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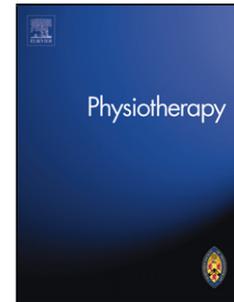
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Keeping physically active with rheumatoid arthritis: semi-structured interviews to explore patient perspectives, experiences and strategies

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Abstract

Background: Regular physical activity is safe and beneficial for people with rheumatoid arthritis (RA) but the majority of people with RA are less active than the general population and have a higher risk of co-morbidities. Exploring strategies used by physically active people with RA could inform effective methods to support those who are less active.

Objective: To explore the perspectives, experiences and strategies employed by people with RA who successfully engage with regular physical activity.

Design: Individual semi-structured interviews and thematic analysis.

Participants: A purposive sample of physically active people with RA.

Results: Twelve females and three males participated (mean age 56, range 29-80; mean disease duration 13 years, range 10 months to 46 years). Analysis revealed eight constructs clustered into three themes. Theme 1: 'the individual' incorporated constructs of symptoms, feelings and role; theme 2: 'management' incorporated medical and self-management; theme 3: 'physical activity' incorporated constructs of type of physical activity, including barriers or facilitators. Participants reported a long history of physical activity prior to diagnosis and good support networks. All participants recognised that physical activity was key to their RA management, acknowledged the benefits from engaging in physical activity and were able to overcome barriers. Participants

had strong beliefs that physical function would decline without regular physical activity.

Conclusions: People with RA who successfully maintain physical activity are motivated by a desire to manage symptoms, resist functional decline and maintain health and independence. These findings should be explored with a wider range of people with RA.

Contribution of paper:

- People with RA who are successfully maintaining physical activity are doing so in order to manage their symptoms, resist functional decline and maintain health and independence.
- Health professionals delivering exercise interventions for people with RA should consider these motivating factors. If people with RA can be facilitated to engage with appropriate levels of physical activity there is potential for enhancing longer term health and function.

Keywords: Rheumatoid Arthritis; Physical Activity; Engagement

Introduction

Rheumatoid Arthritis (RA) is an inflammatory polyarthritis and is the most common form of chronic joint inflammation. It is characterised by synovitis resulting in bone erosion, cartilage damage and joint destruction [1]. RA affects 1% of the population in the United Kingdom (UK) [2] with a higher prevalence among women [3]. Symptoms include pain, fatigue and morning stiffness, leading to impaired physical function [4]. Traditionally, patients with RA were advised to avoid regular exercise as it was thought to exacerbate joint damage

[5]. However, research carried out in the last twenty years has provided strong evidence that regular physical activity is beneficial to patients with RA [5].

A Cochrane review [6] concluded that a combination of aerobic capacity training and strength training should be carried out routinely by patients with RA. Furthermore, exercise has been shown to be fundamentally beneficial for patients with RA and it is recommended that all patients with RA should be encouraged to include aerobic and resistance training as part of their routine care [5]. The benefits noted were increased cardiorespiratory fitness and cardiovascular health, increased muscle mass, decreased adiposity and improved strength and physical functioning. Importantly, no aggravation of symptoms or joint damage was found [5, 6].

Although the benefits of exercise for patients with RA are well documented, many patients with RA are less active than the general population [7-10]. It is recommended that in the general population, individuals undertake at least 150 minutes per week of moderate intensity physical activity, or at least 75 minutes of vigorous intensity physical activity [11]. In a large study across 21 countries, Sokka et al [9] studied the prevalence of physical activity and found that in the UK based sample of patients with RA, 68% carried out no regular physical activity. Studies [5, 12] have identified that fatigue, pain, decreased mobility, lack of professional input, inaccessible facilities, surgery, medications, potential embarrassment, fear of falling and the psychological effects of RA are barriers to physical activity in RA. It is clear that further research on how to incorporate exercise into the lives of people with RA and exercise adherence is required. This is confirmed in the National RA guidelines which highlight that issues of adherence could be as important as the activity itself [13].

