

Feasibility and Acceptability of a Self-Management Program for Patients With Rheumatoid Arthritis

Jung-Hua Shao 🔻 Kuang-Hui Yu 🔻 Su-Hui Chen

BACKGROUND: Joint activity and protection are key components in the management of rheumatoid arthritis (RA). Despite a shift from care in health settings to empowering patients to play an active role in the day-to-day management of their own chronic conditions, there is little evidence on RA self-management, especially for Chinese patients.

PURPOSE: This pilot study sought to determine the feasibility and acceptability of a self-management program for patients with RA in Taiwan.

METHODS: Participants were recruited at a medical center in northern Taiwan. The intervention group participated in a 6-week self-management program; the control group received standard rheumatology care. Both groups underwent baseline assessments before the intervention and at 12 weeks.

RESULTS: A total of 32 participants were recruited: 15 in the intervention group and 17 in the control group. Patients in the intervention group found the self-management protocol beneficial to their joint protection and activity behaviors and reported higher motivation to perform RA self-management. The posttest score for joint protection and activity self-management behavior were significantly greater for the intervention group than for the control group (p = .02).

CONCLUSIONS: Participants in the intervention group were highly satisfied with home visits (which included peer story-telling and goal setting) and telephone calls to support their daily home-based joint protection and selfmanagement activities (which included self-monitoring and self-evaluation). To mitigate the fear of scammers, researchers should begin by building a trust relationship with participants.

Introduction

Rheumatoid arthritis (RA) is a persistent systemic disease of the joints (Flurey et al., 2014). Synovial joint inflammation causes pain and stiffness, turning simple daily activities into challenges (Chiou et al., 2009; Swann, 2011; World Health Organization, 2014). Diagnosis of RA is most common in patients 40 years or older; because the life span is increasing, patients with RA may live with the disease for more than 40 years. When the disease is not in an active stage, the swelling subsides, but the joint capsule remains stretched and unable to maintain its correct position and can affect other parts of the body (Flurey et al., 2014; Swann, 2011). In Taiwan, the Ministry of Health and Welfare (2014) found a prevalence of knee joint degeneration as high as 15%; the most common cause is RA. Because physical disability is the most important outcome of RA (Flurey et al., 2014; Swann, 2011), joint care, which aims to reduce pain and disability and improve function, is a core component of care for patients with arthritis (Dziedzic et al., 2011; Revenäs et al., 2016; van den Berg et al., 2006).

Modern healthcare systems are shifting from an emphasis on hospital care to empowering patients to play an active role in managing their own chronic conditions (Dougados et al., 2015; Leung et al, 2016; Shao & Chen, 2019). Self-management has been defined by Barlow et al. (2002) as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (p. 178). This definition

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implies that self-management is more than simple adherence to treatment guidelines because it incorporates the psychological and social management of living with a chronic illness.

One early study to test the effects of a self-management arthritis education program recruited 167 patients with RA or psoriatic arthritis. The result showed that the program reduced pain and improved self-efficacy at 1 year (Hammond et al., 2008). Later, Hewlett et al. (2011) assessed the effect of fatigue on self-management in 127 patients with RA. The intervention group reported better scores for fatigue, disability, self-efficacy, and sleep. Another study to determine the effect of arthritis self-management on a cohort of patients with RA (N = 104) found a reduction in the tender and swollen joints in both the intervention and control groups over time (Conn et al., 2013). A study conducted more recently to evaluate the impact of a nurse-led program on patient self-management of RA (Dougados et al., 2015) enrolled 970 patients with a 6-month follow-up. The results showed that patients in the intervention group showed statistically better outcomes. However, data on the effectiveness of these self-management programs in Chinese society are sparse. Only one pilot study by Leung et al. (2016) in Hong Kong evaluated the efficacy of a community-based lay-led arthritis selfmanagement program, and found that the interventional group had significantly less pain, used more cognitive coping methods, and practiced more aerobic exercise (N = 97).

Although international research has shown that a self-management program has a beneficial effect on disease-related outcomes in patients with RA (Conn et al., 2013; Dougados et al., 2015; Gaujoux-Viala et al., 2014; Hewlett et al., 2011; Leung et al., 2016), current evidence on RA self-management is still limited, especially for Chinese patients. In addition, self-management programs vary and may include symptom management, physical functioning, sleep disturbances, exercise motivation, and/or problem solving. Although joint protection and activity are key components in the management of patients with RA (Manning et al., 2014), no study has yet evaluated a self-management program for joint protection and activity for patients with RA. This study therefore aimed to determine the feasibility and acceptability of a joint protection and activity self-management program among patients with RA in Taiwan. Patient feedback and recommendations were also collected. This project may therefore provide preliminary data to guide the design of a larger study.

