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Investigating well-being, work limitations and preferences for self-management education and peer support among younger people with hip and knee osteoarthritis: protocol for a cross-sectional study

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ABSTRACT

Introduction: Osteoarthritis (OA) has traditionally been considered a condition of older age. However, younger people are also affected by hip and knee OA, often as a result of sporting and work-related injuries. As OA studies have generally focused on older individuals, little is known about the experience of younger adults with hip or knee OA who can face a distinct set of pressures including work responsibilities and parenting roles. This study aims to investigate well-being and work participation among younger people with hip or knee OA, as well as preferences for OA education and support.

Methods and analysis: 200 people aged 20–55 years with a diagnosis of hip and/or knee OA will be recruited for this cross-sectional study. Participants will be recruited from three major public hospitals in the state of Victoria, Australia following screening of orthopaedic outpatient clinic lists and referrals, and through community-based advertisements. A study questionnaire will be mailed to all participants and written informed consent obtained. Validated measures of Health-Related Quality of Life (HRQoL), health status, psychological distress and work limitations will be used. Information on health services use will be collected, in addition to information on the perceived utility and accessibility of a range of existing and proposed education and peer support models. HRQoL data will be compared with Australian population norms using independent t tests, and associations between HRQoL, health status, psychological distress, work limitations and demographic factors will be evaluated using univariate and multivariate analyses. Data on the perceived utility and accessibility of education and peer support models will be analysed descriptively.

Ethics and dissemination: Ethics approval for the study has been obtained. The study findings will be submitted to peer-reviewed journals and arthritis consumer organisations for broader dissemination, and presented at national and international scientific meetings.

ARTICLE SUMMARY

Article focus

- This study will investigate well-being and work participation among people aged 20–55 years who have hip or knee osteoarthritis (OA), as well as preferences for OA education and support.

Key messages

- As epidemiological studies in OA have generally focused on older individuals, little is known about the experience of younger adults with hip or knee OA who can face a distinct set of pressures including work responsibilities and parenting roles.
- Preferences for OA education and support among younger people are also poorly understood, but this information is essential for designing chronic disease services that are patient-centred and meet the needs of all people with OA.

Strengths and limitations of this study

- The recruitment strategy will involve major metropolitan and regional public hospitals, in addition to community-based recruitment, to improve external validity.
- This study will generate information about the perceived utility and accessibility of existing and proposed models of self-management education and peer support (including online resources, mobile applications and social media).
- A limitation of the cross-sectional design is that causal relationships cannot be established.

INTRODUCTION

Osteoarthritis (OA) is the most common form of arthritis and a leading cause of disability internationally.[1] In Australia, the condition affects over 1.6 million people and

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accounts for over $1 billion annually in direct health expenditure alone.[2 3] Although OA is more common in older age groups, approximately 25% of people with OA in Australia are under the age of 55 years.[3] OA in younger people is commonly secondary to other factors, including congenital disorders, sporting and transport-related trauma and work-related injuries. Data from the Australian National Joint Replacement Registry also highlight the impact of OA on younger people. Although the incidence of joint replacement surgery rises rapidly after the age of 60 years, 10% of hip replacements and 7% of knee replacements are undertaken in people aged less than 55 years, and this age group represents an increasingly large proportion of people undergoing hip resurfacing surgery for OA.[4] Younger people clearly comprise a substantial proportion of those affected by OA in Australia.

Hip and knee OA are associated with pain and a range of physical impairments which can impact profoundly on overall well-being.[5 6] However, despite the unique set of pressures faced by younger people (including work responsibilities and parenting roles), there has been little research into the well-being of those with hip or knee OA. As most research involving younger people with OA has focused on the outcomes of surgery to repair or replace damaged joints,[7 8] the quality of life and health status experienced by younger people remain poorly understood. This would form an important baseline in order to understand the impact of any intervention. Research in the USA has shown substantial arthritis-related activity and work limitations among people aged 18–64 years,[9 10] yet the challenges faced by young Australian workers with OA have not been explored.

Finally, the chronic nature of OA and limited healthcare resources mean that effective education and ongoing self-management are essential, particularly in view of the growing disease burden in many countries. However, the uptake of current arthritis education programmes is low[11 12] and many of the reasons for non-participation (such as work and family responsibilities[13]) are particularly relevant to younger people. In an era of widespread online communication and social media, there is scope to develop state-of-the-art self-management models that enable education to be accessed when convenient. This is particularly relevant for younger people who commonly access news and other information via portable devices. Research is needed to better understand the educational and peer support preferences of younger people with OA; this valuable information would assist in the design of new self-management models that best suit the needs of this group.

