



**Peer-to-Peer Mentoring for Individuals with Early
Inflammatory Arthritis: Feasibility Pilot**

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3 **Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis:**
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5 **Feasibility Pilot**
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ABSTRACT

Objectives: To examine the feasibility and potential benefits of early peer support to improve the health and quality of life of individuals with early inflammatory arthritis (EIA).

Design: Feasibility study using the 2008 Medical Research Council framework as a theoretical basis. A literature review, environmental scan, and interviews with patients, families, and health-care providers guided the development of peer mentor training sessions and a peer-to-peer mentoring program. Peer mentors were trained and paired with a mentee to receive (face-to-face or telephone) support over 12-weeks.

Setting: Two academic teaching hospitals in Toronto, Ontario, Canada.

Participants: Nine pairs consisting of one peer mentor and one mentee were matched based on factors such as age and work status.

Primary outcome measure: Mentee outcomes of *disease modifying anti-rheumatic drugs (DMARDs)/biologic treatment use, self-efficacy, self-management, health-related quality of life, anxiety, coping-efficacy, social support, and disease activity* were measured using validated tools. Descriptive statistics and effect sizes were calculated to determine clinically important (>0.3) changes. Peer mentor *self-efficacy* was assessed using a self-efficacy scale. Interviews conducted with participants examined acceptability and feasibility of procedures and outcome measures, and perspectives on the value of peer support for individuals with EIA. Themes were identified through constant comparison.

Results: Mentees experienced improvements in the overall arthritis impact on life, coping efficacy, and social support (effect size >0.3). Mentees also perceived emotional,

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3 informational, appraisal and instrumental support. Mentors also reported benefits and
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5 learned from mentees' fortitude and self-management skills. The training was well-
6
7 received by mentors. Their self-efficacy increased significantly after training completion.
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10 Participants' experience of peer support was informed by the unique relationship with
11
12 their peer. All participants were unequivocal about the need for peer support for
13
14 individuals with EIA.
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17 **Conclusions:** The intervention was well-received. Training, peer support program and
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19 outcome measures were demonstrated to be feasible with modifications. Early peer
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21 support may augment current rheumatologic care.
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24 **Trial registry:** NCT01054963, NCT01054131
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ARTICLE SUMMARY

Article focus

- Feasibility study for developing, implementing and evaluating a peer support intervention (peer mentor training peer mentoring program consisting of 12-weeks of face-to-face or telephone meetings to support mentees newly diagnosed with early inflammatory arthritis (EIA).

Key messages

- Early peer support is feasible and well-received by both mentors and mentees.
- Individuals with EIA may benefit from peer support, and this may augment current rheumatologic care.

Strengths and limitations of this study

- The study was guided by the 2008 Medical Research Council Framework for Complex Interventions.
- The intervention was well-received and had benefits for both mentors and mentees.
- As rheumatoid arthritis was the diagnosis of all participants, further study is needed to assess benefit of early peer support for other types of inflammatory arthritis.

INTRODUCTION

Inflammatory arthritis (IA) is a leading cause of functional disability, chronic pain, and psychosocial distress (1,2). Patient self-management, education, and social support networks are encouraged as part of a holistic approach to disease management (3). A peer-to-peer mentoring program that aims to provide support based on the sharing of information and experiences (4) may benefit individuals with early inflammatory arthritis (EIA).

Individuals with EIA often reveal a complex and frustrating journey preceding diagnosis. Symptom fluctuations, symptom normalization and dismissal of their symptoms by healthcare providers (HCPs) are factors contributing to misdiagnosis, delays in referral to rheumatology, and psychological distress and frustration (1). Patients' initial reactions to being diagnosed with EIA range from relief and acceptance to anger, fear, denial, and disbelief (1). Once diagnosed, patients face an overwhelming range of biological, psychological, and social issues such as disease course and severity (both of which are often unpredictable), their ability to cope with pain, as well as uncertainties about social and work issues (5). Like other chronic diseases, responsibilities for daily management gradually shift from HCPs to patients (2). Adapting to EIA is complex (6), and patients require support and guidance early in the disease process so they may learn to live and self-manage their symptoms (2). Patient education and self-management is an arthritis "best practice" and a key clinical practice guideline (7,8,9). Peer support is one strategy to increase patients' knowledge and skills for self-management.

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3 Peer support models have been successfully implemented in other chronic health issues
4 such as cancer (10), (HIV/AIDS (11), and diabetes (12). A peer is someone who shares
5 common characteristics (e.g., age, sex, disease status) with the individual of interest, such
6 that the peer can relate to, and empathize with the individual on a level that a non-peer
7 would be unable (4). Dennis defines peer support as "... the provision of emotional,
8 appraisal, and informational assistance by a created social network member who
9 possesses experiential knowledge of a specific behaviour or stressor and has similar
10 characteristics as the target population" (13). Emotional support includes expressions of
11 caring, empathy, encouragement and reassurance, and is generally seen to enhance self-
12 esteem. Appraisal support involves encouraging persistence and optimism for resolving
13 problems, affirmation of a peer's feelings and behaviours, and reassurance that
14 frustrations can be handled. Informational support involves providing advice,
15 suggestions, alternative actions, feedback and factual information (13). All three forms of
16 support are based on experiential knowledge, rather than formal training (13). Peer
17 support interventions fit within a social support model (14). Within this model, peer
18 support could reduce feelings of isolation and loneliness, provide information about
19 accessing available health services, and promote behaviours that positively improve
20 personal health, well-being, and health practices (14).
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48 Currently, the major support program that patients with EIA can access is the Arthritis
49 Self-Management Program (ASMP) (15). While it provides emotional and appraisal
50 support, the standardized outline is not personalizable and the group format limits one-
51 on-one interactions.
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6 We propose that a peer support program with trained mentors with established IA will
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8 assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA,
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10 and help them self-manage their disease. An earlier study exploring the learning and
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12 support needs of patients with IA provides a rationale for using peer support (1) and
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14 previous studies have shown that individuals with rheumatoid arthritis (RA) appear to
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16 benefit from relationships they can rely on for emotional support, information, and
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18 tangible assistance (16). Whether a peer support program may facilitate some of these
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20 benefits in patients with EIA has yet to be explored. This study examines the: 1)
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22 development and 2) feasibility and pilot phases of a peer support intervention using the
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24 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation*
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26 *of Randomized Control Trials for Complex Interventions to Improve Health* (17). The
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28 primary objective is to develop a peer mentor training process and establish the feasibility
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30 and acceptability of a peer support program. Secondary objectives include measuring
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32 changes in various outcomes as a result of this intervention (Figure 1).
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41 **METHODS**

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43 The four phases of the 2008 MRC framework guided this complex intervention: (17)
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45 *development phase*, to establish theoretical underpinnings and modeling to achieve an
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47 understanding of the intervention and its possible effects; *feasibility and piloting phase*:
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49 exploratory trial to test feasibility of key intervention components; *evaluation phase*: to
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51 assess program effectiveness; and *implementation phase*: to examine long-term
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53 implementation and sustainability (Figure 2).
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Development phase

Identifying the evidence base

A qualitative literature search strategy was developed on peer support and chronic diseases using Medline, EMBASE, CINAHL, and Cochrane Systematic Reviews. Reviewers independently evaluated papers using a quality assessment tool. Using meta-ethnography, a methodology to synthesize qualitative literature (18, 19), we determined how studies were related, translated studies into one another, synthesized translations, and expressed the synthesized ethnography (20). Quantitative studies were reviewed, including a draft from a Cochrane Collaboration protocol (4). An environmental scan was performed and grey literature summarized.

Modeling

Needs assessment

A qualitative needs assessment was performed to identify educational preferences and informational, emotional and appraisal support needs of individuals with IA, and to determine the suitability of peer support (1). Semi-structured, one-on-one interviews were performed with patients with IA, their family/friends, and HCPs. Interview audio files, transcripts and field notes were uploaded to a qualitative software package, NVivo 8, for coding and analysis. Themes were identified through constant comparative analysis (21).

Working groups for intervention development

Three working groups (peer mentor training, peer support program, evaluation) of four to six research team and end users were convened to develop the pilot intervention.

Expert review

Using snowball recruiting, expert reviewers were nominated by the research team. They reviewed study information and completed a semi-structured questionnaire by e-mail about the proposed training.

Figure 1 Flow diagram of the peer support intervention program design.

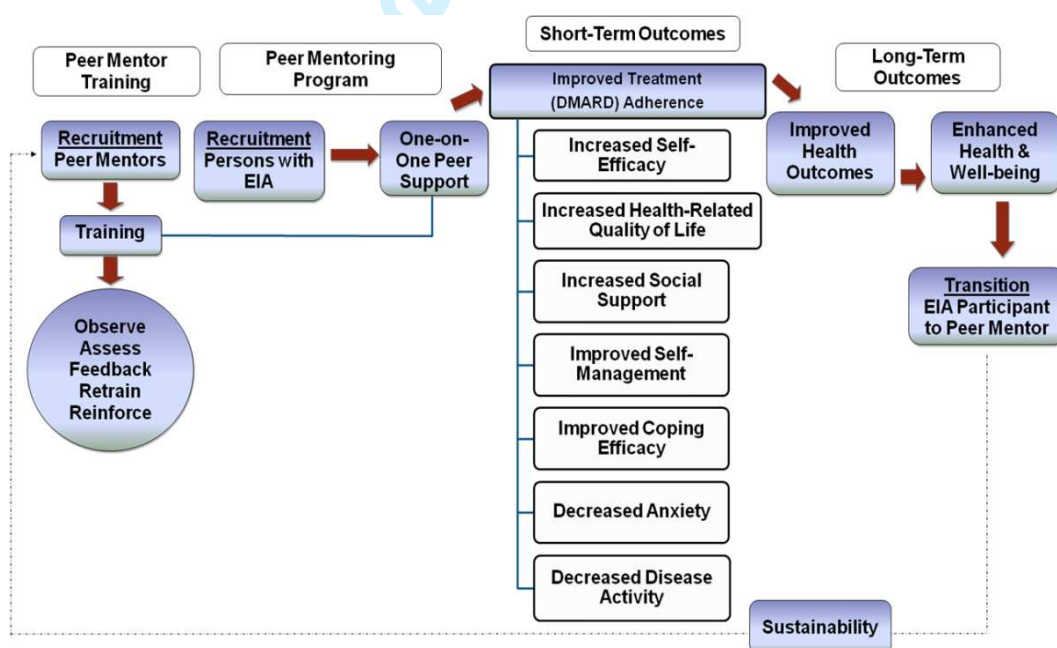


Figure 2 Flowchart outlining steps in the MRC framework.

