Apps for older people's pain self-management: Perspectives of primary care and allied health clinicians

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DECLARATIONS

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Abstract

Introduction

Chronic arthritic pain is one of the major causes of physical suffering and disability among older people. Primary care and allied health clinicians use various approaches to help their older clients better manage their arthritic pain. The growing uptake of technology among older people, offers the potential for clinicians to integrate an arthritic pain app into their patients' self-management plan. This study explored the perspectives of Australian primary care and allied health clinicians regarding the use of pain self-management apps to help their older patients/clients better manage their arthritic pain.

Methods

Qualitative design using <u>an</u> semi-structured interview approach. Interviews were conducted via telephone with primary and allied health clinicians (n=17) across Australia.

Results

The overarching theme underlying participants' views on integration of apps into older people's pain self-management strategy was that this approach is an idealistic, but uniquely challenging endeavour. Four sub-themes emerged, namely: (1) Self-management apps are potentially useful tool but require careful consideration; (2) Clinician²s² involvement is crucial yet potentially onerous; (3) No single app is right for every older person with arthritic pain; and (4) Patient data access is beneficial, but caution is needed for real-time data access.

Discussion

The predominant clinician perspective of integrating apps into their older patients/clients' pain self-management strategiesy was that this approach is an idealistic, but uniquely challenging endeavour. Apps were seen as having potential to support various aspects of patient²s² self-management behaviours, however, there were notable concerns with regards to the challenges inherent in this approach for both clinicians and the older users (patients/clients).

Key words: Older Adults, Smartphone, App, Primary care, Allied health, Pain management

Introduction

Despite population ageing and the growing burden of non-communicable diseases, healthcare and technological advances are enabling more older people (over 65 years) [1, 2] to live at home [3-5]. Many older people have multiple comorbidities, and varying levels of symptom burden and disability which they need to manage [6]. Arthritis is a common cause of unrelieved pain and suffering, experienced by 20-46% of community--dwelling older people [7] and accounts for 4% of all Australian General Practitioner (GP) consults [8, 9]. Chronic pain forms a significant proportion of primary care clinician-s' workload, with one of three older people consulting a GP due to their pain [6, 8]. Innovative and cost-effective approaches to support pain self-management behaviours of community--dwelling older people are required, including the use of pain self-management applications or 'apps'. The multidimensional process of pain self-management commences when the older person experiencing pain perceives the need to take control of their pain and is willing and able to do so. Effective pain self-management requires older people to be aware of their own responses to painful symptoms [11] and to regularly assess their pain, manage their analgesic intake, modify their lifestyle and help-seeking behaviour [12]; and seek regular primary and allied health review. Increasing numbers of older people are adopting smartphones [13], and are keen to utilize this modality to self-manage their pain [14-16]. The advanced computing features of smartphones and tablet-computers present new opportunities to improve health outcomes by empowering patients to assume a more active role in monitoring and managing their health via a partnership with their clinicians [10]

Pain self-management apps offer a range of functions, such as: recording pain assessments, providing pain_-related information, and generating pain self-management plans. While a recent systematic review [17] evaluating the efficacy of apps in <u>the management of any type</u> of pain across all ages indicated this approach to be beneficial, the majority <u>of</u> participants were younger people (one out of 15 included studies had <u>a</u> mean participant age of over 65 years), limiting the applicability of this finding to older people living with chronic pain. However, the growing number of recent study protocols [18, 19] suggest that evaluation of the feasibility and efficacy of apps among older people for their chronic pain management is a growing area of interest.

While evidence indicates enthusiasm among primary care clinicians in applying smartphone technology to care for older people with non-cancer pain [20], their views about integration of apps into their community_-dwelling older patient-s' pain self-management regimes

remains unknown. As apps become more ubiquitous in healthcare, exploring primary care and allied health clinicians' views about the current and future roles of apps as part of an arthritic pain self-management intervention requires further exploration.