In one of the few qualitative studies in this field Wilcox et al [14], using a focus group approach, examined perceived exercise barriers, enablers and benefits among exercising and non-exercising adults with arthritis (largely osteoarthritis). They found that exercisers and non-exercisers were aware of the benefits of exercise and identified similar barriers but the exercisers were able to overcome these barriers whilst non-exercisers were stopped by them. The exercisers identified specific behavioural enablers for exercise, such as prioritisation and scheduling of exercise, and goal setting and stated that internal motivation and self-regulatory skills were also important.

Despite the barriers to physical activity (including exercise), a minority of people with RA do successfully engage with regular, long term physical activity. Exploration of the physical activity experiences, perspectives and strategies used by physically active people with RA could provide useful learning for health professionals attempting to engage those who are less active. The results may inform the development of a theoretical model for enhancing patient engagement with physical activity and therefore promote self-management. If physical activity levels in patients with RA can be successfully increased then this could improve the longer term health status of these patients leading to a reduced need for healthcare. Overall, this may lead to a decreased burden on the NHS and economic savings which are crucial in the current economic climate. The primary aim of this study was to explore the experiences, perspectives and strategies employed by people with RA who are successfully engaging with regular physical activity in its broadest sense, as well as specific exercise.

Method

Ethical approval was granted by the Oxford C Research Ethics Committee (ref 13/SC/0418). Semi-structured interviews were undertaken to allow in-depth exploration of the participant's attitudes, behaviours and experiences surrounding physical activity. Semi-structured interviews were selected to allow the complex issues relating to physical activity adherence to be investigated using the participant's own words. In addition they provided a flexible approach to be taken allowing important topics to be explored and probed [15]. Each participant was interviewed by one researcher (RT) for up to 60 minutes on one occasion. Interviews took place in an outpatient Rheumatology clinic. Socio-demographic details were collected at the beginning of the interview (gender, age, employment, education, ethnic status, duration of RA and co-morbidities).

The interview guide was developed by the research team including input from the patient partner, a physically active female living with RA for a number of years (CS). It consisted of neutral, open questions. To begin the interview general introductory questions relating to disease duration, progression and symptoms experienced were asked. Topics explored were physical activity participation prior to diagnosis and currently, barriers and facilitators to physical activity, and impact of physical activity on physical and psychological functioning. Further to this, strategies that the participants used to engage with physical activity including goal setting and social support were explored. A flexible approach was maintained and any new topics that evolved were discussed if related to physical activity. A pilot interview with the patient research partner (CS) was conducted to ensure that the proposed topics enabled relevant discussion. Interviews were digitally recorded (with the

participant's permission) and only brief notes were made by the researcher during the interview process, enabling the researcher to attend fully to the participant. Authenticity of the data collected was maximised by the researcher providing a neutral introduction to the study aim, emphasising confidentiality and avoidance of leading or biasing questions including the use of neutral probes.

Participants

Inclusion criteria were individuals aged ≥ 18 years who were able to speak and read English, and had a confirmed diagnosis of RA [16] at least 6 months before. Purposeful sampling was used to recruit individuals who self-reported undertaking physical activity at moderate intensity for at least thirty minutes on ≥ 3 days a week for at least six months. Furthermore, sampling aimed to recruit participants of both genders with a range of ages and years since diagnosis. Potential participants were identified via clinicians or responded to posters in an outpatients Rheumatology clinic before being screened by telephone by the researcher (RT) to check for eligibility.

Analysis

Interviews were transcribed, checked and anonymised. Inductive thematic analysis was conducted following a Braun and Clarke approach [17] which allowed for codes and sub-codes to describe themes as they were observed in the data. A deductive approach was not appropriate as theoretically driven coding may not have captured the full experience of the participants. Transcripts were read once to get a sense of the whole then re-read to begin the coding process. Once identified, codes were explored for common groupings and were categorised accordingly. Overarching themes and links

between categories were identified. Themes and sub themes were presented in the form of a thematic map. Anonymised quotations exemplified each sub theme. Analysis of the data from the transcripts was carried out concurrently with data collection in order to improve moderation techniques and maximise information gained. Data collection continued until no new codes or themes emerged. Due to this being a small scale study, data were categorised manually. In order for rigour to be achieved two transcripts were analysed independently by two researchers (RT and FC) and the patient research partner (CS) and findings compared and discussed to reach a common understanding. Themes were compared and discussed prior to the final analytical model being agreed with the full team. Care was taken throughout not to lose the richness of the qualitative data.