AIMS AND OBJECTIVES

The overall objective of this study is to investigate well-being and work participation among younger people with hip or knee OA, and preferences for OA education and support. The specific aims are to

1. Compare the Health-Related Quality of Life (HRQoL) of people aged between 20 and 55 years who have OA of the hip and/or knee with age-matched and sex-matched Australian population norms;
2. Evaluate health status, psychological distress and work limitations in this patient group;
3. Explore the utility of existing and proposed models of OA education and peer support.

METHODS AND ANALYSIS

Study design

A cross-sectional study will be undertaken.

Eligibility criteria

The eligibility criteria for the study are summarised in figure 1. To be eligible to participate, individuals must be aged between 20 and 55 years, have a diagnosis of hip and/or knee OA (based on an X-ray or other imaging, a doctor's report or a referral letter) and be fluent in English or have a proxy to assist with completion of the study questionnaire. Exclusion criteria include concomitant inflammatory arthritis (such as rheumatoid arthritis or ankylosing spondylitis) and overt cognitive dysfunction.

For participants recruited from public hospital sites, assessment of eligibility will start with screening of outpatient clinic lists and/or referrals and be confirmed through subsequent telephone screening by the study research assistant. For participants recruited through community advertising, telephone screening alone will be used to determine eligibility.

Procedure

Figure 2 presents an overview of the study design, including procedures for participant identification and recruitment. Participants will be recruited from the orthopaedic outpatient and Osteoarthritis Hip and Knee Service clinics at The Royal Melbourne, Geelong and Frankston Hospitals (major public hospitals in the state

Figure 1 Eligibility criteria.

Inclusion criteria	Exclusion criteria
• aged between 20 and 55 years • diagnosis of hip and/or knee OA* • be fluent in English or have a proxy to assist with completion of the study questionnaire	• concomitant inflammatory arthritis • overt evidence of cognitive dysfunction

*based on x-ray or other imaging, doctor's report or doctor's referral letter

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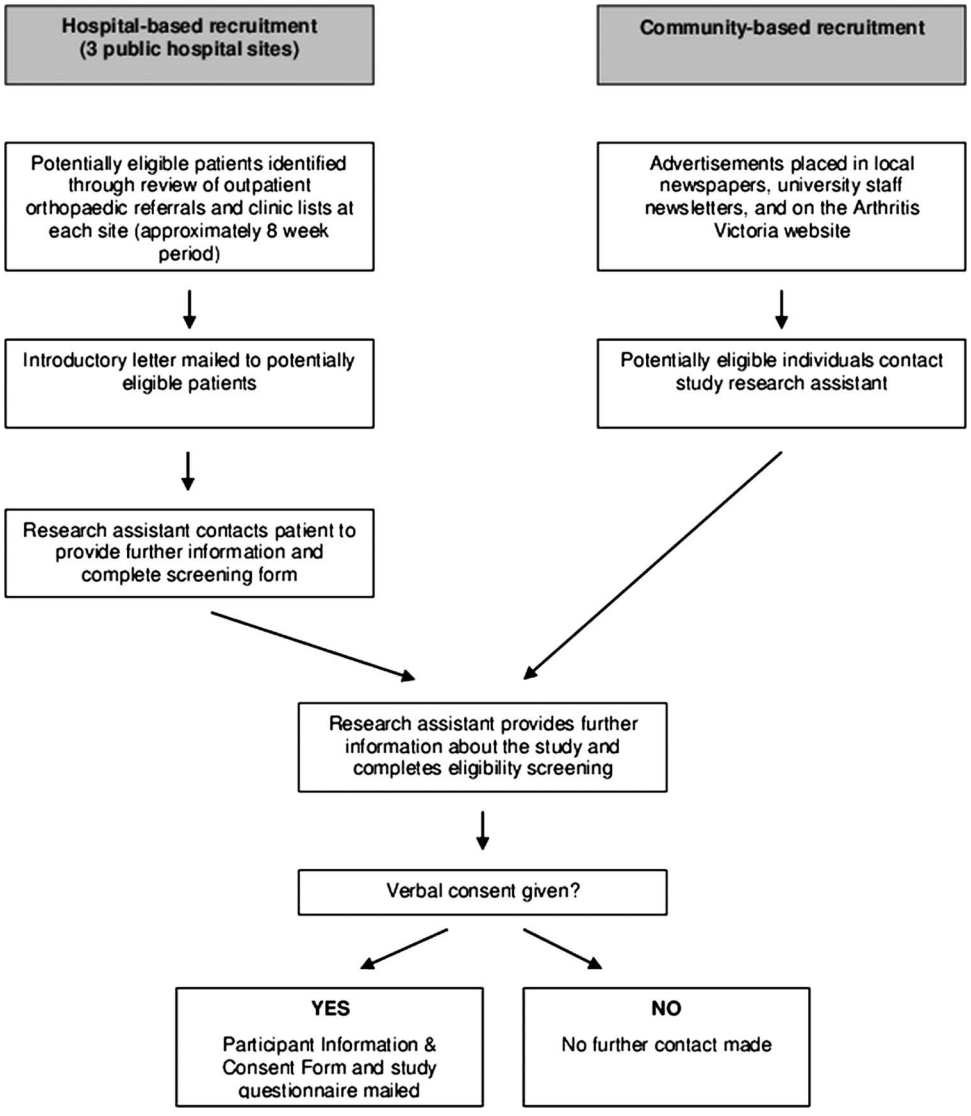

