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Title Page

i) **Title:** Promoting self-management in older people with arthritis: Preliminary findings of the Northern Ireland 'Staying Connected Programme'

ii) **Running title:** Promoting self-management in arthritis

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Introduction

Arthritis includes a range of conditions causing inflamed or damaged joints. The most common forms of arthritis are osteoarthritis (OA) affecting 8.75 million people and rheumatoid arthritis (RA) affecting 400,000 people in the UK (Arthritis Research UK, 2017). Symptoms include high levels of pain, joint stiffness, reduced physical functioning and poor quality of life (Laslett et al., 2012; McHugh et al., 2012; Walsh & McWilliams, 2014; Conaghan et al., 2015). Individuals with arthritis often become socially isolated living with their condition (Smith, 2017). The economic impact of arthritis is high both for individuals and for the health service (Conaghan et al., 2015).

Promoting self-management for long-term conditions is high on the UK government's agenda. Self-management is seen as important in achieving desired treatment outcomes in patients with long-term conditions, including arthritis (Franek 2013). Support for self-management is one of the key approaches to improving services and ensuring individuals remain healthy (DH, 2005). There are a number of self-management programmes available which work and support individuals with arthritis and other long-term conditions, such as the 'Expert Patient Programme' which focuses on empowering and educating patients to take a lead in managing their chronic disease (DH, 2001). A national evaluation found some positive impact on self-efficacy from attending this programme and that the intervention was likely to be cost-effective (Kennedy et al., 2007a). Evidence from other self-care intervention programmes suggests the need to focus on increasing knowledge including individuals' experience of managing their condition (Kennedy et al., 2007b). Specific self-care treatment components that are likely to be beneficial include training self-management skills, information delivery, and goal setting (Kroon et al., 2014).

In Northern Ireland, Arthritis Care, a national charity organisation, identified a need to provide support and guidance to older people with arthritis and other long-term conditions. The 'Staying Connected Programme' was developed, to provide a one-to-one specialised befriending service, with an aim to improve self-management and reduce social isolation among patients with arthritis and other long-term conditions.

The aim of this study was to evaluate the effectiveness of the one-to-one befriending service between June 2014-June 2016. The specific objectives of this evaluation were:

- To assess the impact of the programme on an individual's pain intensity, physical functioning, and participation in daily activities;
- To determine if there were any changes in an individual's self-efficacy.

Methods

This was a quasi-experimental study using single group pretest-posttest study design (Shadish et al., 2002). This study only included patients with arthritis who were part of the Staying Connected Programme between 2014-2016. Ethical approval was obtained (University of Leeds School of Medicine Research Ethics Committee Ref SoMREC/13/075).

Description of Intervention: The Staying Connected Programme is delivered by trained volunteers and supported by a project manager. New volunteers must attend a two-day training course which is led by the project manager and supported by an experienced volunteer. The course covers issues such as: being a volunteer; safety; self-management support; and goal setting. There are specific topics relating to arthritis, which are also covered such as: relaxation; exercise; sleep; and healthy eating.

The programme has 32 trained volunteers aged between 18-85 years and 28 of these volunteers also have a long-term health condition. The programme consists of eight one-to-one sessions lasting one hour only. Each session is delivered to individuals in their own homes or to those in sheltered accommodation. Individuals are supported by the trained volunteers and receive support to help them manage their arthritis more effectively. Individuals are also encouraged to participate in social activities and sessions that are likely to benefit their health. The focus of each weekly session is agreed with the individual and sessions revolve around the following areas:

- Goal setting and achieving goals;

- Communicating effectively with family, friends and healthcare professionals about your condition;
- Education and promoting healthy eating;
- Simple exercises to improve flexibility and mobility e.g. chair based exercise;
- Techniques to deal with problems such as fatigue and isolation;
- Techniques to deal with emotional distress e.g. relaxation techniques, distraction, conscious breathing, positive thinking.

Data collection: All individuals (n=66) who were enrolled in the Staying Connected Programme and had arthritis were invited to participate in the study. Participants who expressed a willingness to participate and signed a consent form completed a set of questionnaires before the start of the first session and at the end of the 8-week programme. Demographic data and outcome measures were collected. The following measurement tools were used:

Pain Numerical Rating Scale (NRS): The pain NRS is a valid and reliable 11-point scale ranging from 0 = no pain to 10 = 'pain as bad as you can imagine' (Farrar et al., 2001).