Results

Twelve female and three male participants were recruited (mean age 56 years, range 29-80; mean disease duration 13 years, range 10 months to 46 years). All participants described their ethnic status as white British. Levels of educational attainment ranged from none to master's degree level. Thirteen participants reported co-morbidities (Table 1). Analysis revealed eight constructs which were clustered into three themes reflecting the interlinking factors affecting participant's engagement with physical activity. Theme 1 was 'the individual' which incorporated constructs of symptoms, feelings and role; theme 2 was 'management' incorporating constructs of medical and self-management; theme 3 was 'physical activity' which incorporated constructs of the type of physical activity undertaken including barriers or facilitators.

The Individual

Symptoms

Both physical and psychological symptoms were reported and included pain, stiffness, swelling, weakness, fatigue, joint deformity, anxiety, depression and flares. Although the severity and frequency of symptoms were wide ranging, many participants described an ability to continue with physical activity:

"I can go in [to the gym] a bit stiff or with pain in my knee and things and if I keep going those pains go"

(Female aged 69, RA for 22 years)

"my flares usually happen like now when I have had to stop my anti TNF but I will still try to do my exercises"

(Female aged 34, RA for 25 years)

Feelings

Participants reported enjoying physical activity and displayed high levels of exercise self-efficacy and strong beliefs that physical function would decline without regular physical activity.

"I am much happier being active and I think it feels really good to get my heart rate up and cycle up a bit of a hill"

(Female aged 29, RA for 10 months)

"I know exactly what I can get out of myself every day"

(Female aged 43, RA for 10 years)

“If I didn’t go to the gym well I would most probably be in a wheelchair.”

(Male aged 54, RA for 17 years)

Role

Participation in physical activity allowed participants to live what they considered a 'normal' life and promoted a sense of belonging to and contribution to society.

“[Without physical activity] I won’t be able to live anywhere near as normal life as possible which is what’s important to me.”

(Female aged 34, RA for 25 years)

“you know you have got a right to be in society as well you shouldn’t be tucked away and apologise for stuff.”

(Female aged 50, RA for 8 months)

Management

Medical management

The need for effective medication was recognised as important to participants.

“It’s [medication] enabled me to have a great 20s/30s.....I have a life, it’s enabled me to do all that.”

(Female aged 34, RA for 25 years)

“If you are on the right medication then you can sort of do things for yourself”

(Male aged 54, RA for 17 years)

Self-management

All participants recognised physical activity played a key role in the management of their RA and all recognised benefits from engaging in physical activity. Planning, pacing and being in control were frequent topics of discussion. Many participants took a whole lifestyle approach to the management of their RA.

“I realise that if I get my small bit in [walking] and have a day you know a day’s break in between so like Monday, Wednesday, Friday then I am all right”

(Female aged 43, RA for 10 years)

“After I have been to the gym I feel really good you know because you get the adrenalin pumping and it does make me feel really good”

(Male aged 54, RA for 17 years)

“I would always plan to walk if I was going anywhere, and could, rather than take the bus”

(Female aged 44, RA for 2 years)

Physical activity

Types

Activities with a social element, dog walking, cycling or walking as a mode of transport, yoga, attending the gym and hydrotherapy were popular types of activity.

“I run around with her [dog] and run up the stairs and play hide and seek with her....she makes me carry on”

(Female aged 67, RA for 3 years)

“you perhaps do things that you don't think you are capable of because you are in group exercise so everybody else is doing it”

(Female aged 52, RA for 26 years)

Facilitators

Many participants reported a long history of being physically active prior to diagnosis and most had good support networks. Presence of symptoms was often used as a motivation to be active.

“I have always been active you know, not sports active, I don't do any sports.”

(Male aged 80, RA for 2 years)

“I suppose one of the main things is if you have got a partner and you both are involved in things the same sort of things it makes a big difference if there are two of you.”