Methods

STUDY AIMS

This study aimed to determine the feasibility and acceptability of a self-management intervention program, focused on joint protection and activity for patients with RA.

DESIGN

A two-group, pre/posttest pilot study design was used.

SETTING AND PARTICIPANTS

Participants were recruited from the outpatient clinic of a rheumatology department at a medical center in northern Taiwan. As this was a pilot study, a purposive sampling was used, consisting of patients who had scheduled outpatient visits between January and July 2016. Patients were deemed eligible if they were adults with a confirmed diagnosis of RA, 20 years or older, considered disease stable for at least 3 months by the treating rheumatologist, no joint surgery within the past 6 months and no plans for joint surgery in the next 6 months, and ability to understand and comply with the study treatment. Patients with RA with comorbid conditions contraindicating physical activity were excluded from the study.

Based on the view of Baker (1994), a pilot study is often used to test a guideline or gather data in preparation for the actual study. The sample size estimation for the actual study was based on Generalized Estimating Equations analysis (Liu & Liang, 1997). As a result, a total of 226 patients with RA would be recruited into the actual study. Hisni et al. (2018) suggested a sample size for a pilot study of 10%–20% of the actual study. Thus, 23 participants were the minimum required for this pilot study.

DATA COLLECTION

Participants were directly invited by face-to-face invitation. Once the inclusion criteria were met and written informed consent was obtained, baseline information was collected. The intervention group received the 6-week RA joint protection and activity self-management program. The control group received standard rheumatology care. The outcome measurement, taken at 12 weeks, included disease activity, self-efficacy, quality of life, and joint self-management behavior. The level of satisfaction with and recommendations for this program were also collected from the intervention group at the end of the study.

DEMOGRAPHIC AND CLINICAL DATA

Demographic information (e.g., age, gender, education, employment status) and arthritis-related information (e.g., duration of disease) were collected only at baseline using a researcher-developed questionnaire.

FEASIBILITY AND ACCEPTABILITY

Feasibility and acceptability were assessed as follows: (1) recruitment—defined as the number of consenting participants as a proportion of those eligible; (2) retention—defined as the number of participants remaining in the trial as a proportion of those enrolled; and (3) acceptability—defined as participants' satisfaction with the program regarding seven items: finding information, intervention setting, program facilitator, setting and acting on attainable goals, self-monitoring, home visit, and phone calls. Each item had five answer options, from 1 ("very little") to 5 ("quite a lot"). Total scores were obtained by summing the item responses, with higher scores indicating greater acceptance of the program. Acceptability was evaluated at the end of the study by asking the experimental group the following

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open-ended question: "Would you please share with us your experience and suggestion of this program?"

PROGRAM EFFECTIVENESS

The Disease Activity Score ([DAS-28]: Prevoo et al., 1995; van der Heijde et al., 1990) was used to measure RA disease activity. Using the "tender and swollen" status of 28 joints, the DAS-28 was developed to provide a quantifiable measure of RA activity (Prevoo et al., 1995; van der Heijde et al., 1990) and is recommended for use in monitoring the effectiveness of clinical practice (Salaffi et al., 2009). The DAS-28 score has been shown to be a strong predictor of physical disability and radiological progression and a sensitive discriminator between patients with high and low disease activity (Prevoo et al., 1995; van Gestel et al., 1998). DAS-28 scores range from 0 to 9.4, with levels of disease activity defined as follows: 3.2 or less, mild; more than 3.2 and 5.1 or less, moderate; and more than 5.1, severe (van Gestel et al., 1998). Cronbach's a for the DAS-28 was .72 (Salaffi et al., 2009). In this study, Cronbach's α for the DAS-28 was .76.