Positioning this qualitative study

This qualitative study reports on the findings of interviews with primary care and allied health clinicians caring for community_-dwelling older people living with arthritic pain. Aim

To explore the attitudes and perspectives of primary care and allied health clinicians regarding <u>the</u> integration of pain apps into their older arthritic patients' pain self-management strategiesy.

Methods

Design

A qualitative study using semi-structured interviews.

Methodological orientation

This qualitative study is part of the DigiTech Pain Project, designed to evaluate the feasibility of integrating pain apps in older people's pain self-management regime [18]. Guided by a constructivist worldview, this study considers knowledge to be produced by understanding the social world of the participant [21]. This allows for significance to be placed on meaning and interpretation of the knowledge, while acknowledging that these meanings are often socially constructed [21]. In this study, the knowledge is being generated based on the views of clinicians, which is founded on their interactions with older patients/clients.

Setting

Primary care

Recruitment of Participants

Purposive sampling method [22] was utilized to recruit primary care and allied health clinicians registered with the Australian Health Practitioner Regulation Agency as 'health professionals'. Invitation to participate was circulated via the following three approaches:

- 1. Participants of the pre-post-test app trial [18] were asked to nominate three clinicians who help them with their pain self-management.
- Electronically via advocacy groups/associations representing the health professions listed below:
 - a. General practitioners (Royal Australian College of General Practitioners)

- b. Practice nurses (Australian Primary Health Care Nurses Association)
- c. Physiotherapists (Australian Physiotherapy Association)
- d. Chiropractors (Australian Chiropractors Association)
- e. Psychologists (Australian Psychological Society)
- f. Exercise physiologist (Exercise and Sports Science Australia);
- 3. Professional networks of the study team.

Referrers were advised to inform their networks to contact the study team (P.B via email or phone) if they had any questions; or wished to participate in the study. Potential participants were asked to contact the study team (instead of study team approaching them); to minimize risk of persuasion or influence. Written consent was obtained from eligible participants before scheduling the interview.

Research team

The interdisciplinary research team included a registered nurse with experience in digital health research, and background in chronic and palliative care research (PB); an experienced clinical academic nurse researcher with <u>a</u> background in palliative care, mixed-methods and clinical trials research (JLP); and a clinical academic psychologist with specialization in pain self-management and expert in <u>the</u> social aspects of chronic pain (TN-J).

Data collection

Data were collected via telephone interviews, between October and December 2018. An interview guide comprising various open-ended questions guided the interviews (Appendix 1). All interviews were conducted by one researcher (PB); were audio recorded and professionally transcribed by an external transcription service. The interviewer also took detailed field notes which were cross compared with the interview transcripts. The interviewer kept a reflective journal, and made entries following each interview to exercise critical self-reflection and to minimize any bias that the interviewer's position may pose. Data collection continued until no new insights were generated.

Data analysis

<u>The</u> NVivo 12 software package was used to manage the qualitative data. <u>An i</u>Inductive thematic analysis approach was utilized for data analysis [23]. One researcher (P.B.) read and re-read the transcripts and field notes to achieve data familiarization, followed by identification of recurring themes and open coding of the content. <u>A h</u>Hierarchical coding approach was adopted utilizsing branching arrangement of sub-codes (Child code) created under each code (parent code). This process was constantly cross validated with the team (JLP. and TN-J) to ensure coding validity. Any discrepancies in coding were discussed by the

research team and resolved via consensus. No formal reliability statistics were calculated. Recurring data patterns and themes were identified using <u>the</u> constant comparison method [24].

Ethical considerations

Ethical approval was granted by The University of Notre Dame Australia Ethics Committee (01749S0). All participants provided written consent. Participants were informed that participation was voluntary and that they could withdraw from the study at any time. No reimbursement was provided for participation. Data were de-identified to ensure confidentiality. Reporting of this study adheres to the Consolidated Criteria for Reporting Qualitative Research [25] (Appendix 2).