(Male aged 71, RA for 10 months)

“It [yoga] loosens up in a gentle way really I am doing lots of sort of breathing with it just sort of a very gentle movement and stretch and just realigning the body for the day”

(Female aged 50, RA for 8 months)

Barriers

Participants were able to overcome barriers such as pain and loss of motivation.

Many demonstrated resilience and felt it was important to 'keep going'. A

minority reported feeling hesitant about group activity with the general population due to fear about not being able to keep up or a lack of understanding of RA.

“I mean I do go when I am in pain and you know can’t do much because I just like it, because socially it is good as well it does cheer you up to see people and talk to them”

(Female aged 69, RA for 22 years)

“Some days I think oh I just don’t really want to do it [exercise] and I think well if you don’t you are going to ache a bit so I do it”

(Female aged 61, RA for 7 years)

“I suppose I would worry I couldn’t do the stuff [group exercise] or keep up I am very wary (laughs) because sometimes people don’t understand”

(Female aged 50, RA for 8 months)

Discussion

The aim of this study was to explore the perspectives, experiences and strategies employed by people with RA who successfully engage with regular physical activity. Findings showed that physically active participants had high levels of exercise self-efficacy and strong beliefs that physical function would decline without regular physical activity. All participants recognised physical activity as key for RA management; recognised the benefits of physical activity; and were able to overcome barriers including pain and loss of motivation. The majority of participants reported a long history of physical activity prior to diagnosis and had good support networks. Participation in physical activity

promoted a sense of a normal life and belonging to and contribution to society. These findings are supported by two recent studies [18, 19]. Iversen et al [18] conducted structured interviews to explore perceptions of physical activity engagement in adults with RA and reported that highly active individuals viewed exercise as symptom management and had a greater perceived ability to overcome setbacks than those who were less active. Furthermore, for highly active individuals, exercise was habitual and participants viewed exercise as a means of achieving control over their RA and maintaining independence. Similarly, Loeppenthin et al [19] conducted semi-structured interviews and concluded that physical activity could be seen as 'a resource to resist disability and stay healthy'. Maintenance of physical activity was a way of taking responsibility for life. Similarities in demographics can be found between the participants in this study and the studies of Iversen et al [18] and Loeppenthin et al [19] yet these studies were conducted in the USA and Denmark respectively where health services differ from the UK. Participants across these studies may therefore have received differing levels of healthcare input.

It could be established that people with RA who are successfully maintaining physical activity are doing so in order to manage their symptoms, resist functional decline and maintain health and independence. Less active people with RA, however, may perceive that they are unable to overcome symptoms in order to maintain physical activity. It was clear from the current study that it was important to participants that in order to be able to maintain physical activity and effectively engage in self-management, medication needed to control their symptoms, a finding supported by Withall et al [20]. Self-management refers to an individual's ability to manage the consequences and lifestyle changes associated with living with a chronic condition [21, 22]. Participants appeared

to be proactive in making lifestyle changes which involved planning, prioritising and pacing leading to what they considered as achieving balance in their lives.

A finding of particular interest was that physically active participants felt a sense of normality and a feeling of being part of society. A similar finding was noted by Loeppenthin et al [19] who summarised this as 'social participation on equal terms with non-arthritis populations'. One participant in the present study explained this by saying,

“..well if you are walking around or you are swimming you are doing the same as everybody else, they may be going faster than you but you are still in that part of society..”

(Female aged 66, RA for 46 years)

Yet those who are less active may not necessarily identify physical activity as 'normal' and exploration of this in future studies is indicated.

Physical activity also contributed to feelings of enjoyment and positivity which reinforced maintenance of and adherence to physical activity in the long term. This has been noted elsewhere by Kamwendo et al [23] who through interviews exploring physical activity in the life of people with RA described satisfaction, joy and a positive attitude as determinants of physical activity adherence. It has been suggested that a further determinant of adherence is self-efficacy and Kamwendo et al [23] proposed that increased happiness and self-efficacy allowed participants to identify with wellness rather than illness. This notion was also described by Loeppenthin et al [19] who noted that participants used

physical activity to shift feelings associated with the ill body towards feelings of independence and well-being.