Health Assessment Questionnaire- Disability Index (HAQ-DI): The HAQ-DI assesses functioning ability of the individual across eight categories including dressing, rising, eating, walking, hygiene, reach, grip, and usual activities (Fries et al., 1982). The responses use a scale from zero (without any disability) to three (unable to do). The highest score for any component question of the eight categories determines the score for that category. A standard disability index is calculated with a higher score indicating a greater degree of disability.

General Self-efficacy Scale: The General Self-Efficacy (GES) scale is a 10-item validated instrument to measure self-efficacy (Schwarzer & Jerusalem, 1995). There are four options for each question: Not at all true (score 1), hardly true (Score 2), moderately true (3) and exactly true (4). The total GSE score is calculated by adding up responses to all ten question and ranges between 10 and 40. Higher score indicate greater self-efficacy (Schwarzer & Jerusalem, 1995)

Arthritis Self-efficacy Scale: The Arthritis Self-Efficacy (ASE) scale is a validated 8-item tool that measures arthritis related self-efficacy (Lorig et al., 1989). Each item comes with a 10-point numerical rating scale with 1 being 'uncertain' and 10 'very certain'. The total score for the scale is the mean of the eight items.

Keele Assessment of Participation Scale: The Keele Assessment of Participation (KAP) is an 11-item generic measure to assess person-perceived performance of participation (Wilkie et al., 2005, 2006). The KAP measures participation across various domains including that of mobility, self-care, domestic life, interpersonal interaction, major life, community and social life. Each item has a 5-point ordinal scale (all of the time, most of the time, some of the time, a little of the time, none of the time). Each item is dichotomized to define the presence (some, a little, none of the time) or absence (all or most of the time) of participation restriction. Total scores are calculated by summing the number of items where restriction occurs (0–11 items) with a higher score indicating greater restriction.

Statistical analysis: Data were entered and analysed using SPSSTM version 23. The GSE, ASE, KAP and HAQ-DI were scored using the methods recommended. The differences between the baseline and follow-up pain intensity, GSE and ASE scores were calculated using paired t-test. Wilcoxon- sign rank test was used to compare HAQ-DI baseline and follow-up scores.

Results

Thirty-three participants (50%) completed questionnaires at baseline. All the participants received the complete 8-week programme and were visited by the volunteers for one hour per week. The majority of the participants were female (27; 81.8%). Participants' ages ranged between 63-91 years with a mean (\pm SD) age of 76.6 (8.6). Twelve (36.4%) of the participants were diagnosed with OA and 7 (21.2%) had RA (Table 1). Pain in lower back (81.8%) followed by hands/fingers (63.6%) and neck (60.6%) were the three most commonly reported pain sites. The mean (\pm SD) number of pain sites per patient was 7.5 (3.1) (Median 7; range 2 to 14).

INSERT TABLE 1 HERE

Support techniques received: The participants received a number of techniques/support from the volunteers and details are provided in Table 2. All the participants received advice on self-management techniques, goal setting and how to problem solve. Other common techniques and support were focused around learning how to relax, positive thinking, and dealing with low mood.

INSERT TABLE 2 HERE

Assessment of outcomes:

Pain intensity: The mean (SD) pain intensity at baseline and follow-up was 7.4 (1.8) and 6.5 (2.1) respectively. There was a statistically significant reduction in pain intensity at the end of the programme ($p= 0.002$) (Table 3).

Functional status. There were no significant improvements in functional status following completion of the programme ($p=0.919$) as measured by HAQ-DI.

Self-Efficacy: There was a statistically significant improvement in arthritis related self-efficacy levels ($p<0.0001$) as measured by ASE scale, indicating better ability to cope with the symptoms of arthritis, such as pain and functioning. However, there was no statistically significant improvement in general self-efficacy at follow-up ($p = 0.148$) (Table 3).

Assessment of participation (KAP): The number having minimal (1-3 restricted aspects of life), moderate (4-6 aspects of life) and substantial (7-11 aspects of life) participation restriction at baseline were 21, 5, and 4 compared to 19, 9 and 2 at follow-up respectively. In terms of overall score, there was no statistically significant improvement in an individuals' ability to participate in daily and social activities ($p = 0.345$) (Table 3).

INSERT TABLE 3 Here

Discussion

This aim of this evaluation was to determine whether the Staying Connected Programme improved pain, self-efficacy, functioning and participation in daily and social activities. Participants with arthritis who were part of this programme showed statistically significant improvements in both pain and arthritis self-efficacy. Pain is one of the key symptoms which individuals with arthritis find difficult to manage (McHugh et al., 2012), so having a self-management programme which improved pain is a positive outcome. A meta-analysis of nine studies evaluating the effectiveness of self-management programmes for people with OA found that these interventions provided no statistically significant benefits in respect to pain intensity in the first 12 months compared to those not receiving the interventions (Smith et al., 2013). However, our evaluation only assessed pain at the end of the 8-week programme and longer-term follow-up was not undertaken.