Development Phase

Identifying the evidence base

Modeling – needs assessment, working groups for peer mentor training development, and expert review



Feasibility and Piloting Phase

Peer mentor recruitment and training

Mentee recruitment

Exploratory trial – pairing peer mentors with mentees, program delivery, qualitative and quantitative data collection, including process and outcome measures



Future RCT, Evaluation and Implementation

Feasibility and piloting phase

Peer mentor recruitment and training

Potential peer mentors were recruited from the Greater Toronto Area (GTA) through: principal investigator's clinic, word-of-mouth, peer mentors, and e-mails from The Arthritis Society. Mentors were selected based on inclusion criteria (Table 1). Eligibility screening occurred by telephone followed by face-to-face interviews.

Table 1 Inclusion criteria for peer mentors and mentees

Peer mentors

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Diagnosis of inflammatory arthritis (IA) from a physician

≥ 18 years of age

Disease duration ≥ 2 years

Currently using medications (DMARDS/biologics) for treatment

Completion of the Arthritis Self-Management Program (ASMP) provided by The Arthritis Society and/or similar program

Able to attend scheduled training sessions

Able to take part in ongoing assessment/evaluation activities (self-reported questionnaires; interviews, observation; activity logs)

Able to commit for duration of study (9-12 months)

Willing to provide ongoing one-on-one support to an individual with newly diagnosed IA

Able to speak, understand, read and write English

Mentees

EIA disease duration 6-52 weeks

At least 3 swollen joints, assessed by the treating rheumatologist, OR

Positive compression test for metacarpophalangeal joints, OR

Positive compression test for metatarsophalangeal joints, OR

At least 30 minutes of morning stiffness

Prescribed a DMARD/biologic by a rheumatologist

Able to speak, understand, read and write English without the aid of a support person

Able to provide informed consent

Peer mentors attended four training sessions (18 hours total). Training provided information on EIA, educational/support resources, and opportunities to learn and

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3 practice peer support techniques (informational, emotional, appraisal support) and skills
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5 (communication, decision-making, goal-setting). Mentors received two initial training
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7 sessions and an additional session based on feedback from researchers and participants.
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10 Peer mentors received a resource binder with information on arthritis and mentoring
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12 resources and ongoing support from the research team via e-mail, telephone, and in-
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14 person.
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17 18 19 20 Mentee recruitment

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22 Patients with EIA were recruited from rheumatology clinics in two GTA teaching
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24 hospitals.
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27 28 29 Exploratory trial

30 31 *Pairing and delivery*

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33 Mentees were paired with peer mentors based on age and work status. The initial meeting
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35 was face-to-face, with subsequent meetings taking place at the discretion of the pair (in-
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37 person or telephone). Dyads met weekly for approximately 12 weeks. Participants were
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39 brought together at the end for debriefing and celebrating.
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45 46 *Quantitative data collection*

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48 A before-and-after design was used to determine changes over time that can be attributed
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50 to the intervention. Peer mentors' self-efficacy was assessed four time points – baseline
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52 (T1), post-training (T2), immediately after program completion (T3) and three months
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54 post-program (T4). Mentee outcomes data were collected at baseline (T1), immediately
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after program completion (T2) and three months post-program (T3) by self-administered questionnaires and clinical assessment. Outcomes are below:

- 1) *Adherence* to DMARD/biologic treatment in EIA patients, determined indirectly through the Morisky scale (22)
- 2) *Self-efficacy* measured by Self-Efficacy for Managing Chronic Disease 6-Item Scale (23, 24)
- 3) Change in *health-related quality of life and anxiety* measured by Arthritis Impact Measurement Scales, 2nd edition (AIMS2) and dimension sub-score for anxiety, respectively (25)
- 4) *Coping-efficacy* assessed by Gignac et al.'s method Gignac et al. (26)
- 5) *Clinical disease activity* assessed by a rheumatologist from the research team using Clinical Disease Activity Index (CDAI) score (27)
- 6) *Social support* measured by Medical Outcomes Study Social Support Survey (MOSSS) (28)
- 7) *Self-management* examined by Patient Activation Measure (PAM) (29)

Descriptive statistics and effect sizes were calculated to determine clinically important (>0.3) changes. Effect size, a unitless measurement of treatment effect, was used to measure the effects of the intervention. An effect size of 0.2 is considered small; 0.5 moderate; and 0.8 large (30).

Qualitative data and process measures

Peer mentors completed a training evaluation questionnaire. Implementation process data was collected to assess acceptability and feasibility. The number and nature of meetings, topics discussed, and problems arising were recorded by peer mentors via activity log.

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3 Research staff called mentors weekly for updates. One-on-one interviews with
4 participants were conducted to determine acceptability and feasibility of procedures and
5 outcome measures, and gain perspectives on the value of peer support. Key themes were
6 identified from transcribed data through constant comparison. Mentees' experiences were
7 explored using a participant diary at three time points.
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17 Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences
18 Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at
19 <http://www.clinicaltrials.gov> (Identification numbers: NCT01054963, NCT01054131).
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27 RESULTS

28 Development phase

29 Identifying the evidence base

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32 21,489 abstracts across six chronic diseases were identified. Twenty-five articles were
33 included in the meta-ethnography. Results are reported elsewhere (20).
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41 Key themes identified about peer mentor training were: setting boundaries around peer
42 mentor roles, ensuring confidentiality, enhancing communication skills, providing
43 continuing education and support for mentors, and sharing personal experiences to aid in
44 decision-making. Literature about the delivery of peer support programs highlighted the
45 importance of peer mentor recruitment, selection/assessment, outcome measures, and
46 mentee recruitment.
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Modeling

Needs assessment

Peer support was a well-received approach for helping individuals with EIA to cope with concerns arising from their diagnosis. Participants perceived that peer mentoring, if context-driven (paying attention to specific disease phases and individual circumstances) and sensitive to their needs, could be valuable in managing their disease. Results are reported elsewhere (1).

Working groups for intervention development

Each of the working groups met multiple times. Additional members with specific expertise were added as needed to finalize the intervention.

Expert review

Eighteen experts (individuals with IA, HCPs, peer support researchers, representatives of arthritis organizations, educators) provided input into the format/content of the peer mentor training.

Feasibility and piloting phase

Peer mentor recruitment and training

Twenty-four potential mentors were identified. Twelve were recruited. Nine completed the training and became peer mentors. Three withdrew due to personal illness and/or family issues. All mentors had RA. See Table 2.

Mentee recruitment

Twenty-nine potential mentees were identified, nine of whom were eligible and enrolled.

One mentee was lost to follow-up. All nine mentees had RA. See Table 2.

Table 2 Peer mentor and mentee demographics

Peer mentors (N = 9)		N
Age (years)	31-40	1
	41-50	2
	51-60	3
	61-70	3
Sex	Female	9
	Male	0
Age at diagnosis (years)	<18	1
	18-30	3
	31-40	3
	41-50	0
	51-60	1
	61-70	1
Work status	Working for pay	5
	Not working/ Homemaker	2
	Retired	2
Mentees (N = 9)		N

Age (years)	18-30	2
	31-50	2
	51-60	3
	61-70	2
Sex	Female	7
	Male	2
Marital status	Single/Never married	1
	Married	4
	Common law/Living with someone	3
	Widowed	1
Living arrangements	Living alone in house or apartment	2
	Living with family or friends in house or apartment	7
Work status	Working for pay	6
	Not working/Homemaker	2
	Retired	1
Highest level of education	Some/Completed high school	1
	Some/Completed college/university	6
	Some/Completed post graduate	2

Exploratory trial

Pairing and delivery

Nine mentor-mentee pairs participated. All mentors were female resulting in two mixed-gender dyads.

Quantitative data collection

Mentors' reported self-efficacy increased significantly after training completion.

However, these measures dropped below baseline upon program completion with recovery to baseline levels at three months post-program (Table 3).