Fear of disease progression and functional decline was identified as a motivating factor in the present study and this has also been noted previously [18, 23]. Interestingly fear of exacerbating or damaging joints through physical activity was not identified as a theme in this study, which has been documented as a fear experienced by those with low activity levels [14]. This could highlight the importance of education as soon as possible after diagnosis. In fact, barriers to physical activity were mentioned much less frequently than facilitators and where mentioned participants identified that they were able to overcome barriers such as pain and lack of motivation. It could be suggested that those participants with high levels of self-efficacy for physical activity who identified with wellness rather than illness did not perceive themselves as facing barriers but instead perceived symptoms such as pain, fatigue and stiffness as their motivations or facilitators for physical activity.

Support from others was a commonly reported facilitator. Most often this support was provided by close family members usually in the form of being a partner to exercise with. Some participants also recognised that owning a dog was a key factor in motivating regular and long term physical activity, illustrated by comments such as,

“..when the dog is lying on the floor....looking at the front door you are not going to say no are you?”

(Female aged 56, RA for 16 years)

Although this isn't a finding previously reported in RA populations, Campbell et al, [24] in a study on healthy adults exploring the influence dog-walking had on perceptions of health and wellbeing, found that a dog's need to exercise was often placed above that of the owners. Due to the emotional connection between the dog and owner, the dog was able to compel its owner to exercise beyond that of a gym or owning exercise equipment could. Campbell et al also noted that interaction with other dog walkers promoted social connections and a sense of community plus exposure to natural environments. The combination of these elements boosted psychological wellbeing of participants.

Support was also provided from instructors at gyms and other gym members or exercise group members. A few participants felt that they would be wary of group activity with the general population for fear of not being able to keep up and a lack of understanding of their condition. One participant commented that she would prefer to exercise with people with a similar stage of disease progression but this was not reported by other participants. These findings could be compared to the feeling of being challenged or intimidated by those without arthritis which was identified in the study by Iversen et al [18]. Following a focus group study to inform physical activity intervention development, Withall et al [20] recommended that there was a need for group physical activity interventions which facilitated peer support and were led by physiotherapists who had an understanding of RA. In a recent literature review, Veldhuijzen van Zanten et al [25] identified a lack of availability of exercise programmes for people with RA and a lack of knowledge about exercise regimens that are appropriate.

Strengths and limitations

A sampling framework facilitated the recruitment of both males and females with a range of age, years of diagnosis, educational attainment and employment history. Data on ethnicity was also collected yet all participants described themselves as white British therefore the findings may not be representative of other ethnic groups. Disease severity was not assessed however which could be recognised as a limitation as it may have affected the ability to participate in physical activity and therefore influenced responses, particularly the experience of barriers and enablers. A further limitation of the study is that people who volunteer to participate in studies may differ from those who do not and therefore may not be representative of the wider RA population. A potential difficulty of using semi-structured interviews is that the interaction between the researcher and the participant is crucial in generating valuable knowledge. The participant may provide socially desirable responses if not feeling comfortable or may provide inaccurate information if unable to recall events precisely.

Conclusions

It could be established that people with RA who are successfully maintaining physical activity are doing so in order to manage their symptoms, resist functional decline and maintain health and independence. These findings support other similar studies in arthritis more generally. The findings should be explored with a wider range of active and inactive people with RA. Health professionals delivering exercise interventions for people with RA should consider the strategies and motivating factors reported by participants. If people with RA can be facilitated to engage with appropriate levels of physical activity there is potential for enhancing longer term health and function.

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Conflicts of interest: None

ACCEPTED MANUSCRIPT

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Table 1: Characteristics of participants (n=15)

Variable	Frequency (range)
<i>Age</i>	
Average age	56 (29-80)
25-34	2
35-44	2
45-54	3
55-64	3
65-74	4
75-84	1
<i>Educational attainment</i>	
None	4
GCSEs/'O' level	2
'A' level	1
Diploma/First degree	6
Masters degree	2
<i>Employment</i>	
Unemployed	2
Employed	6
Retired	7
<i>Duration of RA</i>	
Average years	13 (10 months-46 years)
Up to 5	6
6 to 15	2
16 to 25	5
26 to 35	1
Over 35	1