Improving self-efficacy is a common goal of most, if not all, of the existing self-management programmes (Kroon et al., 2014). The Staying Connected Programme showed a significant improvement in arthritis self-efficacy at the end of the 8-week programme. Other programmes such as the 'Expert Patient Programme' have also shown an improvement in self-efficacy (Kennedy et al 2007a).

Many existing self-management programmes rely on health professionals delivering the programme (Kroon et al., 2014). The Staying Connected programme is unique with using volunteers to support and guide individuals to manage their arthritis using one-to-one home visiting. As volunteers are delivering the intervention, the cost of delivery is potentially less than it would be if the programme was delivered by health care professionals or employed lay workers. There is also flexibility in the delivery of the programme and the volunteers are guided by what the individuals wish to achieve.

The Staying Connected Programme is focused on those individuals who are assessed as being socially isolated. The issues of social isolation and loneliness among older people with musculoskeletal pain due to arthritis cannot be underestimated. The literature has highlighted the limited evidence on the management of social isolation for these individuals (Smith, 2017). The effects of loneliness and social isolation may lead to poorer health outcomes such as

depression (Courtin & Knapp, 2017). Receiving support and encouragement from a volunteer and building the confidence of the individual may be one way to improve social isolation in older people with arthritis. The social support side of these interventions cannot be underestimated and there is evidence that higher levels of social support especially those that are geared specifically for the long-term condition are associated with better self-management (Gallant, 2003).

There were a number of limitations to this evaluation, including the small number of participants in the study and there was some incomplete data collected. Since this was a quasi-experimental study and lacked a control group, threats to internal validity such as history, maturation and testing effect cannot be ruled out. The long-term benefits of the Staying Connected programme require further investigation. Future qualitative research should explore the experiences of participants and volunteers involved in the programme.

Conclusion

Staying Connected, a self-management programme delivered by trained volunteers can potentially reduce pain and improve arthritis-related self-efficacy in older adults living with arthritis. With our ageing population, increasing prevalence of arthritis and the over-burden on the NHS, we need to develop robust and sustainable programmes with a focus on improving self-management.

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Table 1. Demographic and clinical characteristics of patients

Characteristic	N (%)
Gender	
Male	6 (18.2)
Female	27 (81.8)
Diagnosis	
Osteoarthritis (OA)	12 (36.4)
Rheumatoid Arthritis (RA)	7 (21.2)
Psoriatic Arthritis (PA)	1 (3.0)
OA and RA	5 (15.2)
OA and Ankylosing Spondylitis	1 (3.0)
Unknown	5 (15.2)
Missing	2 (6.1)
Physician Diagnosis	
Yes	27 (81.8)
No	3 (9.1)
Missing	3 (9.1)
Joint pain sites	
Lower back	27 (81.8)
Hands/Fingers	21 (63.6)
Neck	20 (60.6)
Shoulder	19 (57.6)
Thumb	17 (51.5)
Both knees	17 (51.5)
Foot	15 (45.5)
Ankles	15 (45.5)
Wrist	14 (42.4)
Groin	12 (36.4)
Both Hips	12 (36.4)
Single hip	10 (30.3)
Single knee	9 (27.3)
Elbow	9 (27.3)
Upper back	7 (23.3)

Table 2: Techniques/support participants received

Techniques	Number*
Self-management	33
Goal setting	33
Feedback/Problem solving	33
Conscious breathing	28
Relaxation for the mind	28
Relaxation	28
Getting through the day	27
Positive thinking	26
Low mood	26
Healthy eating	24
Physical activity/Chair based exercises	21
Effective communication	17
Good night sleep	15
Preventing falls	14

*Individuals received more than one technique

Table 3: Comparison of baseline and 8 week follow-up scores of outcome measures

Outcome measure	N	Baseline Mean (SD)	Follow-up Mean (SD)	P-value
Pain Numerical Rating Scale	31	7.45 (1.8)	6.55 (2.1)	0.002
General Self-Efficacy Scale	32	2.7 (0.8)	2.8 (0.7)	0.148
Arthritis Self-Efficacy Scale	33	4.9 (1.9)	5.6 (1.8)	0.0001
Keele Assessment of participation scale	30	2.4 (2.5)	2.2 (2.3)	0.345