Table 3 Peer mentor and mentee results

Peer mentor self-efficacy scale ratings					
Peer mentor reported self-efficacy	N	Mean	Standard Deviation	p-value	Effect Size
Baseline (T1)	12	8.0093	1.4122		
Post Training (T2)	9	9.1358	0.5577	.008*	1.03
End of Program (T3)	8	7.2917	0.6220	.161	0.42
3 Months after Program Completion (T4)	8	7.8818	0.5898	.859	0.03

* significant (p<0.05)

Mentees' mean outcome scores at baseline (T1) and program completion (T2)					
Measurement	N	T1	T2	T1-T2 (SD)	Effect Size T1-T2 (Mean)

Medication Adherence (Morisky scale)	8	0.78	0.63	0.53	0
Self-Efficacy Scale	8	7.59	7.75	1.01	0.04
Arthritis Impact Measurement Scales (AIMS2) – Short Form (SF)					
• AIMS2-SF	5	30.26	28.96	1.33	0.39
• AIMS2-Physical (/10)	8	8.36	8.60	1.98	0.19
• AIMS2-Symptoms (/10)	8	2.59	1.56	2.23	0.28
• AIMS2-Affect (/10)	8	5.56	5.31	1.03	0.27
• AIMS2-Social (/10)	8	5.76	5.47	0.93	0.47
• AIMS2-Work (/10)	5	7.66	8.13	2.05	0.42
Coping Efficacy (Gignac et al.)	8	4.08	4.41	0.46	0.35
Clinical Disease Activity (CDAI)	6	9.94	5.68	3.91	0.19
Medical Outcomes Study Social Support Survey (MOSSS)	8	3.77	4.11	0.28	0.30
Patient Activation Measure (PAM)	8	75.80	73.11	11.75	0.22

Mentees experienced improvement in overall arthritis impact on health-related quality of life, coping, and social support. Self-reported measures at program completion (12 weeks) showed significant improvements (effect size >0.3) in the overall AIMS2-SF and Social and Work subcomponents. Mentees reported improvements based on Social Support (MOSSS) and Coping Efficacy. There were no significant effects in Disease Activity Measures Index (CDAI), Medication Adherence (Morisky) or Self-Efficacy

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3 Scale. None of these measures showed sustained improvement three months post-
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6 program (T3) (Table 3).
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11 *Qualitative data and process measures*

12 Average number of meetings was 8.11 (range=6-12). Average length of meetings was
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14 36.90 minutes (range=10-120 minutes). Mode of contact after initial face-to-face meeting
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16 was telephone only for four pairs, with the remaining five dyads using a mix of telephone
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18 and face-to-face.
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24 Key themes revealed from the 17 interviews are categorized below:
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27 *Mentor-specific experiences*

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29 Peer mentors largely appreciated their training; they valued the emotional support content
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31 of the training program and being able to work through simulated scenarios. Mentors
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33 reported personally benefiting from the program. They reported it increased their
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35 knowledge, provided new self-management techniques and coping strategies (PM3, PM4,
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37 PM7, PM9, PM12), reinforced self-management strategies they were familiar with, and
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39 made them realize how far they had come in their disease experience (PM12, PM8).
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46 A few mentors experienced challenges (e.g., mentee reluctant to stop consuming alcohol
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48 to take methotrexate (PM7); mentee with problems returning to work after being on long-
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50 term disability (PM8)). These mentors (PM7, PM8) also experienced challenges in
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52 arranging sessions.
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Mentee-specific experiences

Emotional and informational support were most commonly reported. One mentee described his mentor as, “a book, as far as I'm concerned, she has more information than I can absorb, really” (EIA8). Informational support was not confined to program resources, but also included mentors' experiential knowledge:

“I would ask her when she encountered bad weather, how were her joints? What did she do about that? ... Can I do something prior to, when you know the weather is coming” (EIA3).

Appraisal and instrumental support were also exchanged. One mentee said:

“It was great being able to sit down and have a normal conversation, but at the same time throw in, oh yeah, I'm thinking about switching to biologics so what's your opinion?” (EIA1).

The inter-subjective dynamics of peer support

Participants' experience of peer support was informed by the unique relationship they forged with their peer. Many participants spoke of having “a connection” with his/her peer. This was facilitated by similarities in personality, age, gender, interests, life stage, position of responsibility at work, diagnosis, disease severity, and similarity of affected joints. “My hands felt like her hands,” said one mentee (EIA4). Four participants faced challenges building rapport due to differences in gender, sexuality, political views and disease stage. Gender differences restricted the type of conversations in one mixed gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-bound mentor, as she was not able to cope with this:

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3 “... I found myself looking at my mentor and going, that's not me, I don't have that, I'm
4 not going there, I'm not going to be in a wheelchair... or be badly deformed.” (EIA6).
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10 While such experiences complicated the work of providing and receiving peer support,
11 all participants were unequivocal about the need for a peer support program for
12 individuals with EIA. Mentees spoke about the program as “critical” (EIA1), declaring,
13 “It can't stop. It can't” (EIA3). Mentors wished that similar peer support interventions
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20 had been available when they were first diagnosed.
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24 **DISCUSSION**

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27 In this study, we piloted a peer support program for patients with EIA using the 2008
28 MRC framework (17) Information from the development phase, with input from working
29 groups and expert reviewers and a qualitative needs assessment were used to develop a
30 pilot peer support intervention. A complementary, inductive approach helped to make
31 additional sense of learning and support needs, how and why the intervention met (or
32 failed to meet) these needs and to generate information and hypotheses for testing with
33 quantitative research methods.
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46 A peer support program could help patients with EIA navigate the issues surrounding
47 their disease. The potential advantage of peer support relates to its focus on impacts on
48 daily activities and functioning rather than medical information (4). Peer support
49 encourages sharing of experiences between participants with personalized and flexible
50 content. Our results suggested that both mentors and mentees perceived benefits from the
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3 program. Mentors described largely positive benefits including role satisfaction, and
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5 increase in their own knowledge and self-management techniques.
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11 Few qualitative studies to date have rigorously evaluated the effect of peer support on
12
13 mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-
14
15 efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores
16
17 of mentors increased after training, scores decreased below baseline after 12 weeks of
18
19 mentoring and three months post- program. This raises concerns that being a peer mentor
20
21 could be a demanding and stressful experience (33), especially for mentors who
22
23 expressed concerns with their mentees. The success of a peer support program also relies
24
25 on the skills and retention of peer mentors. Our preliminary results suggest that regular
26
27 training and practice sessions may be necessary to maintain mentors' self-efficacy.
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35 Mentees showed improvements in a number of outcome measures including the Social
36
37 and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a
38
39 small improvement in Affect and Symptom components of AIMS2-SF. Our study did not
40
41 demonstrate a significant effect of the intervention on disease activity (CDAI) and this
42
43 mirrors previous quantitative studies (34), which found no significant reduction in joint
44
45 counts in RA patients who received patient-education interventions. However, the main
46
47 thrust behind the study was to develop an individualized support program that was
48
49 responsive to the needs of each patient. Thus, improvements in the Coping Efficacy and
50
51 Social Support scores are encouraging. The fact that improvements were not sustained
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53 three months post-program would suggest that three months may be insufficient for
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3 mentees to develop knowledge and skills to help them adapt to their disease. We know
4
5 from education literature that “booster sessions” may be required to sustain knowledge
6
7 and skill sets (35), although other studies have questioned their effectiveness (36).
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12 Our study did not demonstrate any effect on medication adherence. This reflects previous
13
14 data that interventions to increase medication adherence in chronic conditions are
15
16 complex, and that a large proportion of patient education interventions in this setting have
17
18 been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded
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20 null results, but participants thought they would benefit from peer support early after
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22 diagnosis (33).
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29
30 A limitation is the small sample size. However, this study was designed as a feasibility
31
32 and pilot study. The goal was to determine change over time in the outcome measures
33
34 that can be attributed to the intervention and to obtain initial data for planning and
35
36 implementing a larger scale study. As such, results from this preliminary pilot are not
37
38 meant to be generalized. All trained mentors and mentees had RA, limiting the
39
40 generalizability to other types of IA. Matching pairs based on personal and social
41
42 characteristics was important. Unfortunately, were unable to match all pairs by gender.
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44 The two mixed gender dyads reported that this may have limited the types of
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46 conversations they had.
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53
54 In summary, this study showed that developing and delivering a peer support program
55
56 was acceptable, feasible with modifications, and well-received by peer mentors and
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3 mentees. Peers can be instrumental in promoting self-management and improving one's
4 ability to cope with the diagnosis of a chronic disease. Peers also facilitate social support
5 and may be a useful adjunct to standard rheumatologic care. The information gleaned
6 from this study has been incorporated into a randomized, wait-list controlled study now
7 in progress to further assess the benefits of peer support in EIA management.
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32 **Author Contributions**

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34 Mary Bell – Principal Investigator, intervention development, implementation and
35 evaluation, data analysis, manuscript writing
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38 Sharron Sandhu – Co-investigator, intervention development and implementation, data
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48 Gayathri Embuldeniya, Research Assistant, intervention development, implementation
49 and evaluation, data analysis, manuscript writing
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54 evaluation, data analysis, manuscript writing
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6 Sicong Huang – Medical student, data analysis, manuscript writing

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8 Alex Zhao - Medical student, data analysis, manuscript writing

9
10 Dawn Richards - Research team member/consumer collaborator, intervention
11
12 development, implementation and evaluation, manuscript writing

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24 **Data sharing statement** No additional data available