Figure 2 Overview of study design.

of Victoria) over approximately 8 weeks. Clinic referrals and clinic list records at each site will be screened regularly by a senior physiotherapist to identify potentially eligible individuals, based on their age and diagnosis. Completed screening forms will then be forwarded to the research team, and potentially eligible individuals will be sent an introductory letter signed by the head of orthopaedics at that site. The introductory letter will provide preliminary information about the study and invite participation in the research. We have used similar screening and recruitment procedures successfully in a previous hospital-based cohort study of people with severe arthritis waiting for joint replacement surgery and a multicentre trial involving people with hip or knee OA. After mailing of the introductory letter, potentially eligible individuals will be contacted by the study research assistant to provide more detailed information about the study. At this time, a short screening survey to confirm eligibility will also be conducted, as mentioned previously. Eligible participants who provide verbal consent will then be mailed a Participant Information and Consent Form and study questionnaire. A reply-paid envelope will also be provided to maximise response rates.

Community-based recruitment will be achieved through advertisements placed in local newspapers, university staff newsletters and on the Arthritis Victoria website. Interested, potentially eligible individuals will be invited to contact the study research assistant for further information and screening to confirm eligibility. As for the hospital-based recruitment strategy, eligible participants who provide verbal consent will then be mailed a Participant Information and Consent Form and study questionnaire, together with a reply-paid envelope.

Follow-up procedures

Non-returned questionnaires and missing item responses will be followed up by telephone and/or mail by the study research assistant.

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Outcome measures

A number of validated instruments will be administered in the study questionnaire. HRQoL will be assessed using the Assessment of Quality of Life (AQoL) instrument, a generic multi-attribute measure which has been used previously in studies involving people with arthritis.[5 14] The 12-item AQoL-4D will be used for this study; it covers the dimensions of independent living, relationships, mental health and senses. AQoL produces a utility score which ranges from –0.04 (worst possible HRQoL) to 0.00 (death equivalent) to 1.00 (full HRQoL). Negative AQoL utility scores represent a health state worse than death.[15] AQoL has been shown previously to have good psychometric properties.[16] For this study, AQoL scores will be compared with published Australian population norms which are stratified by age group and sex.[17]

Health status will be evaluated using the Western Ontario and McMaster Universities Osteoarthritis (WOMAC) Index. The WOMAC Index is a disease-specific health status measure widely used in OA research, and its validity and reliability have been demonstrated across multiple settings.[18] It consists of 24 items (5 pain, 2 stiffness and 17 physical function items) and produces 3 subscale scores which are summed to produce a total score. The WOMAC Likert V.3.1 will be used for this study. Total WOMAC scores will be transformed to a 0 (best health) to 100 (worst health) scale. The total WOMAC score will also be used to categorise OA severity, as validated previously.[19] A WOMAC score <7 is considered to be asymptomatic joint disease, 7–38 is considered to be a mild-moderate disease and ≥39 is considered to be severe joint disease.

