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Research for Rehabilitation and Resilience

Effective pain management in everyday life: Contextualising a model of peer support in the local context of persistent pain

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Metro South Health



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There is a gap in persistent pain care

- Daily management of persistent pain is complex and difficult to sustain (1)
- Problematically, specialised pain services which build skills in pain management are not adequately resourced to help patients incorporate complex regimens in their everyday lives
- Innovations to support transition into self-management in the community have been labelled as priority areas in Queensland (2,3)

1. Dueñas M, Ojeda B, Salazar A, Mico JA, Failde I. A review of chronic pain impact on patients, their social environment and the health care system. *Journal of pain research*. 2016;9:457-67. 2. Queensland Health. Persistent Pain Service Action Plan 2016–19. 2016. 3. Queensland Health. Statewide Persistent Pain Management Clinical Network Report. 2017.

Trained peer supporters could help address this gap in care

- Globally, trained peer supporters have been included in health services with resource constraints to provide complimentary care (1)
- The WHO and Peers for Progress recommends standardised functions of peer support as a template for model development (2, 3)



Figure 1. Functions of peer support (1)

1. Peers for Progress. Program Development Guide.2015. Available from: <http://peersforprogress.org/resource-guide/preface/>. 2. Fisher EB, Ayala GX, Ibarra L, Cherrington AL, Elder JP, Tang TS, et al. Contributions of Peer Support to Health, Health Care, and Prevention: Papers from Peers for Progress. The Annals of Family Medicine. 2015;13(Suppl 1):S2-S8. World Health Organization. Peer Support Programmes in Diabetes: Report of a WHO Consultation2008. Available from: http://www.who.int/diabetes/publications/Diabetes_final_13_6.pdf.

The present study

- To inform the development of a conceptual framework, this study aims to contextualise the main functions of peer support in the local context of persistent pain
- Qualitative pilot study
- Conducted according to the principles of co-design and complex intervention guidelines

Method

- 18 people with persistent pain completed semi-structured qualitative interviews
 - 7 patients (PPMS, DoR)
 - 7 peer support providers (APMA)
 - 4 peer support users (APMA)
- Peers for Progress model informed interview guide and deductive thematic analysis
 - First three functions of peer support
- Preliminary findings are presented

Theme 1: Assistance in daily management

Access & timing of support

- But anyway over the time she said to me, “I’m going to see if I can arrange something for you... there’s a wonderful service that I know of that the PA are doing, it’s in the early stages and there’s a waiting list”... [T]hey put me into a group to teach you how to control the pain or to help give me ways of coping and to, yeah, give me ways of coping with pain other than drugs... I still have my folder that sits beside my chair and I still refer to it because they taught us mindfulness and they taught us, oh, so many things and I have gone back to that folder many, many times... I cope very well now but there are days I don’t, I don’t cope at all, I lose everything that I’ve been taught, that’s where I think a follow-up program would be good [ID1215, PPMS patient]
- [Peer support] would have helped me a lot especially in the early days when I didn’t know anything, when I was just – basically when I was in pain, real bad pain and not knowing what was going to happen to me... Having someone there to help in the early days would have been so beneficial to me. [ID1214, PPMS patient]
- *While participants appeared to value the idea of practical help in carrying out strategies advised by persistent pain service, support at an earlier time (during the wait-list period) appears to be higher priority.*

Theme 2: Social/emotional support

Stigma & emotional isolation

- Well most of the time it's just people haven't got anyone to talk to, so they just need an ear to talk to and then it's just finding out – and myself – that you're not the only one... As soon as you talk to someone that's been through similar to yourself you instantly feel better. You feel that it's not only you, you're not a lost cause, there's someone else suffering just like you... and you just feel like you're not alone. [ID1102, APMA peer support user]
- I think because of my own experience I found that it could be quite isolating. That people don't really understand. People that don't deal with chronic pain don't really understand how much it can affect your life... It really helped to talk to somebody that understood what I was going through... because the doctors don't really help you a lot. And I think when they can talk to somebody that has had the similar experiences. It's like a relief, it's like oh thank god I'm not crazy. I'm not going mad. I'm not a drama queen. All these things that you sort of feel like you are. [ID2107, APMA peer support provider]
- Emotional isolation stemmed from the lack of understanding about chronic pain by society. Peer supporters could help by providing empathy from the perspective of shared experience.

Theme 2: Social/emotional support (cont.)

Negativity & acceptability of peer support

- [T]hey have [stoma] support groups... people there were very, very negative and that's where – some of them were getting psychological support but others weren't and I'm not someone that will – some people like to just complain, complain, complain and that's all they do, they can't see a positive side to anything, and this is what I've come across over the years. So I tended to step away from that support group. [ID1213, PPMS patient]
- If you're going to have a peer support worker, they can't have that victim narrative. They can't – it's almost like they have to be psychologically vetted... because someone in pain who's just come in and they're getting a support worker, doesn't want to hear from the support worker how hard it is all the time. The support worker is there to A, support them, so you don't support them by pushing their head under water, by painting a bleak future... You've got to be realistic, but you can't have someone that's caught in that narrative because if they're caught in that, you'll just push all these people down. [ID1211, PPMS patient]
- In order to be acceptable, peer supporters need to be able to manage negative emotions connected to persistent pain

Theme 3: Linkage to resources

Navigating the (lack of) resources

- Well, I think they said there's, like, one in five people in Australia that have chronic pain. That's massive. They said there's only like 400 pain specialists in the whole of Australia. That's not enough. [ID1102, APMA peer support user]
- A lot of things that people keep saying to me all the time is, they don't know what services are out there and how to access them... if we had a person that could do a one-on-one with them and also guided them, and also facilitated for them to get things done, I think, in the community, that would probably take away about half of the issues that people have, because a lot of this stuff they're frustrated and the only outlet that they've got is A, complaining and B, their GP [ID2104, APMA peer support provider]
- *Peer supporters could assist patients in finding appropriate resources*

Theme 3: Linkage to resources (cont.)

Stigma & healthcare professionals

- A lot of the greatest frustrations over there with this chronic pain is that people don't believe you... It's such a battle to feel believed and you feel like you have to doctor shop until you find a doctor that is managing chronic conditions.
[ID1216, PPMS patient]
- Yes, it's so, so hard to explain, no-one understands, no doctor have I found understands what pain is all about, what causes it, why you get so depressed about it and there's heaps of things, it's like your life is never going to be the same again so how do I deal with it? To be able to ring somebody and talk to them, someone that's trained... to be able to ring that person and say, "I need some guidance."
[ID1215, PPMS patient]
- *Peer supporters could assist in managing stigma in healthcare interactions*

Discussion

- Timing of support implied by this peer support model may not be suitable to the access barriers in this context (e.g. long wait-list)
- Stigma was a salient feature of context
- Acceptability of peer support – how to manage the negativity surrounding persistent pain?
- Would peer support be better suited as part of a multi-component complex intervention to improve access and/or reduce stigma?

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