**An exploration of the facilitators and barriers for people with osteoarthritis to engage in exercise – an exploratory approach with participant involvement’.**

Research Article

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**Abstract**

Background/Aims

The benefits of exercise on general health are well publicised and indeed more so for people with osteoarthritis (OA), but there is a lack of engagement in exercise by the general public, and further lack of engagement by people with OA. The reasons for this are not known, despite the clear benefits for both groups. The aim of the study was to explore the perceptions of Patient and Public Involvement representatives with OA on the facilitators and barriers for their engagement with exercise.

Methods

Using a qualitative semi-structured interview, transcripts of the participants’ conversations with the interviewer were analysed using thematic analysis.

Findings

Seven separate themes were identified. These were: type of exercise; benefits of exercise; drawbacks of exercise; effects of exercise; public information; psychological impact; and social support. The main findings indicate:

1. When a person knows and understands the health benefits of exercise, then they are more likely to engage in exercise.

2. For those with OA, greater emphasis on physical activity may be more useful to encourage engagement.

3. Simple, clear consistent messages related to exercise for people with OA are required from public health bodies.

Conclusions

These findings are useful to guide future research by informing which areas are important to people with OA when considering engagement with exercise. These may help with the design of studies and interventions. The use of language was particularly important when engaging with this group with older people expressing feelings of isolation where particular terms were used. There is a need for a consistent public information message to clearly communicate to the public about the benefits of exercise both on general health and for OA.

**Key Words**

Osteoarthritis

Exercise

Patient and Public Involvement

**An exploration of the facilitators and barriers for people with osteoarthritis to engage in exercise – a pilot study.**

**Introduction**

It is accepted that exercise promotes general health and well-being. The benefits of engaging with exercise are wide ranging and include decreases in joint pain, stiffness and anxiety, and improvements in sleep, mood, wellbeing and energy level (Andersen *et al.*, 1997; Marks & Allegrante, 2005; Deyle *et al*., 2005). Additionally for people with OA, exercise has specific noted benefit of strengthening muscles around joints to protect and absorb joint forces, reducing localised and generalised pain and decreasing the risk of co-morbidities such as heart disease (Andersen *et al.*, 1997; Marks & Allegrante, 2005; Deyle *et al*., 2005). In 2001, a study found that participation in moderate activity at least three times a week by older adults with knee OA resulted in a 47% reduction in the risk of developing arthritis-related disabilities (Penninx, et al., 2001). Arthritis Research UK (2013) advises regular exercise to ease joint stiffness and improve movement; strengthen muscles; aid weight-loss, thereby putting less strain on joints; aiding self-confidence and positivity, which can affect the way in which a patient copes with the condition. The National Institute for Health and Care Excellence (NICE) (2014) has recently updated its guidance for treatment of OA to include exercise as a core treatment, with advice to clinicians to encourage all patients with OA to participate regularly in some form of exercise.

Despite the known benefits of exercise on general health and, more specifically, on the effects of OA, people do not engage with exercise to recommended levels. NHS Choices (2013) details recommended activity levels for adults aged 19-64, stating that to sustain health benefit at least 150 minutes of moderate-intensity aerobic activity and muscle-strengthening activities on at least two days should be the minimum amount of exercise per week. However, only a minority of people attain these levels(British Heart Foundation Health Promotion Research Group, 2012)and for the OA population thisis even less. In 2006 it was reported that 44% of people with OA do not engage in any form of exercise compared to 36% of people without OA (Shih et al., 2006).

The reasons behind lower than recommended engagement with exercise for people with OA remain unclear. It is unknown to what degree people with OA feel supported to engage with exercise and what barriers exist to their participation in exercise. This study explored the facilitators and barriers to engaging in exercise for people with OA

A facilitator is defined as a factor that encourages, aids or enables a participant to engage in exercise.

A barrier is defined as a factor that discourages or prevents a participant engaging in exercise.

**Patient and public involvement in research**

This study recruited people who had self-reported OA and were already registered as Patient and Public Involvement (PPI) group members on a national data base held by the University of Southampton. This study aimed to ask PPI group members their opinions about what helps and limits their ability to exercise to help inform wider research approaches carried out within the Arthritis Research UK Centre of Excellence for Sport, Exercise and OA. The engagement of patients and the public in helping research staff to understand key issues relating to specific research enquiry from an early stage of the research process helps ensures quality, appropriateness, acceptability and relevance of research by making sure that the research addresses important issues for patients and the public (Staniszewska & Denegri, 2013; INVOLVE, 2013). The National Institute for Health Research (NIHR) (2013) encourages the active involvement of patients and members of the public in NIHR-funded research to deliver people focused clinical research leading to better research, clearer, more relevant outcomes and faster uptake of new evidence. The involvement of patients and the public also helps inform the development of effective interventions.