The Kessler Psychological Distress Scale (K10) will be used to assess psychological distress.[20] The K10 scale was developed as a screening scale to detect non-specific psychological distress in the American population, and has also been used in the WHO World Mental Health Survey[20] and the Australian National Health Survey.[21] High K10 scores representing high psychological distress are known to be strong predictors of depression and anxiety.[22] The scale has previously demonstrated high internal consistency and discriminant validity.[20] This instrument contains 10 questions relating to anxiety, depression and worry and produces a total score ranging from 10 (lowest psychological distress) to 50 (highest psychological distress). For this study, K10 scores will also be categorised into levels of psychological distress according to the definitions adopted for the 2007–2008 Australian National Health Survey.[21] A K10 score <16 is considered to be low distress, 16–21 is considered to be moderate distress, 22–29 is considered to be high distress and ≥30 is considered to be very high psychological distress.

Work limitations will be assessed using the Workplace Activity Limitations Survey (WALS). WALS was designed to measure arthritis-related limitations associated with workplace activities, including difficulty in concentrating at work.[23] It consists of 12 items which also include response options for difficulty unrelated to arthritis and for tasks unrelated to the individual's job. The WALS produces a total score ranging from 0 (no workplace activity limitations) to 36 (greatest workplace activity limitations). Research undertaken by the instrument's developer found that scores of 0–4 were indicative of little or no difficulty at work, 5–8 indicated moderate disability and a score of ≥9 represented considerable workplace difficulty associated with poorer job outcomes (eg, greater absenteeism, more work interruptions and an inability to attend meetings or business trips) and a greater need for work modifications such as assistive devices and assistance from other people.[24] The instrument's psychometric properties have been summarised in a recent review of work disability and productivity measures[25]; there is evidence of internal consistency[23] and construct validity[26] from studies involving people with OA and inflammatory arthritis.

Participants will be asked about their previous use of different methods for obtaining information and support for their OA including group-based arthritis or chronic disease self-management programmes, online resources, telephone helplines and social media, and whether they have developed a goal setting care plan with a health professional. They will also be asked about the perceived utility of a range of existing and proposed models of self-management education and peer support, as listed in figure 3. Participants will be asked to respond to the question 'How useful would the following methods of providing education and support be for you?' on a visual analogue scale (VAS) ranging from 1 (not at all useful) to 10 (extremely useful) in relation to each model. Participants will also be asked to rate the perceived accessibility of each model ('How easy would it be for you to access education about your hip or knee osteoarthritis or support using the methods listed below?') on a VAS scale ranging from 1 (very difficult) to 10 (very easy).

The study questionnaire will also be used to collect information on educational attainment, marital status and paid and unpaid employment, as well as doctor-diagnosed comorbidities (asthma, diabetes, hypertension, increased cholesterol, coronary artery disease, anxiety or depression and other comorbidities), health services use for hip or

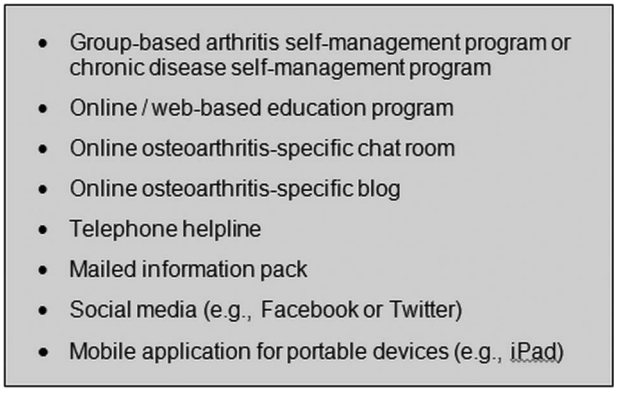

Figure 3 Existing and proposed models of self-management education and peer support.

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knee OA, medication use for hip or knee OA (including prescribed and non-prescribed medications) and past hip and knee surgery.

Sample size considerations

Sample size calculations are based on aim 1, using normative AQoL data from the Australian population aged 20–59 years.[17] A sample size of 175 is estimated to provide 80% power to detect a difference in HRQoL of 0.06 AQoL units between participants with OA and the age-matched and sex-matched population (assuming SD=0.2, 2-tailed test, α=0.05). This is considered to be a conservative estimate of difference and is based on the published minimal important difference for the AQoL instrument.[17] Our previous studies involving predominantly older people with hip or knee OA from the general community,[27] or people with severe arthritis waiting for hip or knee replacement surgery[5] showed much larger differences in HRQoL between the study samples and the overall (non-age-specific) population norms (≥0.18 AQoL units and 0.44 AQoL units, respectively). We plan to recruit approximately 50 participants from each of the three hospital sites and from the community, producing a total sample size of 200.