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3 We have adhered to guidelines for Mixed Methods studies as per:
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- 8 • Is the quantitative component feasible? Yes
- 9 • Is the qualitative component feasible? Yes
- 10 • Is the mixed methods design feasible? Yes
- 11 • Have both qualitative and quantitative components been completed? Yes
- 12 • Were some quantitative methods planned but not executed? No
- 13 • Were some qualitative methods planned but not executed? No
- 14 • Did the mixed methods design work in practice? Yes
- 15 • Is the use of mixed methods research justified? Yes
- 16 • Is the design for mixing methods described?
 - 17 ○ Priority Yes
 - 18 ○ Purpose Yes
 - 19 ○ Sequence Yes
 - 20 ○ Stage of integration Yes
- 21 • Is the design clearly communicated? Yes
- 22 • Is the design appropriate for addressing the research questions? Yes
- 23 • Has rigour of the design been considered (proposal) or adhered to (report)? Yes
- 24 • Is the role of each method clear? Yes
- 25 • Is each method described in sufficient detail? Yes
- 26 • Is each method appropriate for addressing the research question? Yes
- 27 • Is the approach to sampling and analysis appropriate for its purpose? Yes
- 28 • Is there expertise among applicants/authors? Yes
- 29 • Is there expertise on the team to undertake each method? Yes
- 30 • Have issues of validity been addressed for each method? Yes
- 31 • Has the rigour of any method been compromised? Yes
- 32 • Is each method sufficiently developed for its purpose? Yes
- 33 • Is the (intended) analysis sufficiently sophisticated? Yes
- 34 • Is the role of each method clear? Yes
- 35 • Is each method described in sufficient detail? Yes
- 36 • Did appropriate members of the team participate in integration? Yes
- 37 • Is there evidence of communication within the team? Yes
- 38 • Has rigour been compromised by the process of integration? No
- 39 • Is there clarity about which results have emerged from which methods? Yes
- 40 • Are inferences appropriate? Yes
- 41 • Are the results of all the methods considered sufficiently in the interpretation? Yes
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**Peer-to-Peer Mentoring for Individuals with Early
Inflammatory Arthritis: Feasibility Pilot**

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Manuscripts

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3 **Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis:**
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6 **Feasibility Pilot**
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14 Rheumatoid Arthritis
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ABSTRACT

Objectives: To examine the feasibility and potential benefits of early peer support to improve the health and quality of life of individuals with early inflammatory arthritis (EIA).

Design: Feasibility study using the 2008 Medical Research Council framework as a theoretical basis. A literature review, environmental scan, and interviews with patients, families, and health-care providers guided the development of peer mentor training sessions and a peer-to-peer mentoring program. Peer mentors were trained and paired with a mentee to receive (face-to-face or telephone) support over 12-weeks.

Setting: Two academic teaching hospitals in Toronto, Ontario, Canada.

Participants: Nine pairs consisting of one peer mentor and one mentee were matched based on factors such as age and work status.

Primary outcome measure: Mentee outcomes of *disease modifying anti-rheumatic drugs (DMARDs)/biologic treatment use, self-efficacy, self-management, health-related quality of life, anxiety, coping-efficacy, social support, and disease activity* were measured using validated tools. Descriptive statistics and effect sizes were calculated to determine clinically important (>0.3) changes. Peer mentor *self-efficacy* was assessed using a self-efficacy scale. Interviews conducted with participants examined acceptability and feasibility of procedures and outcome measures, and perspectives on the value of peer support for individuals with EIA. Themes were identified through constant comparison.

Results: Mentees experienced improvements in the overall arthritis impact on life, coping efficacy, and social support (effect size >0.3). Mentees also perceived emotional,

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3 informational, appraisal and instrumental support. Mentors also reported benefits and
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5 learned from mentees' fortitude and self-management skills. The training was well-
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7 received by mentors. Their self-efficacy increased significantly after training completion.
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10 Participants' experience of peer support was informed by the unique relationship with
11
12 their peer. All participants were unequivocal about the need for peer support for
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14 individuals with EIA.
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17 **Conclusions:** The intervention was well-received. Training, peer support program and
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19 outcome measures were demonstrated to be feasible with modifications. Early peer
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21 support may augment current rheumatologic care.
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24 **Trial registry:** NCT01054963, NCT01054131
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ARTICLE SUMMARY

Article focus

- Feasibility study for developing, implementing and evaluating a peer support intervention (peer mentor training peer mentoring program consisting of 12-weeks of face-to-face or telephone meetings to support mentees newly diagnosed with early inflammatory arthritis (EIA).

Key messages

- Early peer support is feasible and well-received by both mentors and mentees.
- Individuals with EIA may benefit from peer support, and this may augment current rheumatologic care.

Strengths and limitations of this study

- The study was guided by the 2008 Medical Research Council Framework for Complex Interventions.
- The intervention was well-received and had benefits for both mentors and mentees.
- As rheumatoid arthritis was the diagnosis of all participants, further study is needed to assess benefit of early peer support for other types of inflammatory arthritis.

INTRODUCTION

Inflammatory arthritis (IA) is a leading cause of functional disability, chronic pain, and psychosocial distress (1,2). Patient self-management, education, and social support networks are encouraged as part of a holistic approach to disease management (3). A peer-to-peer mentoring program that aims to provide support based on the sharing of information and experiences (4) may benefit individuals with early inflammatory arthritis (EIA).

Individuals with EIA often reveal a complex and frustrating journey preceding diagnosis. Symptom fluctuations, symptom normalization and dismissal of their symptoms by healthcare providers (HCPs) are factors contributing to misdiagnosis, delays in referral to rheumatology, and psychological distress and frustration (1). Patients' initial reactions to being diagnosed with EIA range from relief and acceptance to anger, fear, denial, and disbelief (1). Once diagnosed, patients face an overwhelming range of biological, psychological, and social issues such as disease course and severity (both of which are often unpredictable), their ability to cope with pain, as well as uncertainties about social and work issues (5). Like other chronic diseases, responsibilities for daily management gradually shift from HCPs to patients (2). Adapting to EIA is complex (6), and patients require support and guidance early in the disease process so they may learn to live and self-manage their symptoms (2). Patient education and self-management is an arthritis "best practice" and a key clinical practice guideline (7,8,9). Peer support is one strategy to increase patients' knowledge and skills for self-management.

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3 Peer support models have been successfully implemented in other chronic health issues
4 such as cancer (10), HIV/AIDS (11), and diabetes (12). A peer is someone who shares
5 common characteristics (e.g., age, sex, disease status) with the individual of interest, such
6 that the peer can relate to, and empathize with the individual on a level that a non-peer
7 would be unable (4). Dennis defines peer support as "... the provision of emotional,
8 appraisal, and informational assistance by a created social network member who
9 possesses experiential knowledge of a specific behaviour or stressor and has similar
10 characteristics as the target population" (13). Emotional support includes expressions of
11 caring, empathy, encouragement and reassurance, and is generally seen to enhance self-
12 esteem. Appraisal support involves encouraging persistence and optimism for resolving
13 problems, affirmation of a peer's feelings and behaviours, and reassurance that
14 frustrations can be handled. Informational support involves providing advice,
15 suggestions, alternative actions, feedback and factual information (13). All three forms of
16 support are based on experiential knowledge, rather than formal training (13). Peer
17 support interventions fit within a social support model (14). Within this model, peer
18 support could reduce feelings of isolation and loneliness, provide information about
19 accessing available health services, and promote behaviours that positively improve
20 personal health, well-being, and health practices (14).
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48 Currently, the major support program that patients with EIA can access is the Arthritis
49 Self-Management Program (ASMP) (15). While it provides emotional and appraisal
50 support, the standardized outline is not personalizable and the group format limits one-
51 on-one interactions.
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6 We propose that a peer support program with trained mentors with established IA will
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8 assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA,
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10 and help them self-manage their disease. An earlier study exploring the learning and
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12 support needs of patients with IA provides a rationale for using peer support (1) and
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14 previous studies have shown that individuals with rheumatoid arthritis (RA) appear to
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16 benefit from relationships they can rely on for emotional support, information, and
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18 tangible assistance (16). Whether a peer support program may facilitate some of these
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20 benefits in patients with EIA has yet to be explored. This study examines the: 1)
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22 development and 2) feasibility and pilot phases of a peer support intervention using the
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24 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation*
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26 *of Randomized Control Trials for Complex Interventions to Improve Health* (17). The
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28 primary objective is to develop a peer mentor training process and establish the feasibility
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30 and acceptability of a peer support program. Secondary objectives include measuring
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32 changes in various outcomes as a result of this intervention (Figure 1). The development
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34 phase of the study has been described elsewhere (20). This paper reports on the feasibility
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36 and acceptability of the peer support program and on the secondary outcome measures.
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45 46 **METHODS**

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48 The four phases of the 2008 MRC framework guided this complex intervention: (17)
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50 *development phase*, to establish theoretical underpinnings and modeling to achieve an
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52 understanding of the intervention and its possible effects; *feasibility and piloting phase*:
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54 exploratory trial to test feasibility of key intervention components; *evaluation phase*: to
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1
2
3 assess program effectiveness; and *implementation phase*: to examine long-term
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5
6 implementation and sustainability (Figure 2).
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10 **Development phase**

11 Identifying the evidence base

12
13 A qualitative literature search strategy was developed on peer support and chronic
14
15 diseases using Medline, EMBASE, CINAHL, and Cochrane Systematic Reviews.
16
17 Reviewers independently evaluated papers using a quality assessment tool. Using meta-
18
19 ethnography, a methodology to synthesize qualitative literature (18, 19), we determined
20
21 how studies were related, translated studies into one another, synthesized translations,
22
23 and expressed the synthesized ethnography (20). Quantitative studies were reviewed,
24
25 including a draft from a Cochrane Collaboration protocol (4). An environmental scan was
26
27 performed and grey literature summarized.
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36 Modeling

37 *Needs assessment*

38
39 A qualitative needs assessment was performed to identify educational preferences and
40
41 informational, emotional and appraisal support needs of individuals with IA, and to
42
43 determine the suitability of peer support (1). Semi-structured, one-on-one interviews were
44
45 performed with patients with IA, their family/friends, and HCPs. Interview audio files,
46
47 transcripts and field notes were uploaded to a qualitative software package, NVivo 8, for
48
49 coding and analysis. Themes were identified through constant comparative analysis (21).
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Working groups for intervention development

Three working groups (peer mentor training, peer support program, evaluation) of four to six research team and end users were convened to develop the pilot intervention.