Arthritis self-efficacy was measured using the Arthritis Self-Efficacy (ASE) scale developed by Lorig, Chastain, et al. (1989) and Lorig, Seleznick, et al. (1989). The ASE scale measures a patient's perceived self-efficacy to cope with the consequences of chronic arthritis and includes the following three subscales: Pain (PSE, five items); Function (FSE, nine items); and Other Symptoms (OSE, six items). For our study, two subscales (ASE-Pain and ASE-Other Symptoms) were used as the outcome measures. The ASE scale uses visual analog scales (0-10), in which 0 represents "very uncertain" and 10 represents "very certain"; a higher score indicates greater self-efficacy. The reliability of the two subscales was good (coefficient α estimates = .76 for PSE and .87 for OSE), and test-retest reliability was acceptable (.87 for PSE and .90 for OSE) (Barlow et al., 1997). The Chinese version developed by Wu et al. (2011) had a Cronbach's α of .81 for the PSE scale and .91 for the OSE scale. In this study, Cronbach's α was .85 for PSE and .83 for OSE.

The Short-Form Health Survey ([SF-36]; Ware & Sherbourne, 1992) includes one multi-item scale that assesses the following eight dimensions of health, used to assess the quality of life in this study: physical functioning, social functioning, role limitations due to physical health problems, bodily pain, general mental health, limitations in usual role activities due to emotional problems, vitality, and general health perceptions. Each subscale is scored from 0 to 100, with 0 indicating extreme problems and 100 indicating no problems. The reliability and validity of SF-36 are well established (Ware, 2011). The SF-36 (Taiwanese version) was translated and developed from the original English version by Lu et al. (1996), and the reliability and validity are acceptable, as correlations between items and the corresponding subscale were generally .70 or more, and Cronbach's α coefficients were more than .70 for nearly all subscales (Shyu et al., 2009). In this study, Cronbach's α was .70 for the physical component summary (PCS) and .76 for the mental component summary (MCS).

Finally, because no scale fit our study purpose, the self-management behavior scale used in this study was modified from that of Lorig, Chastain, et al. (1989) to focus on joint protection and activity behaviors. Seven items were set: four items on joint protection and three items related to joint activity, such as "I stretch my every joint" and "I take a rest when I am not feeling well of my joints." Self-management level of use was recorded for the past week using a response scale ranging from 0 for "never" to 4 for "always." Higher scores indicate a higher level of use of each of the self-management strategies.

THE SELF-MANAGEMENT PROGRAM

The RA joint protection and activity self-management program was based on Bandura's theory of self-efficacy, which proposes that self-efficacy is influenced by the following four information sources: mastery of experience; social modeling; social persuasion; and one's physical and emotional states (Bandura, 1977, 1997). For participants, a simple behavioral approach is more focused and reduces the burden relative to using intervention components that comprehensively address the problem (Nigg & Long, 2012). Manning et al. (2014) suggest that the most important measure for patients with RA is joint care; therefore, we simplified the program by focusing on joint protection and activity selfmanagement.

To enhance patients' self-management behavior, the following strategies were employed (see Figure 1): (1) Home visit-Participants' RA status was assessed and information about and discussion of self-management behaviors were delivered individually; (2) Peer storytelling—During the home visit, the researcher shared peer experiences of self-management to provide information that participants could use for social modeling; (3) Goal setting—Participants were encouraged to set attainable objectives, such as "following standard joint activity and protection behaviors every day"; (4) Selfmonitoring—A picture provided an easy-to-use weekly self-monitoring tool for indicating the location of joint pain or discomfort; (5) Self-evaluation-Participants were instructed in self-evaluation of their self-management behaviors to increase mastery of their own physical and emotional states; (6) Phone calls-Phone calls during Weeks 2, 4, and 6 allowed participants to report any concerns and also allowed the researcher to provide ongoing encouragement. The program was outlined in a booklet and video, and five experts (rheumatology nurses, nursing researcher, and self-management nursing professionals) evaluated this material to determine the program's content validity index prior to the intervention. Each patient received the booklet and video for home reference to facilitate self-management. All research team members were nurses who were educated about the protocol and all intervention contents before data collection.