Findings

Data were collected from 17 primary care and allied health clinicians including: gGeneral pPractitioners (GP) (n= 4), physiotherapists (n= 8), clinical psychologists (n=2), an osteopath (n=1), emergency department physician (n=1), and a specialist pain physician (n=1) (Table 1). Participants were spread across Australia with the majority being based in New South Wales (n=10). Most participants were female (n=10; 59%), with a mean age 45.8 years (\pm 10). Over half of the participants worked fulltime (n=11), and the mean <u>number of years inof</u> practice was 20 years (\pm 10). The mean duration of the interview was 23.4 minutes. [INSERT Table 1 here]

The overarching theme underlying participants' views on integration of apps into older people's pain self-management strategy was that this approach is an idealistic, but uniquely challenging endeavour. Four sub-themes emerged, namely: (1) Self-management apps are a potentially useful tools but require careful consideration; (2) Clinician²s² involvement is crucial yet potentially onerous; (3) No single app is right for every older person with arthritic pain; and (4) Patient data access is beneficial, but caution is needed for real-time data access.

1. Potentially useful self-management tool but requires careful consideration

Most participants were positive about the integration of apps into older people's pain selfmanagement strategies.

I think generally the concept of tools like app being useful in self-management of chronic disease is definitely one that would seem to have traction on. ... I can really see the potential in that (HP01, 57, M, GP).

Participants were open towards recommending a pain self-management Apps to their older patients.

I think I would (sic, recommend a pain self-management App), I guess I would have to know how aware they (sic, patients) are with technology and if they are using smartphones or not. I think if they were and they seemed like they are the right kind of person and they are interested to learn, I think I would definitely recommend it (HP06, 30, F, GP).

However, this positivity was accompanied by concerns about the challenges inherent with app utilization, with an older population.

There are a lot of barriers to using apps... apps can be quite intimidating and overwhelming to the older person. A lot of my clients won't even let me assist them to set up an alarm on their phone for their medications, because it all sounds too difficult (HP11, 31, F, Physio).

1.1. App as an empowerment tool

The integration of apps into the pain self-management process was considered to empower older people by fostering a sense of responsibility and engagement.

Most people want something to do, they wan<u>t tona</u> feel as though they are doing something actively towards helping their pain. And that (sic, using an app) is a way of engaging them in an activity that can help them get mastery, or at least help them feel like they are doing something towards their self-management (HP02, 54, F, Clinical psychologist).

Participants considered apps to be a helpful educational tool that could facilitate digital delivery of point-of-care information and instructions to older people, instead of using paper-based action plans.

I guess in the past we've always relied on paper plans to help guide people in what they do, like the 'COPD Action Plan'. So, I guess that sort of stuff could be incorporated into an app for arthritis... (HP06, 30, F, GP).

An app's ability to share data with clinicians was perceived as a potential motivator, which could improve their adherence to the self-management instructions.

If we could look at their (sic, patient's) practices and they knew we could look at their practices, I think they might be more keen to engage (sic, in self-management) (HP10, 41, *M*, Physio).

1.2 Digital familiarity still an unmapped territory for older people

While participants acknowledged the increasing uptake of smart devices among older people, they were unsure if this has yet translated into increased user engagement with apps.

A lot of older clients are getting mobile phones and smartphones, but of my clients who have a mobile phone, probably 60% of them only use it for calling or texting. Not many use it for its other features, and it can be quite overwhelming and intimidating to them to think about using an app (HP11, 31, F Physio).

However, there was an acknowledgement that this situation is continually changing, and that clinicians should be open to such engagements.

... I think I'm seeing more and more of my clients with mobile phones and smartphones. ...the proportion of my clients with mobiles that are over the age of even 70, they have the phones!! I think, we could be utilizing it more... we should be using it to our advantage (HP11, 31, F Physio).