Expert review

Using snowball recruiting, expert reviewers were nominated by the research team. They reviewed study information and completed a semi-structured questionnaire by e-mail about the proposed training.

Figure 1 Flow diagram of the peer support intervention program design.

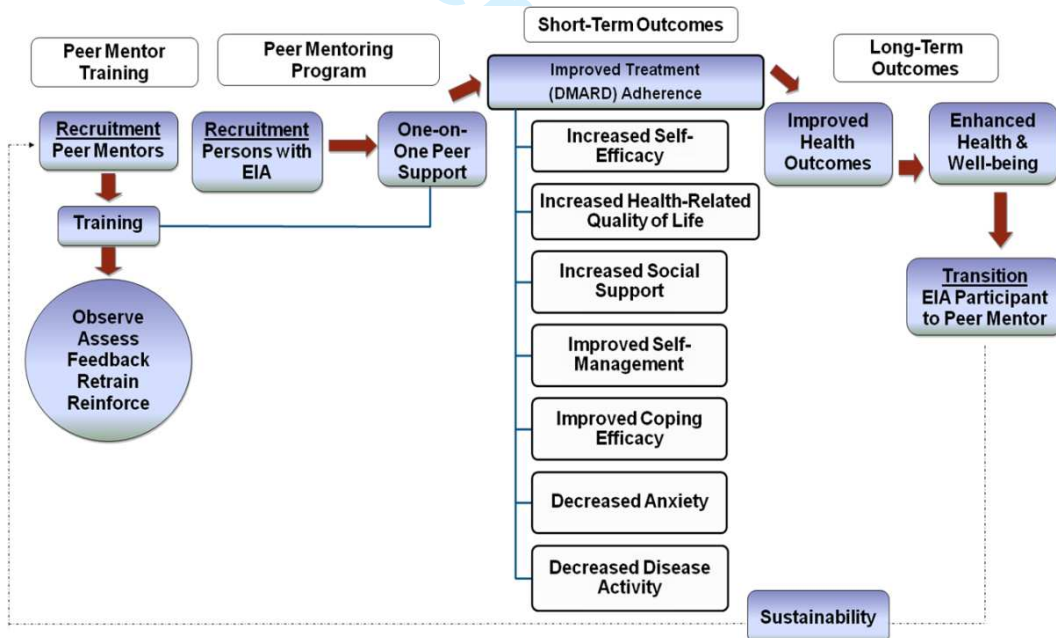


Figure 2 Flowchart outlining steps in the MRC framework.

Development Phase

Identifying the evidence base

Modeling – needs assessment, working groups for peer mentor training development, and expert review



Feasibility and Piloting Phase

Peer mentor recruitment and training

Mentee recruitment

Exploratory trial – pairing peer mentors with mentees, program delivery, qualitative and quantitative data collection, including process and outcome measures



Future RCT, Evaluation and Implementation

Feasibility and piloting phase

Peer mentor recruitment and training

Potential peer mentors were recruited from the Greater Toronto Area (GTA) through: principal investigator's clinic, word-of-mouth, peer mentors, and e-mails from The Arthritis Society. Mentors were selected based on inclusion criteria (Table 1). Eligibility screening occurred by telephone followed by face-to-face interviews.

Table 1 Inclusion criteria for peer mentors and mentees

Peer mentors

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Diagnosis of inflammatory arthritis (IA) from a physician

≥ 18 years of age

Disease duration ≥ 2 years

Currently using medications (DMARDS/biologics) for treatment

Completion of the Arthritis Self-Management Program (ASMP) provided by The Arthritis Society and/or similar program

Able to attend scheduled training sessions

Able to take part in ongoing assessment/evaluation activities (self-reported questionnaires; interviews, observation; activity logs)

Able to commit for duration of study (9-12 months)

Willing to provide ongoing one-on-one support to an individual with newly diagnosed IA

Able to speak, understand, read and write English

Mentees

EIA disease duration 6-52 weeks

At least 3 swollen joints, assessed by the treating rheumatologist, OR

Positive compression test for metacarpophalangeal joints, OR

Positive compression test for metatarsophalangeal joints, OR

At least 30 minutes of morning stiffness

Prescribed a DMARD/biologic by a rheumatologist

Able to speak, understand, read and write English without the aid of a support person

Able to provide informed consent

Peer mentors attended four training sessions (18 hours total). Training provided information on EIA, educational/support resources, and opportunities to learn and

1
2
3 practice peer support techniques (informational, emotional, appraisal support) and skills
4
5 (communication, decision-making, goal-setting). Mentors received two initial training
6
7 sessions and an additional session based on feedback from researchers and participants.
8
9
10 Peer mentors received a resource binder with information on arthritis and mentoring
11
12 resources and ongoing support from the research team via e-mail, telephone, and in-
13
14 person.
15
16

17 18 19 20 Mentee recruitment

21
22 Patients with EIA were recruited from rheumatology clinics in two GTA teaching
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24 hospitals.
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27 28 29 Exploratory trial

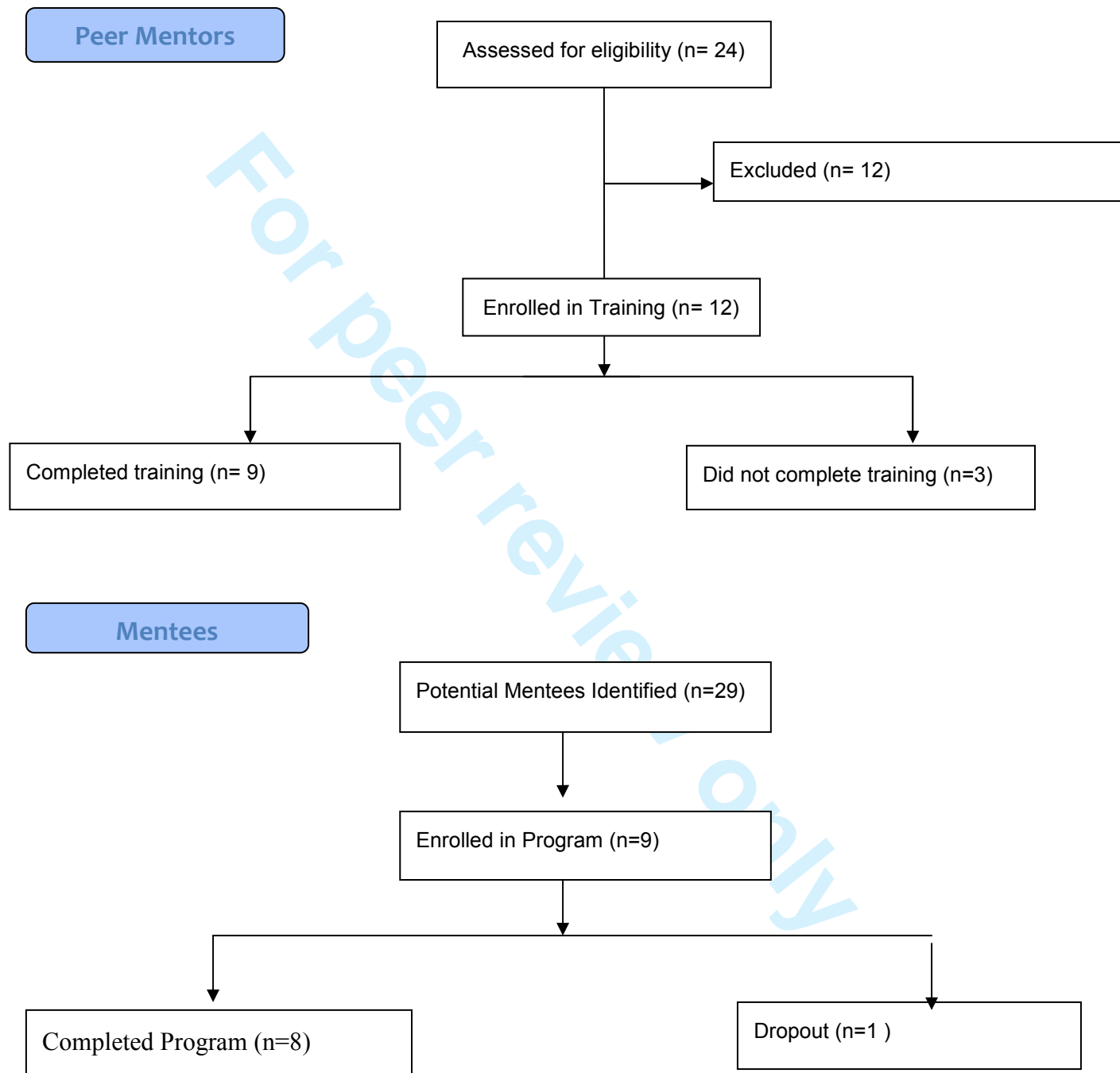
30 31 *Pairing and delivery*

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33 Mentees were paired with peer mentors based on age and work status. The initial meeting
34
35 was face-to-face, with subsequent meetings taking place at the discretion of the pair (in-
36
37 person or telephone). Dyads met weekly for approximately 12 weeks. Participants were
38
39 brought together at the end for debriefing and celebrating.
40
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45 46 *Quantitative data collection*

47
48 24 potential mentors were identified, of which 12 were eligible and 9 completed training.
49
50 29 potential EIA participants were identified, 9 were enrolled and 8 completed the
51
52 program (Figure3)
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Figure 3: Flow Diagram for Peer Mentor and Mentee Recruitment



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4 A before-and-after design was used to determine changes over time that can be attributed
5 to the intervention. Peer mentors' self-efficacy was assessed via a self-administered
6
7 questionnaire at four time points – baseline (T1), post-training (T2), immediately after
8
9 program completion (T3) and three months post-program (T4). Mentee outcomes data
10
11 were collected by self-administered questionnaires and clinical assessment at baseline
12
13 (T1), immediately after program completion (T2) and three months post-program (T3)..