STATISTICAL ANALYSES

Data were analyzed using SPSS Version 20 for Windows (IBM Corporation, Armonk, NY). Characteristics and baseline measurements for participants were analyzed with descriptive statistics. Because the sample size was

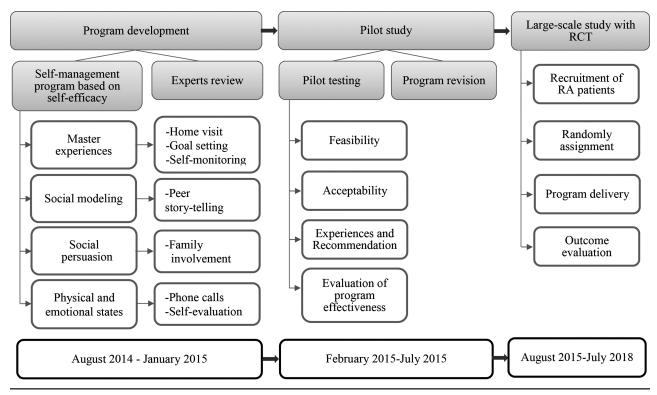


FIGURE 1. Program development and research schedule. RCT = randomized controlled trial; RA = rheumatoid arthritis.

small, the effectiveness of the program was analyzed with the Mann–Whitney *U* test. The level of significance was set at an α of .05. Finally, the experiences of and recommendations about the program were analyzed using qualitative content analysis.

ETHICAL CONSIDERATIONS

This study was approved by the Research Ethics Committee of the researchers' university (No. 103-7345B; the date of approval: January 15, 2015). Patients with RA who met the study criteria were provided a detailed explanation of the study, and when they agreed to participate, written informed consent was obtained. All participants were assured that their anonymity and confidentiality would be preserved and they could withdraw from the study at any time.

Results

DEMOGRAPHIC DATA AND HEALTH-RELATED

A total of 32 participants were recruited (intervention group: n = 15; control group: n = 17). The majority of the present sample was female (n = 23; 71.9%), married (n = 28; 87.5%), had a mean age of 58.37 years (standard deviation [*SD*] = 9.76 years), and nearly all of our participants were living with their families (96.9%). Regarding the duration of RA, our participants had been living with RA for an average of 10.32 years (*SD* = 8.37 years). It is worth noting that only four patients with RA (12.5%) had previously received RA education/ counseling. There were no significant differences in patient characteristics and health-related information

between the two groups (see Table 1). The study flow diagram is shown in Figure 2.

FEASIBILITY AND ACCEPTABILITY

From January to July 2016, 102 patients were evaluated for eligibility, of whom 60 failed to meet the inclusion criteria. Of the 42 patients who met the inclusion criteria, 10 were not approached because of physical condition (n = 4), lack of a phone (n = 1), declined home visit (n = 3), and not interested (n = 2). The remaining 32 patients were successfully recruited; all of the enrollees completed the 12-week evaluation assessments (see Figure 2; recruitment rate $32/40 \times 100 = 80\%$; retention rate: $32/32 \times 100 = 100\%$).

Participants in the intervention group were contacted through a home visit, and the related strategies such as goal setting, self-monitoring, phone delivery, and self-evaluation were provided successfully during the home visit. In general, patients in the intervention group found the protocol beneficial to their joint protection and activity behaviors. Furthermore, participants in the intervention group reported higher motivation to perform RA self-management and evaluated the program as "satisfied" or "very satisfied." Participants reported the highest levels of satisfaction with home visits and telephone calls (4.7 ± 0.49 points; range = 1–5 points) and the lowest level of satisfaction with setting and acting on attainable goals (4.2 ± 0.78 ; range = 1–5).

From those in the intervention group, we collected recommendations about the program using one openended question. Of the 15 participants of the intervention group, 10 provided comments (66.7%). Most of the patients' feedback was positive; they acknowledged that the opportunity to participate in the program allowed