The complexity involved in downloading and purchasing apps was raised as an important element in the context of user burden when considering app use by the older group.

It's not just about usability of it, it's the actual process: "Do I know my apple ID and password ...? No, I don't. Now I need to reset it. I don't know how to reset it. Ooh... Wait, I don't have a credit card saved on my device..." All this stuff that comes with the mandatory download of something from an app store (HP16, 33, F, physio).

2. Clinician²s² involvement is crucial yet potentially onerous

Participants perceived that integration of apps into older people's pain self-management regime will be taxing on clinicians' time.

Firstly, participants considered it crucial to assess their patients for suitability of app use.

Yeah, I think some people just shouldn't go down that rabbit hole because they are already there. They already over-focus on the negative: the pain. ... if you give them an outlet to complain more about the pain, they'll take it... I think you just have to be really careful with who accesses the app (HP11, 31, F, Physio).

Secondly, participants noted a range of factors they would consider if they had to identify and recommend a pain self-management app for their patient.

I think I would want to see a level of evidence-based endorsement, in the literature. So, I would be looking for.... A clear endorsement of a particular app, from a recognized authority and some evidence base for it (HP01, 52, F, GP).

This meant that participants had to download the app and familiarize themselves with it before recommending it to their patients.

The problem with recommending an app for patients is you have to be familiar (sic, with the app). Making sure myself or other clinicians using an app will have adequate training to know all the functions. Because, if recommending things you don't necessarily agree with then we probably shouldn't be recommending the app (HP06, 30, F, GP).

Consequently, time constraints in relation to app use were noted by participants

Most of the work that I do with these apps is outside of the consultation time. I am finding myself needing more and more time at the end of the day (HP09, 59, M, Osteopath).

3. No single app is right for every older person with arthritic pain

Participants reinforced the importance of personalizsing care and that no single pain management approach is right for everyone.

The ability of an app to offer personalization in relation to self-management skills building was considered important.

Exercise should be tailored to the individual and if they're not there's a risk that (sic, they) could be doing something that's inappropriate (HP10, 41, M, Physio).

This suggestion of personalizes ation extended to <u>the</u> types of self-management strategies that are suitable and preferred by each user, suggesting that an app had the potential to be a companion tool that assisted older people to build their <u>c</u>Cognitive <u>b</u>Behaviour <u>t</u>Therapy (CBT) (CBT) and physical exercise-based skills.

Maybe some kind of goal setting with that. I would suggest physical activity of course, and then some way to track their progress toward that goal and maybe some reward system when they achieve that goal (HP05, 35, F, Physio).

... things like meditation, mindfulness, relaxation, that side of it. Something like that in an app would be really great (HP11, 31, F Physio).

Apps were considered capable of offering prompts and motivation to exercise, provide accurate instructions to exercise, and be an exercise support/progress-monitoring tool for older people.

I think videos of the exercises are very useful because I do often go back to clients and as much as we write it out and draw it out for them, you do often go back and they have been doing it wrong or they have been a bit confused about it. So I think videos are a really useful tool. I think videos of the clients doing it themselves <u>areis</u> even more useful (HP11, 31, F Physio).

In addition, successful integration of apps was perceived to be very much dependent upon its user-friendliness, ease of use and intuitiveness.

I guess user-friendliness is probably the main thing. If it's not user-friendly then it is probably not going to be something that they (sic, patients) are going to engage with (HP10, 41, M, Physio).

Age-related limitations and challenges such as poor-vision and dexterity were also considered important when thinking of suggesting an app to an older person.

Some patients in this demographic you are addressing have limited ability to manipulate a handheld device to work some of these things, so that's a bit of a catch 22 (HP09, 59, M, Osteopath).

4. Patient data access considered beneficial, but caution needed for real-time data access. The capability of apps to collect and share various patient assessment data was perceived to be beneficial. Participants were interested in a range of different data points.