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18 Outcomes are below:

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21 1) *Adherence* to DMARD/biologic treatment in EIA patients, determined indirectly
22
23 through the Morisky scale (22)
- 24
25
26 2) *Self-efficacy* measured by Self-Efficacy for Managing Chronic Disease 6-Item Scale (23,
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28 24)
- 29
30
31 3) Change in *health-related quality of life and anxiety* measured by Arthritis Impact
32
33 Measurement Scales, 2nd edition (AIMS2) and dimension sub-score for anxiety,
34
35 respectively (25)
- 36
37
38 4) *Coping-efficacy* assessed by Gignac et al.'s method Gignac et al. (26)
- 39
40
41 5) *Clinical disease activity* assessed by a rheumatologist from the research team
42
43 using Clinical Disease Activity Index (CDAI) score (27)
- 44
45
46 6) *Social support* measured by Medical Outcomes Study Social Support Survey
47
48 (MOSSS) (28)
- 49
50
51 7) *Self-management* examined by Patient Activation Measure (PAM) (29)

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54 Descriptive statistics and effect sizes were calculated to determine clinically important
55
56 (>0.3) changes. Effect size, a unitless measurement of treatment effect, was used to
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1
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3 measure the effects of the intervention. An effect size of 0.2 is considered small; 0.5
4
5 moderate; and 0.8 large (30).
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10 *Qualitative data and process measures*

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12 Peer mentors completed a training evaluation questionnaire. Implementation process data
13
14 was collected to assess acceptability and feasibility. The number and nature of meetings,
15
16 topics discussed, and problems arising were recorded by peer mentors via activity log.
17
18 Research staff called mentors weekly for updates. One-on-one interviews with
19
20 participants were conducted to determine acceptability and feasibility of procedures and
21
22 outcome measures, and gain perspectives on the value of peer support. Key themes were
23
24 identified from transcribed data through constant comparison. Mentees' experiences were
25
26 explored using a participant diary at three time points.
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34 Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences
35
36 Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at
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38 <http://www.clinicaltrials.gov> (Identification numbers: NCT01054963, NCT01054131).
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43 **RESULTS**

44 **Development phase**

45 Identifying the evidence base

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48 21,489 abstracts across six chronic diseases were identified. Twenty-five articles were
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50 included in the meta-ethnography. Results are reported elsewhere (20).
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3 Key themes identified about peer mentor training were: setting boundaries around peer
4 mentor roles, ensuring confidentiality, enhancing communication skills, providing
5 continuing education and support for mentors, and sharing personal experiences to aid in
6 decision-making. Literature about the delivery of peer support programs highlighted the
7 importance of peer mentor recruitment, selection/assessment, outcome measures, and
8 mentee recruitment.
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17 18 19 20 Modeling

21 22 *Needs assessment*

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24 Peer support was a well-received approach for helping individuals with EIA to cope with
25 concerns arising from their diagnosis. Participants perceived that peer mentoring, if
26 context-driven (paying attention to specific disease phases and individual circumstances)
27 and sensitive to their needs, could be valuable in managing their disease. Results are
28 reported elsewhere (1).
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39 40 *Working groups for intervention development*

41 Each of the working groups met multiple times. Additional members with specific
42 expertise were added as needed to finalize the intervention.
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48 49 *Expert review*

50 Eighteen experts (individuals with IA, HCPs, peer support researchers, representatives of
51 arthritis organizations, educators) provided input into the format/content of the peer
52 mentor training.
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Feasibility and piloting phase

Peer mentor recruitment and training

Twenty-four potential mentors were identified. Twelve were recruited. Nine completed the training and became peer mentors. Three withdrew due to personal illness and/or family issues. All mentors had RA. See Table 2.

Mentee recruitment

Twenty-nine potential mentees were identified, nine of whom were eligible and enrolled. One mentee was lost to follow-up. All nine mentees had RA. See Table 2.

Table 2 Demographics : Peer mentors, mentees and peer mentors who withdrew

Peer mentors (N = 9)		N
Age (years)	31-40	1
	41-50	2
	51-60	3
	61-70	3
Sex	Female	9
	Male	0
Age at diagnosis (years)	<18	1
	18-30	3
	31-40	3

	41-50	0
	51-60	1
	61-70	1
Work status	Working for pay	5
	Not working/ Homemaker	2
	Retired	2
Mentees (N = 9)		N
Age (years)	18-30	2
	31-50	2
	51-60	3
	61-70	2
Sex	Female	7
	Male	2
Marital status	Single/Never married	1
	Married	4
	Common law/Living with someone	3
	Widowed	1
Living arrangements	Living alone in house or apartment	2
	Living with family or friends in house or apartment	7
Work status	Working for pay	6

	Not working/Homemaker	2
	Retired	1
Highest level of education	Some/Completed high school	1
	Some/Completed college/university	6
	Some/Completed post graduate	2
Peer mentors who withdrew (N = 3)		N
Age (years)	41-50	2
	51-60	1
Age at diagnosis (years)	<18	1
	18-30	1
	41-50	1
Sex	Female	3
	Male	0
Diagnosis	RA	2
	Psoriatic Arthritis	1
Work	Working for pay	3

Exploratory trial

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3 *Pairing and delivery*
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5 Nine mentor-mentee pairs participated. All mentors were female resulting in two mixed-
6
7
8 gender dyads.
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12 *Quantitative data collection*
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14 Mentors' reported self-efficacy increased significantly after training completion.
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16 However, these measures dropped below baseline upon program completion with
17
18 recovery to baseline levels at three months post-program (Table 3).
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23

24 **Table 3** Peer mentor and mentee results
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Peer mentor self-efficacy scale ratings					
Peer mentor reported self-			Standard		Effect Size
efficacy	N	Mean	Deviation	p-value	
Baseline (T1)	9	7.91	1.18		
Post Training (T2)	9	9.14	0.56	0.01*	1.04
End of Program (T3)	9	7.55	0.97	0.26	-0.31
3 Months after Program Completion (T4)	9	7.88	0.59	0.86	-0.03

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Mentees' mean outcome scores at baseline (T1) and program completion (T2)					
Measurement	N	T1	T2	T1-T2 (SD)	Effect Size T1-T2

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					(Mean)
Medication Adherence (Morisky scale)	8	0.78	0.63	0.53	0
Self-Efficacy Scale	8	7.59	7.75	1.01	0.04
Arthritis Impact Measurement Scales (AIMS2) – Short Form (SF)					
• AIMS2-SF	5	30.26	28.96	1.33	0.39
• AIMS2-Physical (/10)	8	8.36	8.60	1.98	0.19
• AIMS2-Symptoms (/10)	8	2.59	1.56	2.23	0.28
• AIMS2-Affect (/10)	8	5.56	5.31	1.03	0.27
• AIMS2-Social (/10)	8	5.76	5.47	0.93	0.47
• AIMS2-Work (/10)	5	7.66	8.13	2.05	0.42
Coping Efficacy (Gignac et al.)	8	4.08	4.41	0.46	0.35
Clinical Disease Activity (CDAI)	6	9.94	5.68	3.91	0.19
Medical Outcomes Study Social Support Survey (MOSSS)	8	3.77	4.11	0.28	0.30
Patient Activation Measure (PAM)	8	75.80	73.11	11.75	0.22

Mentees experienced improvement in overall arthritis impact on health-related quality of life, coping, and social support. Self-reported measures at program completion (12 weeks, T2) showed significant improvements (effect size >0.3) in the overall AIMS2-SF and Social and Work subcomponents. Mentees reported improvements based on Social Support (MOSSS) and Coping Efficacy. There were no significant effects in Disease

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3 Activity Measures Index (CDAI), Medication Adherence (Morisky) or Self-Efficacy
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5 Scale. None of these measures showed sustained improvement three months post-
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7 program (T3)..
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10 11 12 *Qualitative data and process measures*

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15 Average number of meetings was 8.11 (range=6-12). Average length of meetings was
16
17 36.90 minutes (range=10-120 minutes). Mode of contact after initial face-to-face meeting
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19 was telephone only for four dyads, with the remaining five dyads using a mix of
20
21 telephone and face-to-face.
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27 Key themes revealed from the 17 interviews are categorized below:
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29 30 *Mentor-specific experiences*

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32 Peer mentors largely appreciated their training; they valued the emotional support content
33
34 of the training program and being able to work through simulated scenarios. Mentors
35
36 reported personally benefiting from the program. They reported it increased their
37
38 knowledge, provided new self-management techniques and coping strategies (PM3, PM4,
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40 PM7, PM9, PM12), reinforced self-management strategies they were familiar with, and
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42 made them realize how far they had come in their disease experience (PM12, PM8).
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48 A few mentors experienced challenges (e.g., mentee reluctant to stop consuming alcohol
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50 to take methotrexate (PM7); mentee with problems returning to work after being on long-
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52 term disability (PM8)). These mentors (PM7, PM8) also experienced challenges in
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54 arranging sessions.
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Mentee-specific experiences

Emotional and informational supports were most commonly reported. One mentee described his mentor as, “a book, as far as I'm concerned, she has more information than I can absorb, really” (EIA8). Informational support was not confined to program resources, but also included mentors' experiential knowledge:

“I would ask her when she encountered bad weather, how were her joints? What did she do about that? ... Can I do something prior to, when you know the weather is coming” (EIA3).