Characteristics	All Participants $(N = 32)$	Group	
		Intervention ($n = 15$)	Control $(n = 17)$
Age (range = $38-78$), <i>M</i> (<i>SD</i>), years	58.37 (9.76)	60.40 (12.04)	56.59 (7.12)
Female, <i>n</i> (%)	23 (71.9)	10 (66.7)	13 (76.5)
Married/partnered, n (%)	28 (87.5)	12 (80.0)	16 (94.1)
Work status, n (%)			
Employed	10 (31.3)	4 (26.7)	6 (35.3)
Unemployed	22 (68.7)	11 (73.3)	11 (64.7)
Education level, n (%)			
Elementary school or less	8 (25.1)	2 (13.3)	6 (35.3)
Junior high school	9 (28.1)	8 (53.3)	1 (5.9)
Senior high school	12 (37.5)	3 (20.0)	9 (52.9)
Bachelor's degree or higher	3 (9.4)	2 (13.3)	1 (5.9)
Living arrangement, n (%)			
Living with family	31 (96.9)	14 (93.3)	17 (100)
Living alone	1 (3.1)	1 (6.7)	0 (00)
RA variables			
Previous RA education/counseling, n (%)			
Yes	4 (12.5)	1 (6.7)	3 (17.6)
No	28 (87.5)	14 (93.3)	14 (82.4)
Duration of RA (range = 1–40), M (SD), years	10.32 (8.37)	9.57 (9.74)	10.88 (7.32)
DAS-28 score (range = 1.50-5.17), M (SD)	3.47 (0.90)	3.77 (0.74)	3.19 (0.96)
SF-36 subscale scores			
PCS (range = $36.44-60.19$), <i>M</i> (<i>SD</i>)	46.92 (5.50)	45.22 (6.21)	48.31 (4.57)
MCS (range = 0.00–67.71), <i>M</i> (<i>SD</i>)	50.34 (13.56)	48.19 (16.50)	52.23 (10.50)
ASE subscale scores			
ASE-Pain (range = 10–50), M (SD)	35.16 (11.17)	31.80 (13.32)	38.11 (8.15)
ADE-OS (range = 15–60), <i>M</i> (<i>SD</i>)	48.88 (10.36)	48.00 (9.38)	49.65 (11.38)
SM behaviors score (range = $8-20$), <i>M</i> (<i>SD</i>)	12.72 (3.10)	12.80 (3.12)	12.64 (3.18)

Note. ASE = arthritis self-efficacy; ASE-OS = arthritis self-efficacy of other symptoms; ASE-Pain = arthritis self-efficacy of pain; DAS-28 = Disease Activity Score; MCS = mental component summary; PCS = physical component summary; RA = rheumatoid arthritis; SF-36 = Short Form-36; SM = self-management.

them to feel cared for and suggested that the program should be available to all patients with RA. Four participants reported that the self-monitoring tool was interesting and useful, and the picture provided an easy-to-use weekly self-monitoring guide for indicating the location of joint pain or discomfort. Regarding the joint protection and activity video, most patients appreciated day-today access to the video preceding joint activity and protection. As one female participant said, "I follow the video and exercise every day and then I feel better." Some participants said the individual guidance and phone calls helped them feel safe about their joint activity.

Participants also provided valuable information in other ways. Three patients initially declined the home visit and phone calls because they thought that the researcher was a scammer or they had job obligations. We also found that, although we guided and monitored patients with RA on how to protect joints and perform joint activities, some hesitated to engage in joint activity. One 55-year-old patient stated: "Are you sure that I can do this activity? I think it is better to have more rest for my joints."

EFFECTIVENESS OF THE INTERVENTION

The Mann–Whitney U test indicated that the posttest score for joint protection and activity self-management behavior score were significantly greater for the intervention group than for the control group (p = .02). There was no significant difference between the two groups in other outcomes (see Table 2).

Discussion

Research on the development, optimization, and implementation of self-management programs for patients

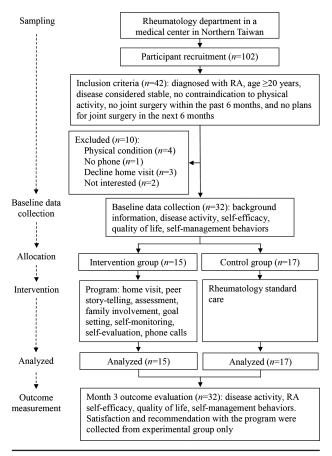


FIGURE 2. Study flow diagram. RA = rheumatoid arthritis.

with RA focused on joint protection and activity is still in its infancy. This pilot study provides new information about developing a self-management program specifically aimed at joint protection and activity for patients with RA. The intervention was feasible and safe for patients with RA, with recruitment and retention rates of 80% and 100%, respectively, and with no serious adverse events. The high recruitment and retention rates may be related to the use of face-to-face recruitment and the phone delivery of the intervention, respectively. Moreover, during the study, patients with RA were able to set small, achievable goals and adjust them throughout the intervention. This allowed them to reevaluate their strategies to help them achieve their goals or make new ones better suited to their level of ability. This flexibility allowed participants to continue at their own level of participation rather than withdrawing completely when a goal could not be achieved. Our findings echo those of Nigg and Long (2012) that an intervention to improve a single behavior of joint care is more focused, less confusing, and more effective than approaches that aim to address multiple patient behaviors.

