References

Noblit, G. W. & Hare, R. D. (1988) Meta-Ethnography: Synthesizing Qualitative Studies. Sage Publications, Inc.

Rees, C. E. et al. (2020) Re-visioning Academic Medicine Through a Constructionist Lens. Academic Medicine: June 2020, Vol. 95, 6.

White, K. (2011) An Introduction to the Sociology of Health and Illness 2nd Edition. Sage Publications.