**Research Aim**

This study aimed to explore the perceptions of people with self-reported OA registered on a national PPI database about what facilitated their engagement with exercise and what acted as barriers to them engaging in exercise.

**Research Question**

What are the facilitators and barriers for people with OA to engage in exercise?

**Methodology**

The use of qualitative research makes sense of people making sense by exploring the issues and understanding phenomena. The importance is placed on what has been said rather than how many times it has been said, creating an in-depth understanding of human behaviour through the “how and why” not the “where and what”.

The data were analysed through thematic analysis. Thematic analysis is used to identify, analyse and report upon themes within a data set – a selection of interviews in this instance - often interpreting various aspects of the topic of research through analysis of repeated patterns of meaning (Boyatzis, 1998; Braun & Clark, 2006). The advantages of using thematic analysis include the flexible, numerous ways in which it can be applied. Thematic analysis was chosen for this study as it is useful in a situation where the participants are collaborators within the study (Braun & Clark, 2006). It can be used to show clear themes making sense of the data to persuade the reader that the argument is plausible, thus resulting in a data set that can be used to inform future research (Foster & Parker, 1995).

**Inclusion Criteria**

Participants were included in the study if they had already registered as Patient and Public Involvement (PPI) Representatives for the University of Southampton Health Sciences OA research group and had already expressed an interest in taking part in studies that sought PPI associated with the Arthritis Research UK Centre of Excellence for Sport, Exercise and OA.

**Recruitment**

Participants were identified by alphabetically going through the data base and consecutively contacting people by telephone to ask if they would be happy to learn more about the study and take part in a telephone interview exploring the facilitators and barriers to engaging with exercise. Those that agreed to take part were sent a participant information sheet and a consent form to complete.

**Ethical Considerations**

As this study facilitates the active involvement of PPI reps in the role of specialist advisers providing guidance and valuable knowledge from a unique perspective, ethical approval was not needed (NIHR, 2009). However, the principles of research governance were still applied. . Participants’ information was kept confidential with anonymity assured. The participants were encouraged to pose questions throughout the study and were informed of their right to withdraw at any time.

**Participants**

Eight PPI representatives were approached to take part in the study, seven agreed to do so and one declined. They lived across the UK and had experienced OA from between 4-20 years. Three participants had already undergone joint replacement surgery and hip OA was the most commonly reported OA site. The demographical data are shown in Table 1.

**Table 1: The demographics of the participants**

(n = 7)

|  |  |  |
| --- | --- | --- |
| **Gender** | Male | 3 |
|  | Female | 4 |
| **Age of participants (years)****Median and range from x-7**  | MedianRange | 6865 – 78 |
| **Length of time since diagnosis of OA median and range (years)** | MedianRange | 174-20 |

**Feasibility study**

A feasibility study was carried out with one participant to test the data collection procedures and ensure the face validity of the interview questions. This interview showed that more time for the interviewee to respond to each question was required and also re-ordering the questions would help the interview to flow more smoothly. An introductory paragraph was also added to the interview script to clearly explain the purpose of the study and the aim of the questions.

**Results**

Seven themes surrounding the facilitators and barriers for people with OA to engage in exercise were identified. These were:

 1) Type of exercise

 2) Benefits of exercise

 3) Effects of exercise

 4) Drawbacks of exercise

 5) Accessibility of Public Information

 6) Psychological impact

 7) Social support

A summary of the findings from this study are outlined in Table 2.

**Table 2: Summary of findings**

|  |
| --- |
| * Type of exercise – informal, formal, structured
* Benefits of exercise – physical, mental, for OA
* Drawbacks of exercise – effect on activity, part of exercise, none identified, none personally
* Effects of exercise – lack of exercise on health and OA – negative
* Public Information – activity vs. exercise, lack of knowledge about cause of OA and benefits of exercise for OA. General public information message about exercise
* Psychological Impact – denial and age, motivation, goals, perception of OA, acceptance, resignation, coping strategies, continue life as normal, longevity
* Social support - influence and support of others
 |

**Theme 1: Type of exercise**

The participants defined ‘exercise’ as a broad term covering many different activities.