Appraisal and instrumental support were also exchanged. One mentee said:

“It was great being able to sit down and have a normal conversation, but at the same time throw in, oh yeah, I'm thinking about switching to biologics so what's your opinion?” (EIA1).

The inter-subjective dynamics of peer support

Participants' experience of peer support was informed by the unique relationship they forged with their peer. Many participants spoke of having “a connection” with his/her peer. This was facilitated by similarities in personality, age, gender, interests, life stage, position of responsibility at work, diagnosis, disease severity, and similarity of affected joints. “My hands felt like her hands,” said one mentee (EIA4). Four participants faced challenges building rapport due to differences in gender, sexuality, political views and disease stage. Gender differences restricted the type of conversations in one mixed

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3 gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-
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5 bound mentor, as she was not able to cope with this:
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7
8 “... I found myself looking at my mentor and going, that's not me, I don't have that, I'm
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10 not going there, I'm not going to be in a wheelchair... or be badly deformed.” (EIA6).
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14 While such experiences complicated the work of providing and receiving peer support,
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16 all participants were unequivocal about the need for a peer support program for
17
18 individuals with EIA. Mentees spoke about the program as “critical” (EIA1), declaring,
19
20 “It can't stop. It can't” (EIA3). Mentors wished that similar peer support interventions
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22 had been available when they were first diagnosed.
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29 **DISCUSSION**

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31 In this study, we piloted a peer support program for patients with EIA using the 2008
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33 MRC framework (17). Information from the development phase, with input from
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35 working groups and expert reviewers and a qualitative needs assessment were used to
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37 develop a pilot peer support intervention. A complementary, inductive approach helped
38
39 to make additional sense of learning and support needs, how and why the intervention
40
41 met (or failed to meet) these needs and to generate information and hypotheses for testing
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43 with quantitative research methods.
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51 A peer support program could help patients with EIA navigate the issues surrounding
52
53 their disease. The potential advantage of peer support relates to its focus on impacts on
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55 daily activities and functioning rather than medical information (4). Peer support
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3 encourages sharing of experiences between participants with personalized and flexible
4 content. Our results suggested that both mentors and mentees perceived benefits from the
5 program. Mentors described largely positive benefits including role satisfaction, and
6 increase in their own knowledge and self-management techniques.
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15 Few qualitative studies to date have rigorously evaluated the effect of peer support on
16 mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-
17 efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores
18 of mentors increased after training, scores decreased below baseline after 12 weeks of
19 mentoring and three months post- program. This raises concerns that being a peer mentor
20 could be a demanding and stressful experience (33), especially for mentors who
21 expressed concerns with their mentees. The success of a peer support program also relies
22 on the skills and retention of peer mentors. Our preliminary results suggest that regular
23 training and practice sessions may be necessary to maintain mentors' self-efficacy.
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39 Mentees showed improvements in a number of outcome measures including the Social
40 and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a
41 small improvement in Affect and Symptom components of AIMS2-SF. Our study did not
42 demonstrate a significant effect of the intervention on disease activity (CDAI) and this
43 mirrors previous quantitative studies (34), which found no significant reduction in joint
44 counts in RA patients who received patient-education interventions. However, the main
45 thrust behind the study was to develop an individualized support program that was
46 responsive to the needs of each patient. Thus, improvements in the Coping Efficacy and
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3 Social Support scores are encouraging. The fact that improvements were not sustained
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5 three months post-program would suggest that three months may be insufficient for
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7 mentees to develop knowledge and skills to help them adapt to their disease. We know
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9 from education literature that “booster sessions” may be required to sustain knowledge
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11 and skill sets (35), although other studies have questioned their effectiveness (36).
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17 Our study did not demonstrate any effect on medication adherence. This reflects previous
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19 data that interventions to increase medication adherence in chronic conditions are
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21 complex, and that a large proportion of patient education interventions in this setting have
22
23 been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded
24
25 null results, but participants thought they would benefit from peer support early after
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27 diagnosis (33).
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34 A limitation is the small sample size. Also, there was no control group in this study.
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36 However, this study was designed as a feasibility and pilot study. The goal was to to
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38 obtain initial data for planning and implementing a larger scale study. As such, results
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40 from this preliminary pilot are not meant to be generalized. In addition, all trained
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42 mentors and mentees had RA, limiting the generalizability to other types of IA. Matching
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44 pairs based on personal and social characteristics was important but unfortunately, were
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46 unable to match all pairs by gender. The two mixed gender dyads reported that this may
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48 have limited the types of conversations they had.
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3 In summary, this study showed that developing and delivering a peer support program
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In summary, this study showed that developing and delivering a peer support program was acceptable, feasible with modifications, and well-received by peer mentors and mentees. Peers can be instrumental in promoting self-management and improving one's ability to cope with the diagnosis of a chronic disease. Peers also facilitate social support and may be a useful adjunct to standard rheumatologic care. The information gleaned from this study has been incorporated into a randomized, wait-list controlled study comparing the "peer support program" with a "standard care" control group to further assess the benefits of peer support in EIA management.

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Author Contributions

Mary Bell – Principal Investigator, intervention development, implementation and

evaluation, data analysis, manuscript writing

Sharron Sandhu – Co-investigator, intervention development and implementation, data

analysis, manuscript writing

Paula Veinot - Intervention development, implementation and evaluation, data analysis,

manuscript writing

1
2
3 Gayathri Embuldeniya - Intervention development, implementation and evaluation, data
4
5 analysis, manuscript writing
6
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9
10 evaluation, data analysis, manuscript writing
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12 Joanna Sale – Co-investigator, intervention development, evaluation, manuscript writing
13

14 Sicong Huang – Data analysis, manuscript writing
15

16 Alex Zhao - Data analysis, manuscript writing
17

18 Dawn Richards - Intervention development, implementation and evaluation, manuscript
19
20 writing
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24 **All authors approved the final version for publication**
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26

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28
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30
31 of Health Research, and Ontario Rehabilitation Research Advisory Network.
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36 **Data sharing statement** No additional data available
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41 **Competing interests** The authors have no competing interests to declare.
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8 **Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis:**

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10 **Feasibility Pilot**

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16 **Key Indexing Terms:** Arthritis, Early Rheumatoid Arthritis, Health Services Research,
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ABSTRACT

Objectives: To examine the feasibility and potential benefits of early peer support to improve the health and quality of life of individuals with early inflammatory arthritis (EIA).

Design: Feasibility study using the 2008 Medical Research Council framework as a theoretical basis. A literature review, environmental scan, and interviews with patients, families, and health-care providers guided the development of peer mentor training sessions and a peer-to-peer mentoring program. Peer mentors were trained and paired with a mentee to receive (face-to-face or telephone) support over 12-weeks.

Setting: Two academic teaching hospitals in Toronto, Ontario, Canada.

Participants: Nine pairs consisting of one peer mentor and one mentee were matched based on factors such as age and work status.

Primary outcome measure: Mentee outcomes of *disease modifying anti-rheumatic drugs (DMARDs)/biologic treatment use, self-efficacy, self-management, health-related quality of life, anxiety, coping-efficacy, social support, and disease activity* were measured using validated tools. Descriptive statistics and effect sizes were calculated to determine clinically important (>0.3) changes. Peer mentor *self-efficacy* was assessed using a self-efficacy scale. Interviews conducted with participants examined acceptability and feasibility of procedures and outcome measures, and perspectives on the value of peer support for individuals with EIA. Themes were identified through constant comparison.

Results: Mentees experienced improvements in the overall arthritis impact on life, coping efficacy, and social support (effect size >0.3). Mentees also perceived emotional,

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8 informational, appraisal and instrumental support. Mentors also reported benefits and
9 learned from mentees' fortitude and self-management skills. The training was well-
10 received by mentors. Their self-efficacy increased significantly after training completion.
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12 Participants' experience of peer support was informed by the unique relationship with
13 their peer. All participants were unequivocal about the need for peer support for
14 individuals with EIA.
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20 **Conclusions:** The intervention was well-received. Training, peer support program and
21 outcome measures were demonstrated to be feasible with modifications. Early peer
22 support may augment current rheumatologic care.
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25 **Trial registry:** NCT01054963, NCT01054131
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ARTICLE SUMMARY

Article focus

- Feasibility study for developing, implementing and evaluating a peer support intervention (peer mentor training peer mentoring program consisting of 12-weeks of face-to-face or telephone meetings to support mentees newly diagnosed with early inflammatory arthritis (EIA).

Key messages

- Early peer support is feasible and well-received by both mentors and mentees.
- Individuals with EIA may benefit from peer support, and this may augment current rheumatologic care.

Strengths and limitations of this study

- The study was guided by the 2008 Medical Research Council Framework for Complex Interventions.
- The intervention was well-received and had benefits for both mentors and mentees.
- As rheumatoid arthritis was the diagnosis of all participants, further study is needed to assess benefit of early peer support for other types of inflammatory arthritis.

INTRODUCTION

Inflammatory arthritis (IA) is a leading cause of functional disability, chronic pain, and psychosocial distress (1,2). Patient self-management, education, and social support networks are encouraged as part of a holistic approach to disease management (3). A peer-to-peer mentoring program that aims to provide support based on the sharing of information and experiences (4) may benefit individuals with early inflammatory arthritis (EIA).