The program resulted in significant improvements in self-management behaviors in the intervention group compared with the control group. Improved self-management behavior is an important step for patients with RA. Based on participant feedback, it may be that, by self-monitoring their behavior, following the video for joint protection and day-to-day activity, and having a discussion with the researcher on the telephone, our patients with RA learned how to self-manage their joints and enhance their self-management behavior.

Although joint activity is a key component in the management of RA, some of our patients believed it unsafe to exercise their joints or that exercise would exacerbate their pain. These findings echo those of Chang et al. (2014), who reported a lack of physical activity in persons with RA. Breedland et al. (2011) emphasized that appropriate physical activity is both safe and beneficial for people with RA. Because healthcare systems are shifting from an emphasis on hospital care to empowering patients to play an active role in managing their own chronic conditions (Dougados et al., 2015; Leung et al, 2016; Shao & Chen, 2019), it is time to empower patients to take a more active role in self-managing their chronic condition. Because Taiwanese have a high regard for health and the authority of physicians and other healthcare professionals (Chen et al., 2016; Chen & Shao, 2012), we suggest that the intervention include a physical therapist to provide consultations explaining the importance and appropriateness of joint activity.

Variable	Group				
	Intervention $(n = 15), M (SD)$	Control ($n = 17$), M (SD)	Mann–Whitney <i>U</i> Test <i>z</i>	Р	
DAS-28	3.17 (0.95)	3.37 (1.17)	-0.70	.49	
ASE subscale					
ASE-Pain	37.47 (10.74)	37.47 (12.58)	-0.25	.81	
ASE-OS	55.33 (7.75)	51.12 (11.53)	-1.64	.10	
SF36					
PCS	50.65 (5.24)	51.34 (4.25)	-0.36	.72	
MCS	52.59 (8.46)	50.86 (8.19)	-0.66	.51	
SM behavior	17.60 (1.45)	14.53 (3.39)	-2.35	.02	

Note. ASE = arthritis self-efficacy; ASE-OS = arthritis self-efficacy of other symptoms; ASE-Pain = arthritis self-efficacy of pain; DAS-28 = Disease Activity Score; MCS = mental component summary; PCS = physical component summary; SF-36 = Short Form-36; SM = self-management behavior.

Patients not feeling comfortable with in-home care and healthcare via telephone are a serious drawback to conducting such research. Because scammers have become more prevalent in Taiwan recently (Chen et al., 2017), participants initially treated the researcher as a scammer and declined home visits or telephone calls. Lack of trust influences the relationship between patients and healthcare providers (Shao & Chen, 2016). The home visit allowed us to evaluate each participant's living environment and specific needs for joint protection and activity, which enabled the researchers to provide individual strategies; participants therefore reported a high level of satisfaction with the home visits. This result emphasizes that, despite the challenges presented by a home visit, it is a good strategy for delivering a self-management program to patients with chronic disease. To resolve the trust issue, we suggest setting up the home visit and telephone call schedules, assigning a researcher to be responsible for home visits and telephone calls, and making a reminder call before the home visit. Moreover, an e-health program may play a crucial role in future studies of this type because it will protect participants' private environment.

This study had several limitations. First, the small sample size may have prevented detection of other areas of significant improvement in RA-related outcomes. Second, because this was a pilot study, only pre- and posttest data were included; no follow-up measures were used to evaluate long-term effects. Third, the willingness of the participants to participate in the study may have biased the sample selection toward those patients who were better at self-managing their health. Larger studies should seek to enroll patients with a wide range of self-management abilities.

Conclusion and Implications

The results suggest that the program is feasible and acceptable and can improve joint activity and protection self-management behaviors in patients with RA. Our intervention focused on joint activity and protection self-management behaviors that are simple and easy to learn or perform. Providing an intervention through home visits and phone calls allowed us to individualize delivery of the program; however, lack of trust of outsiders and worry about joint damage should be considered when contacting patients. To overcome these issues, we suggest that nurses (1) build a trust relationship with patients prior to data collection, (2) develop a multidisciplinary study with a physical therapist and incorporate appropriate explanations and consultations, and (3) provide a reminder call and explanation before the first home visit or phone call.

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