*“It’s a very wide term that covers almost anything that involves some sort of heightened physical activity.” (PPI2)*

The type of exercise could further be split into formal and informal exercise. Formal exercise was defined as structured, often gym-based, fitness regimes.

*“Something…I take very seriously and is a very regular part of my regime, is I do pilates…it’s quite intensive.” (PPI2)*

Informal exercise was considered to be housework, gardening or taking the dog for a walk. Exercise was also prescribed as a treatment.

**Theme 2: Benefits of exercise**

All participants identified the physical benefits of exercise.

*“Increased stamina, strength…in fact, I remarked after I’d been going for a couple of years, I felt that I was more robust than I was ten years before.” (PPI3)*

Equally as important were the mental health benefits.

 *“It does help, it’s the only thing I’ve found that does help… It’s just giving you something to live for, and well you feel stronger immediately, it’s better than a pill, it really is.” (PPI6)*

Benefits of exercise for OA were also mentioned.

*“I understand that exercise is important for people who’ve had osteoarthritis.” (PPI2)*

Between them, the participants identified that benefits of exercise exist both for overall wellbeing and specifically for OA.

**Theme 3: Drawbacks of exercise**

Some participants identified drawbacks of exercising directly affecting their own activity level.

 *“If I overdid it, could that actually bring forward the time when I might need to have surgery on my other hip.” (PPI2)*

Drawbacks that were accepted as part of exercise were also mentioned. However it was not a complete consensus and other participants expressed the belief there were no drawbacks of exercising. Others were aware of drawbacks, but did not link them to their own condition.

 *“Well you can overdo it obviously can’t you. I suppose, pull your muscle or something… But er… no I can’t, not for myself, I can’t see any drawbacks at all.” (PPI4)*

This theme indicated a variation in experiences and opinions from each participant on the drawbacks of exercise.

**Theme 4: Effects of exercise**

All participants identified effects of a hypothetical lack of exercise on their general health and on their OA.

*“I think it would affect me on two levels. I think it would affect my physical state – I’d become less active, less fit and less active, and I think in a way it’s a sort of downward spiral actually because your body begins to go to fat. But for me, equally important for the physical, is the mental state” (PPI2)*

*“I would feel very sluggish and not very well at all to be honest. I think the joints would be much more swollen for a longer period.” (PPI5)*

The consensus of all participants was that a lack of exercise is detrimental to the health and wellbeing of an individual.

**Theme 5: Accessibility of Public Information**

The use of language when engaging with this group of people was considered to be very important by all participants. They felt that the use of the word “activity” was a much better replacement for “exercise”, stating that exercise brings to mind ideas of sweating in a gym, whereas activity can be used to cover anything that involves physical activity.

*“I think if you’re trying to appeal to a really wide audience, activity may be a better word. Some people may think exercise means, “oh God I’ve got to join a gym, I need to buy special kit.” You know. Erm… whereas activity, to me, covers a range of things, erm… and, er… some people may interpret things as an activity, which have exercise benefits.” (PPI2)*

*“Exercise is a bit too scary sounding, you know. I think activity is a much better word.” (PPI6)*

This is of particular note for this pilot study, as it will inform future studies into the engagement in exercise of people with OA. In order to engage the participants in the study, the language used should be considered. Instead of “exercise”, the word “activity” was suggested by more than one participant, chosen as a broad, encompassing word designed to define any form of heightened physical activity and to include all groups of people.

There was also a lack of knowledge about the cause of OA, and additionally regarding the benefits of exercising with OA. It was suggested that a public information message would be helpful, such as those targeted for various health problems to the areas of the population most likely to develop them.

“*I think more could be done to target people with information. And a good example that I can give you of that is that…I received a very good little information leaflet on prostate cancer. Now I’m clearly a prime candidate for prostate cancer –I’m a 68 year old male, and prostate difficulties are something that’s extremely prevalent in my age group and my gender. And it made me think, I wonder if part of a public information campaign, whether there could be a similar kind of targeting of information about osteoarthritis.” (PPI2)*

**Theme 6: Psychological impact**

The idea of denial in relation to age was mentioned by one participant, who admitted he had also been in denial about his OA and the need for surgery, because that was something old people had.