...quite accurate measure of activities and also the pain relief and a quite accurate picture of how much pain relief and when they are taking it... It's also quite useful to know what's happening to people's activity levels and what they do with their pain. So, for example – you can see that people's movements going up, and mood decreasing, and at the same time the pain is increasing. That leads you down the set of ideas that what happens if the pain was going up and down? Then that leads you down a certain set of ideas. That would be really useful (HP03, 47, M, GP).

However, participants were mindful of the possibility of data overload that might be brought upon by this level of data sharing from the App, especially with the real-time data sharing feature.

You wouldn't want to be in the position where you were having lots of data sent your way that you are meant to be looking at outside consultations. If you weren't being appropriately reimbursed. GPs are not going to go for that (HP13, 57, F, GP).

Consequently, most participants wished to access (and review) aggregated patient data, preferably during the consult

I find summaries of recent data much more useful, so what I mean is -I don't know what people are doing on a day-to-day basis, but that doesn't really tend to give me anything that I need to know. But having a summary of what happened is useful (HP03, 47, M, GP).

Discussion

This study adds to the growing empirical literature on the use of pain self-management apps. Various factors that should be considered before and during the integration of apps into older people's pain self-management strategy from the perspectives of primary care and allied health clinicians have been identified, many of which have not been previously reported.

In line with the growing evidence on the role of apps in self-management of various chronic illnesses [26, 27], clinicians of this study perceived apps to be useful in facilitating the pain self-management process of older people. Patient empowerment is considered one of the critical elements of any self-management intervention [28]. Apps were considered capable ofto empowering older users by helping them to assume responsibility for aspects of their of care, become more knowledgeable, and subsequently be committed to their treatment regimens [28]. However, this optimism was accompanied by a feeling of ambivalence when considering digital familiarity of older people. These concerns relating to low-level proficiency in app download and use among older people, reflect the published literature with studies conducted in the United States [29], Hong Kong [30], and Germany [31] that reported ing similar-low levels of technical readiness and computer literacy prevalent among older adults the elderly [30, 31].

Growing concerns about the quality of health-related apps is known to cause uncertainty among clinicians in recommending these apps to their patients [32]. An app's ability to be a good vehicle of electronic information and instruction relay makes it useful, but at the same time it-highlights the concern among clinicians regarding the quality of the app's content [33, 34]. Clinicians of this study similarly felt a need to personally evaluate the evidence-base and the credibility of the developer/endorser of the app. Consequently, the pressure this puts in the clinicians' existing workload was a reasonable concern. This concern resonates with reports in the literature [35, 36] indicating that making apps mainstream demands a considerable time commitment from clinicians. The literature also points towards the potential risks of this modality [32] indicating a need for individualized suitability assessment before an app is recommended to patients, confirming the perception of the clinicians inof this study. However, when considering older people with a possibility of cognitive decline, a preliminary assessment on commencement of app use may not suffice.⁵ Insteadrequiring ongoing technical support and regular assessment of their ability to appropriately engage may be required.

Ease of use (use requiring minimal effort), is a preferred design feature of disease selfmanagement apps [34, 37], including pain apps [38]. However, when considering older users, this concept extends beyond intuitive and user-friendly design to considerations of unique needs related to ageing [34, 39]. This view was confirmed by the clinicians of this study with recommendations regarding the inclusion of exercise personalization features. While the recent guideline on arthritis management stipulates the value of personalized regular physical exercise [40], lack of access to a personal coach or ability to develop one's own personalized training regime remains a well-known barrier to exercise engagement [41, 42]. Given this reality, apps with advanced personalized exercise prescription features may be able to offer an acceptable way of facilitating evidence-based physical exercise therapy to older people. Furthermore, the clinician's² suggestion of integrating various CBT₋-based approaches into the App is largely aligned with the published evidence on elements of a comprehensive pain self-management plan [43, 44].