Planned statistical analyses

Analysis will be undertaken using IBM SPSS Statistics 21 (IBM, Armonk, New York, USA). Published scoring guidelines will be used to generate AQoL, WOMAC, K10 and WALS scores.[22 28–30] HRQoL, health status, psychological distress and work limitations data will be reported descriptively. HRQoL data will be compared with population norms using independent t tests, and associations between HRQoL, health status, psychological distress, work limitations and demographic factors will be evaluated using univariate (eg, analysis of covariance or linear regression) and multivariate analyses, as appropriate. Analysis of covariance will also be used to explore differences in HRQoL, psychological distress and work participation according to OA severity. A Bonferroni adjustment will be used for multiple comparisons to minimise the chance of type 1 error. Data on previous use of educational resources, and the perceived utility and accessibility of education and peer support models will be analysed descriptively and reported using frequencies.

Limitations

While these exploratory data will provide new information in this field, causal relationships cannot be established given the cross-sectional design. Although all recruitment and data collection will be undertaken within one Australian state, we anticipate that our use of both hospital-based (comprising metropolitan and regional hospitals) and community-based recruitment strategies will enable the findings to be generalised more broadly to younger Australians with hip and knee OA. Finally, we acknowledge that participants will not be recruited specifically through private hospitals; however, it is quite likely that some patients who receive OA care through the private health system will be recruited via the community-based advertisements.

Significance and expected outcomes

OA is the most common form of arthritis and a major public health problem in Australia and internationally. Studies on hip and knee OA have mainly included older adults and have shown that these conditions are associated with significant disability and reduced quality of life. However, little is known about the well-being or work limitations experienced by younger adults with OA, particularly in Australian settings. These data would also form an important baseline for understanding the impact of future interventions. Preferences for OA education and support among younger people are also poorly understood. This information is essential for designing chronic disease services that are patient-centred and meet the needs of all people with OA. Using an efficient methodology, the proposed study will generate comprehensive information about well-being, work participation and self-management preferences in younger people with OA. The findings will also directly inform a subsequent programme of related research, including the development and implementation of new models of OA education and support tailored to meet the requirements of this younger age group.

Ethics and dissemination

Ethics approval for the hospital-based recruitment has been obtained from the Melbourne Health, Barwon Health and Peninsula Health Human Research Ethics Committees. Ethics approval for the community-based recruitment has also been obtained from the Melbourne Health Human Research Ethics Committee. The study protocol has also been peer-reviewed by the Arthritis Australia Research Grants Assessment Committee. This study will be carried out according to the National Statement on Ethical Conduct in Human Research produced by the National Health and Medical Research Council of Australia.[31] Written informed consent will be obtained from all study participants, and participants are free to withdraw from the study at any time. Given the study design (cross-sectional, non-interventional), we do not anticipate any risks to individuals as a result of their participation in this research and access to OA care and management will not be affected.

All data will be stored securely at the co-ordinating site (Melbourne EpiCentre) and will only be accessed by authorised study staff. The data will be reidentifiable, with a unique code assigned to each participant for use on the questionnaires. Name and contact information will be stored separately from any information provided as part of the study questionnaire. Participants will be asked (as part of the study questionnaire) whether they would be happy for the researchers to contact them about future research studies involving younger people with hip or knee OA; however, participation in future

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studies is entirely voluntary and would require a separate ethics approval and informed consent process.

The study findings will be submitted to peer-reviewed journals for publication, and presented at national and international scientific meetings. The results will also be submitted to arthritis consumer organisations for broader dissemination, for example, via their websites, consumer publications and/or policy documents. A detailed summary of the results will also be submitted to Arthritis Australia to fulfil grant reporting requirements.

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Contributors INA and CAB conceived and designed the study, with additional input from RSP and PS. All authors contributed to drafting the article or revising it critically, and have approved the final version for publication.

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Competing interests None.

Ethics approval Melbourne Health, Barwon Health and Peninsula Health Human Research Ethics Committees.

Provenance and peer review Not commissioned; externally peer reviewed.

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Correction

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