*“And I don’t know whether it’s to do with thinking that, you know, having surgery is a sign of aging and therefore if I have it done, I’m acknowledging the fact that I’m getting old.” (PPI2)*

Conversely, the acceptance that age will limit the range of activities was another idea put forward. However, whilst one participant accepted that age was inevitable, he admitted he would not be held back by it.Age was also identified as a motivator for continuing to exercise and maintain a level of fitness. Whilst another participant accepted that she was getting older and was somewhat resigned to that fact, motivation was a key psychological factor for engaging in exercise. Goal driven exercise meant the participants had something to work towards. And the perception of OA was that it was something that was part of life and there were others with worse problems. Whilst mostly positive in nature, there was a general acceptance and resignation amongst the participants.

*“I’m well aware that, I’m now 70, and I’m well aware of the “use it or lose it” element.” (PPI3)*

*“I don’t do cycling obviously because I’m an old lady (laughs). And the only difference really is because I’m getting older I’m getting a bit slower at doing everything.” (PPI4)*

The acceptance of aging could be considered a facilitator to a healthy, sensible level of exercise. However, all participants reported they were able to take part in some form of activity.

All PPI participants described their experiences that illustrated an attempt to continue their life as normal by taking control.

*“In some things I’ve devised strategies which have become second nature now, so that I’ve just modified the way I do things. Picking things up for example, taking the weight on my fingers rather than the thumbs, and things like that, you know? So that it’s no longer an issue because I’ve thought my way round it.” (PPI3)*

The participants mentioned the need to maintain their quality of life by making changes to their activities and behaviour in order to take control of their situation. The majority acknowledged that it was their responsibility to manage their OA and they expressed pride in being able to complete tasks without assistance. They explained that taking control was important for management of OA as no one else would be as personally invested in the maintenance of the condition.

**Theme 7: Social support**

An important factor was the influence of others, including the effect of the strong words of a friend as a catalyst for one participant to move forward with a hip resurface.

*“Friends of mine were saying, “look, you’re walking like an old man.” (PPI2)*

The support of others was also highlighted by participants.

*People say to me, they’re so encouraging, [they] have never seen me other than walking with a stick and being tired. “…now you are almost a completely different person!” (PPI6)*

The support of others is defined by the participants as emotional support, positive feedback and negative feedback. It is interesting to note from the two examples above that one participant found the comment that they were looking old as motivating, whilst another participant found a positive compliment provided the support and motivation required. These two opposite forms of feedback were both considered supportive, and it is important to be aware of the individual and how they may react to perceived social interactions.

**Discussion**

The type of exercise, and the differences in opinion on what constitutes exercise shows the importance of finding the type of activity that works for each individual. The type of exercise chosen by an individual varies depending on personal opinion or experience. The acceptance that each individual will find a certain form of exercise to be the type that they enjoy, plus the acknowledgement that there is no one “correct” form, is a facilitator of the engagement in exercise. The participants agreed that a barrier for their engagement in exercise was the idea that it had to be structured and formal. This was felt to be intimidating and off-putting for most and participation suffered as a result. However, the participants did identify less formal and unstructured exercise, such as housework or walking the dog and some were aware that this “counted” as completion of activity. This acknowledgement was identified as a facilitator in their engagement in the activity. The prescription of exercise as treatment could be considered a facilitator if the patient perceives the physician as autocratic and relies heavily upon their judgement and advice (Goold & Lipkin Jr., 1999).

If people are able to recall knowledge of the benefits of exercise, whether this be physical, mental or for the positive effect on OA, this can act as a facilitator in the engagement in exercise. The participants in this study knew of the benefits of exercise on their general health and well-being. However, a perceived lack of knowledge of the benefits would be a barrier to the engagement in exercise, as without knowing the positive effects exercise has on OA, or indeed general health, a person may be unlikely to partake in physical activity.

The physical benefits of exercise are well publicised with numerous studies providing evidence to support these claims and it is useful to identify that this research indicated that these benefits can be recalled by people with OA (Centers for Disease Control and Prevention, 2011; NHS Choices, 2013; Warbuton, Nicol, & Bredin, 2006). The literature indicates that people with OA are less engaged in exercise than the general public (Shih et al., 2006).It is also interesting to note that the participants identified the mental health benefits, which whilst identified as a benefit by some is less well known or understood (Sharma, Madaan, & Petty, 2006).

