

Painful transitions

Young peoples' experiences of living with persistent pain, their interactions with health services and their needs and preferences for pain management, including digital technologies



A RESEARCH PROJECT PLAIN LANGUAGE SUMMARY

Researchers and partners

Researchers: Associate Professor Helen Slater¹, Dr Joanne Jordan², Jason Chua^{1,3}, Robert Schütze⁴, Associate Professor Andrew Briggs⁵

Partners: Arthritis and Osteoporosis Victoria and Arthritis and Osteoporosis Western Australia and the School of Physiotherapy and Exercise Science, Curtin University, Perth Western Australia. Other partner organisations included HealthSense (Aust) Pty Ltd and Wisdom Health

¹ School of Physiotherapy and Exercise Science, Curtin University, GPO Box U1987, Perth, WA 6845, Australia

² HealthSense (Aust) Pty Ltd, VIC 3204, Australia

³ Health Networks, System Policy and Planning Division, Department of Health, Government of Western Australia, Perth, PO Box 8172, Perth Business Centre WA 6849, WA, Australia

⁴ School of Psychology and Speech Pathology, Curtin University, GPO Box U1987, Perth, WA 6845, Australia

⁵ Arthritis and Osteoporosis Victoria, PO Box 130, Caulfield South, VIC 3162, Australia

Project timeline

2014-2015

Background

This research is about young people aged 16-24 years living with musculoskeletal pain. 'Musculoskeletal' means pain associated with muscles, bones, joints and nerves and 'persistent' means pain that lasts for a long time, usually more than 3 months. Persistent musculoskeletal pain affects about 1 in 4 young people^{1,2}.

Common conditions associated with persistent musculoskeletal pain include: inflammatory arthritis, non-inflammatory arthritis, joint and soft tissue conditions, fibromyalgia, low back pain, neck pain and widespread muscle and joint pain³.

Persistent pain has a negative impact on young lives². Chronic pain, a large component of which relates to musculoskeletal conditions, costs Australia about \$55 billion per year⁴.

Pain affects nearly every aspect of life, negatively impacting physical, psychological and social wellbeing. Young people's ability to effectively study, work, socialise, stay physically active and enjoy their lives is challenged. As young



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people move from adolescence through to young adulthood they are especially vulnerable to mood disorders such as depression and anxiety, and this is even more so when they have persistent pain. Pain in childhood and adolescence can continue into adulthood with long-term consequences for their health, wellbeing, relationships and work productivity.

Each person's experience of pain and their needs for care are different: some need simple solutions and can self-manage their pain once they have the right tools. Other young people with more complex pain problems may require more components of care and a team to help them co-manage their pain. This means there is no 'one size fits all' for treatment. At the moment, health systems are fragmented. It is hard to get access to the best care. This issue is also complicated by a poor understanding about why pain can persist by health professionals, by employers and the broader community. Young people seeking care often do not get the 'right care at the right time and from the right team', although there is good evidence that suitable treatments are available.

The study

We explored young people's experiences of living with persistent musculoskeletal pain, their perceptions about the associated challenges, health service gaps, and their perceived needs and preferences for modes of service delivery, particularly as they related to the use of digital technologies.

Young people living in Australia with persistent musculoskeletal pain between the ages of 16 and 24 years participated. The research was undertaken in two phases between October 2014 and April 2015 in Australia. Both qualitative (interviews) and quantitative (standardised questionnaires) research was undertaken. Phase 1 involved participants completing questionnaires to characterise their musculoskeletal pain. Phase 2 involved a subset of participants from Phase 1, undertaking an in-depth qualitative interview.

Findings

Young people described the complex, challenging and individualised nature of living with persistent musculoskeletal pain. Pain has a profound effect on young lives, particularly on the capacity to study, work, socialise and manage the financial burden of pain.

Key issues highlighted were:

- the two-way relationship between pain and mood
- approximately 2/3 of young people experienced both pain and mental health problems, with mental health problems usually preceding the pain experience
- young people perceived that health professionals failed to understand why their pain was persistent, especially where there was no specific diagnosis
- this lack of understanding created uncertainty for young people, and fuelled fear about what their future lives would be like
- health services and resources oriented to young people's specific needs and preferences were largely absent
- the use of digital technologies including apps, websites, online peer support groups and social media were seen as key to providing reliable and sustainable resources for pain care that could be accessed from anywhere, and at any time throughout Australia
- young people wanted to be actively engaged in co-developing pain care specifically for young people to help improve their health and wellbeing.

Recommendations

Transforming the way we think and what we do for, and with, young people living with persistent pain is essential. Young people want and need health services that are age-sensitive and which use digital technologies to engage and



connect them to appropriate evidence-based care, at both an individual and broader population levels. Young people want and need to be part of any solution to improved pain care. We make five main recommendations based on our findings.

Recommendation 1 - Transform systems for delivery of pain care for young people in Australia

Cost effective delivery of pain care for young people in Australia urgently requires transforming to provide readily accessible, flexible, efficient and evidence-based best practice care regardless of where in Australia young people live.

How could this be achieved?

- engage young people in e-health system 'user-centric' redesign of pain care
- utilise new and emerging technologies to capture data, streamline care and enable integrated systems of pain care
- build research capacity to support innovative e-health pain care

Recommendation 2 - Address pain literacy from a broad community perspective

Understanding the multidimensional nature of pain, the complexity, the nuance and the individuality of persistent pain is essential to informing truly 'user-centric' pain care.

How could this be achieved?

- utilise cross-sector buy-in
- develop public health campaigns aimed at better informing the public about pain
- build capacity for the dissemination of information and skills for evidence-based pain care

Recommendation 3 - Re-design musculoskeletal pain care to align with, and where possible seek synergies with, current innovations in e-mental health

How could this be achieved?

- integrate pain and co-morbid mental health care for the benefit of young Australians
- enhance the interoperability of e-health systems across care settings

Recommendation 4 - Build health workforce capacity

Upskilling of the emerging and current health workforce about pain is required in order to meet the current and predicted future burden of care for young Australians

How could this be achieved?

- build workforce capacity by targeting both the emerging and current health workforces.
- upskill the health workforce within the context of a biopsychosocial framework
- use innovative digital technologies as levers to drive upskilling

Recommendation 5 - Build research capacity to support innovative e-health pain care

Building research capacity is essential in order to encourage the development, testing, implementation and evaluation of evidence-based interventions specifically for young people that are designed for use on e-health platforms

How could this be achieved?

- seek cross-sector partnerships models
- support innovative development of digital technologies to support improved pain care
- enhance interoperability of e-health systems across care settings to improve health system efficiencies and patient reported outcomes.

The future

Working in collaboration with young people to co-develop, test, implement and evaluate care that is specific to their needs could help transform the access to best pain care, limit the health service gaps created by lack of time, cost or



location. Digital technologies provide an opportunity to provide readily accessible, cost effective care to complement conventional clinical services and improve health service efficiency. These technologies also allow for treatments to be made specific to each person's needs and enable monitoring of how well the treatments and way of delivering treatments, works.

References

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263 Kooyong Road Elsternwick 3185 | Postal address: PO Box 130 Caulfield South 3162

Telephone: 03 8531 8000 | Help Line: 1800 263 265 | Email: afv@arthritisvic.org.au | Website: www.arthritisvic.org.au