An app's potential to share patient data with clinicians has been widely lauded in the context of chronic disease self-management [45, 46], where regular communication with and support from the clinicians is considered beneficial. Previous studies exploring the views of people with chronic conditions [47, 48], and primary care providers [20] on the data sharing features of apps have similarly valued this capability. In line with this evidence, the clinicians of this study also perceived access to patient²s' data to be beneficial in their care planning and provisioning process. The data points of interest to the clinicians were mostly relating to the assessment and documentation of pain and analgesia intake, and physical activity tracking,

which also confirms the reports of the literature [20]. As clinicians play a pivotal role in helping patients accept and adhere to pain self-management treatments and plans [49], their interest <u>in patients</u>' self-management activity related data is understandable.

However, this openness towards data access was correspondingly balanced by some level of cautiousness. In line with previously published literature [20], clinicians were cognizesant of the challenges of potentially unlimited access to patient data, including the need to consider its value and systems regarding its management [50]. In addition, there was some uncertainty regarding how this level of data access by clinicians could impact the patient and their behaviours. Although patients in general are open to sharing their self-assessment data with clinicians via an app [47, 48], some authors consider clinicians' ability to scrutinize their patients' actions and communications on a very fine-grained level to be unnecessarily intrusive [51]. Pain app studies involving older people who use the data sharing feature of the app areis needed to better understand this area.

Implication for practice

Based on the findings of this study, the following recommendations for practice are made:

- Clinicians need to be well-supported to review, identify and recommend pain selfmanagement apps suitable for their older clients/patients.
- As the systematic integration of apps into clinical care requires a considerable time investment, there should be a clear discussion around reimbursements of the clinicians from the health systems level.
- Future pain self-management apps should offer personalized tailoring to meet the needs and preferences of users with different pain types and self-management needs.
- While access to patient data generated via apps could enable improved monitoring and management of older people, clinicians may benefit from health systems level policies and procedures outlining appropriate management and use of such data.

Implication for research and development

Future research should focus on evaluating the value-add<u>ed nature of smartphone apps, i.e., of evaluating their unique and advanced features of smartphone apps in that can potentially help to enhance the pain self-management process. Furthermore, to gain a comprehensive understanding of this area, studies investigating the feasibility of apps among older people <u>areis</u> warranted.</u>

Future pain app development work should consider a co-design approach involving academic experts in pain self-management, experts in technology implementation, primary and allied health clinicians, and older people to ensure the app is rigorously built, while also being relevant and effective. These recommendations agree with the newly published report [52] outlining <u>athe</u> research agenda on mHealth technology for chronic pain management in <u>older adults the elderly</u>.

Strengths and limitations

Several limitations of this study should be considered. Firstly, the sample was small, nonrandom, and limited to primary care and allied health clinicians within Australia. Therefore, the findings may not be generalizable to other settings, or areas with different data accessibility patterns and laws. Secondly, the profession-specific breakdown of the sample is uneven with small numbers of participants from some disciplines and higher numbers from others. Therefore, our findings reflect the collective perspective of primary care and allied health clinicians, rather than the perspective of a single discipline. And fF inally, although there was nothing in the data to suggest a selection bias, we cannot discount the possibility that providers who chose to take part may have differed in some important ways from those who didn't. For example, recruited providers may have had a greater affinity with technology, or viewed the implementation of mhealth strategies more positively, than those who did not take part.

Conclusion

A range of factors that should be considered before and during implementation of a pain selfmanagement app into older people's pain self-management regimes has been identified and discussed in this paper. Ultimately, we hope that the findings of this study can help inform the development of future pain self-management apps where due consideration is given to the needs of older people and their clinicians. There is a possibility that apps could offer <u>a</u> costeffective and time-efficient method to assist primary care and allied health clinicians in planning and <u>provisionimplement</u>ing pain self-management <u>care plansprocess</u> for their older patients, while also improving patient outcomes.

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