Whilst some participants did not agree there were drawbacks of exercise, others expressed the belief that too much can be damaging through overuse injury. The mix of individual experiences within this theme indicates that perhaps further public information on the potential problems of exercise would be beneficial to ensure the correct techniques, or the types of exercise to avoid injury, especially to arthritic joints. Clear simple messages on how much exercise may be too much and what may constitute over use are required. Knowledge of drawbacks and awareness and limits of exercising with arthritis could facilitate a healthy engagement in exercise. The role that excessive exercise and lack of knowledge about whether this can be detrimental to joint health and overall wellbeing could act as a barrier to participation in exercise. It is interesting to note that some participants did not identify any drawbacks at all, and this may either be a lack of awareness of the problems associated with overuse injuries and joint damage from too much exercise, or a positive outlook on the beneficial effects exercise has. From our study it was evident that people need to have accessible information available to help support them make an informed decision about how much exercise to do.

The awareness of the effects of exercise was identified by all participants, and this awareness facilitates an informed engagement in exercise. This awareness of the hypothetical effects of a lack of exercise could be a facilitator in the engagement in exercise to ensure no negative effects or to prevent the progression of problems, prolonging the movement at a joint and slowing the progression of pain and OA.

Participants identified the lack of clear messages regarding the benefits of exercise, and this could act as a barrier to those who are not already aware of the benefits. The public health information message identified is very useful for the education of the wider population as to the benefits of exercise. With a focussed campaign it may be that the progression of the damage, pain and disability in an individual could be slowed merely from an increase in daily activity. The use of language should be carefully considered, as many participants agreed that “activity” was a much friendlier word. Indeed, an individual may be of the opinion that they are not able to take part in “exercise” but that they participate in “activity” on a daily basis. Additionally, the use of the word “exercise” could actually be a barrier for certain demographic groups due to the imagery associated with it.

The psychological impact of exercise and whether this is a barrier or facilitator depends upon the impact itself, but also on the individual person. The denial of aging could be either a facilitator or a barrier depending on whether or not this denial results in over-exercise and resultant injury. Motivation is a facilitator where it exists, but a lack of motivation will of course be a barrier. Having goals set to achieve can also be either a facilitator or a barrier depending on whether or not those goals are achievable. An unachievable or high-pressure goal will likely serve to demoralise the person and put up a future barrier to their participation in exercise.

An awareness of the need to take control through the development of coping strategies, the need to continue life as normal and maintain longevity is a facilitator to the engagement in exercise as it gives the individual power and control over their condition.

The support and influence of members of an individual’s social group will facilitate supported participation in exercise. This can be either positive or negative, and the perceived benefit will depend upon the individual receiving the input.

It is clear that being the recipient of some form of social support had been beneficial to the participants (Vassilev, et al., 2013).

The use of group therapy, team work, team programmes and shared goals could also be beneficial for individuals, and could be considered for the public information messages mentioned previously (Vassilev et al., 2011).

**Conclusion & Clinical Application**

The themes in this study identified facilitators and barriers for the engagement in exercise of those people with OA.

The findings of this exploratory PPI study can be used to guide what should be asked in future studies into the facilitators and barriers of the engagement in exercise and activity of people with OA, helping to inform the design of effective interventions.

The key findings were as follows:

1. The use of language to engage with this participant group.
	1. Elite athletes will understand terms currently used
	2. Older people with OA who do not have a sporting background could be isolated by terms such as “sport” and “exercise”
	3. Use of language should be considered depending on target audience in practice.
	4. Use of word “activity” to engage ordinary older people in practice.
2. Lack of knowledge recall for benefits of exercise for OA
	1. Need for a clear public health information message to educate general public
	2. Include details about:
		1. benefits of exercise for OA
		2. general physical and mental health benefits
	3. Use of the word “activity” in place of “exercise”
	4. Send to a target audience in a similar vein to at-risk groups receiving targeting information.
3. Group and team work for social support
	1. Dealing with OA
	2. Engaging in some form of activity
	3. Guide support programmes
		1. Support
		2. Shared goals

**Limitations**

There were limitations associated with this study. We recruited people who were already proactive individuals who had already demonstrated a keenness to participate in research and had registered as PPI representatives. They also all engaged in some form of exercise. Thus this study cannot report on people who are not currently engaging in exercise and we recommend further study in this area. This study recruited a small convenient sample size due to time limits and project boundaries and it is not known if data saturation was reached. In addition, respondent validation which was not carried out due to time limits would have been beneficial. However, this research did identify some key issues that have so far not been reported in the literature and provide a sound understanding for developing future research into the factors behind engagement with exercise.

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