Individuals with EIA often reveal a complex and frustrating journey preceding diagnosis. Symptom fluctuations, symptom normalization and dismissal of their symptoms by healthcare providers (HCPs) are factors contributing to misdiagnosis, delays in referral to rheumatology, and psychological distress and frustration (1). Patients' initial reactions to being diagnosed with EIA range from relief and acceptance to anger, fear, denial, and disbelief (1). Once diagnosed, patients face an overwhelming range of biological, psychological, and social issues such as disease course and severity (both of which are often unpredictable), their ability to cope with pain, as well as uncertainties about social and work issues (5). Like other chronic diseases, responsibilities for daily management gradually shift from HCPs to patients (2). Adapting to EIA is complex (6), and patients require support and guidance early in the disease process so they may learn to live and self-manage their symptoms (2). Patient education and self-management is an arthritis "best practice" and a key clinical practice guideline (7,8,9). Peer support is one strategy to increase patients' knowledge and skills for self-management.

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8 Peer support models have been successfully implemented in other chronic health issues
9 such as cancer (10), HIV/AIDS (11), and diabetes (12). A peer is someone who shares
10 common characteristics (e.g., age, sex, disease status) with the individual of interest, such
11 that the peer can relate to, and empathize with the individual on a level that a non-peer
12 would be unable (4). Dennis defines peer support as "... the provision of emotional,
13 appraisal, and informational assistance by a created social network member who
14 possesses experiential knowledge of a specific behaviour or stressor and has similar
15 characteristics as the target population" (13). Emotional support includes expressions of
16 caring, empathy, encouragement and reassurance, and is generally seen to enhance self-
17 esteem. Appraisal support involves encouraging persistence and optimism for resolving
18 problems, affirmation of a peer's feelings and behaviours, and reassurance that
19 frustrations can be handled. Informational support involves providing advice,
20 suggestions, alternative actions, feedback and factual information (13). All three forms of
21 support are based on experiential knowledge, rather than formal training (13). Peer
22 support interventions fit within a social support model (14). Within this model, peer
23 support could reduce feelings of isolation and loneliness, provide information about
24 accessing available health services, and promote behaviours that positively improve
25 personal health, well-being, and health practices (14).
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45 Currently, the major support program that patients with EIA can access is the Arthritis
46 Self-Management Program (ASMP) (15). While it provides emotional and appraisal
47 support, the standardized outline is not personalizable and the group format limits one-
48 on-one interactions.
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10 We propose that a peer support program with trained mentors with established IA will
11 assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA,
12 and help them self-manage their disease. An earlier study exploring the learning and
13 support needs of patients with IA provides a rationale for using peer support (1) and
14 previous studies have shown that individuals with rheumatoid arthritis (RA) appear to
15 benefit from relationships they can rely on for emotional support, information, and
16 tangible assistance (16). Whether a peer support program may facilitate some of these
17 benefits in patients with EIA has yet to be explored. This study examines the: 1)
18 development and 2) feasibility and pilot phases of a peer support intervention using the
19 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation*
20 *of Randomized Control Trials for Complex Interventions to Improve Health* (17). The
21 primary objective is to develop a peer mentor training process and establish the feasibility
22 and acceptability of a peer support program. Secondary objectives include measuring
23 changes in various outcomes as a result of this intervention (Figure 1). [The development](#)
24 [phase of the study has been described elsewhere \(20\). This paper reports on the feasibility](#)
25 [and acceptability of the peer support program and on the secondary outcome measures.](#)
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43 METHODS

44 The four phases of the 2008 MRC framework guided this complex intervention: (17)
45 *development phase*, to establish theoretical underpinnings and modeling to achieve an
46 understanding of the intervention and its possible effects; *feasibility and piloting phase*:
47 exploratory trial to test feasibility of key intervention components; *evaluation phase*: to
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8 assess program effectiveness; and *implementation phase*: to examine long-term
9 implementation and sustainability (Figure 2).
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13 14 **Development phase**

15 Identifying the evidence base

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17 A qualitative literature search strategy was developed on peer support and chronic
18 diseases using Medline, EMBASE, CINAHL, and Cochrane Systematic Reviews.
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20 Reviewers independently evaluated papers using a quality assessment tool. Using meta-
21 ethnography, a methodology to synthesize qualitative literature (18, 19), we determined
22 how studies were related, translated studies into one another, synthesized translations,
23 and expressed the synthesized ethnography (20). Quantitative studies were reviewed,
24 including a draft from a Cochrane Collaboration protocol (4). An environmental scan was
25 performed and grey literature summarized.
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35 Modeling

36 *Needs assessment*

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38 A qualitative needs assessment was performed to identify educational preferences and
39 informational, emotional and appraisal support needs of individuals with IA, and to
40 determine the suitability of peer support (1). Semi-structured, one-on-one interviews were
41 performed with patients with IA, their family/friends, and HCPs. Interview audio files,
42 transcripts and field notes were uploaded to a qualitative software package, NVivo 8, for
43 coding and analysis. Themes were identified through constant comparative analysis (21).
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Working groups for intervention development

Three working groups (peer mentor training, peer support program, evaluation) of four to six research team and end users were convened to develop the pilot intervention.

Expert review

Using snowball recruiting, expert reviewers were nominated by the research team. They reviewed study information and completed a semi-structured questionnaire by e-mail about the proposed training.

Figure 1 Flow diagram of the peer support intervention program design.

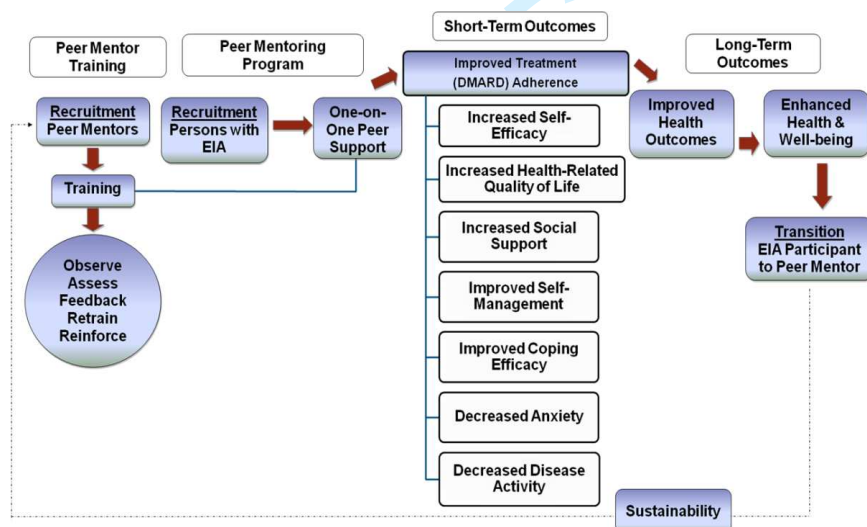


Figure 2 Flowchart outlining steps in the MRC framework.

Development Phase

Identifying the evidence base

Modeling – needs assessment, working groups for peer mentor training development, and expert review



Feasibility and Piloting Phase

Peer mentor recruitment and training

Mentee recruitment

Exploratory trial – pairing peer mentors with mentees, program delivery, qualitative and quantitative data collection, including process and outcome measures



Future RCT, Evaluation and Implementation

Feasibility and piloting phase

Peer mentor recruitment and training

Potential peer mentors were recruited from the Greater Toronto Area (GTA) through: principal investigator's clinic, word-of-mouth, peer mentors, and e-mails from The Arthritis Society. Mentors were selected based on inclusion criteria (Table 1). Eligibility screening occurred by telephone followed by face-to-face interviews.

Table 1 Inclusion criteria for peer mentors and mentees

Peer mentors

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Diagnosis of inflammatory arthritis (IA) from a physician

≥ 18 years of age

Disease duration ≥ 2 years

Currently using medications (DMARDS/biologics) for treatment

Completion of the Arthritis Self-Management Program (ASMP) provided by The Arthritis Society and/or similar program

Able to attend scheduled training sessions

Able to take part in ongoing assessment/evaluation activities (self-reported questionnaires; interviews, observation; activity logs)

Able to commit for duration of study (9-12 months)

Willing to provide ongoing one-on-one support to an individual with newly diagnosed IA

Able to speak, understand, read and write English

Mentees

EIA disease duration 6-52 weeks

At least 3 swollen joints, assessed by the treating rheumatologist, OR

Positive compression test for metacarpophalangeal joints, OR

Positive compression test for metatarsophalangeal joints, OR

At least 30 minutes of morning stiffness

Prescribed a DMARD/biologic by a rheumatologist

Able to speak, understand, read and write English without the aid of a support person

Able to provide informed consent

Peer mentors attended four training sessions (18 hours total). Training provided

information on EIA, educational/support resources, and opportunities to learn and

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8 practice peer support techniques (informational, emotional, appraisal support) and skills
9 (communication, decision-making, goal-setting). Mentors received two initial training
10 sessions and an additional session based on feedback from researchers and participants.
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12 Peer mentors received a resource binder with information on arthritis and mentoring
13 resources and ongoing support from the research team via e-mail, telephone, and in-
14 person.
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20 21 22 Mentee recruitment

23 Patients with EIA were recruited from rheumatology clinics in two GTA teaching
24 hospitals.
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28 29 30 Exploratory trial

31 *Pairing and delivery*

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33 Mentees were paired with peer mentors based on age and work status. The initial meeting
34 was face-to-face, with subsequent meetings taking place at the discretion of the pair (in-
35 person or telephone). Dyads met weekly for approximately 12 weeks. Participants were
36 brought together at the end for debriefing and celebrating.
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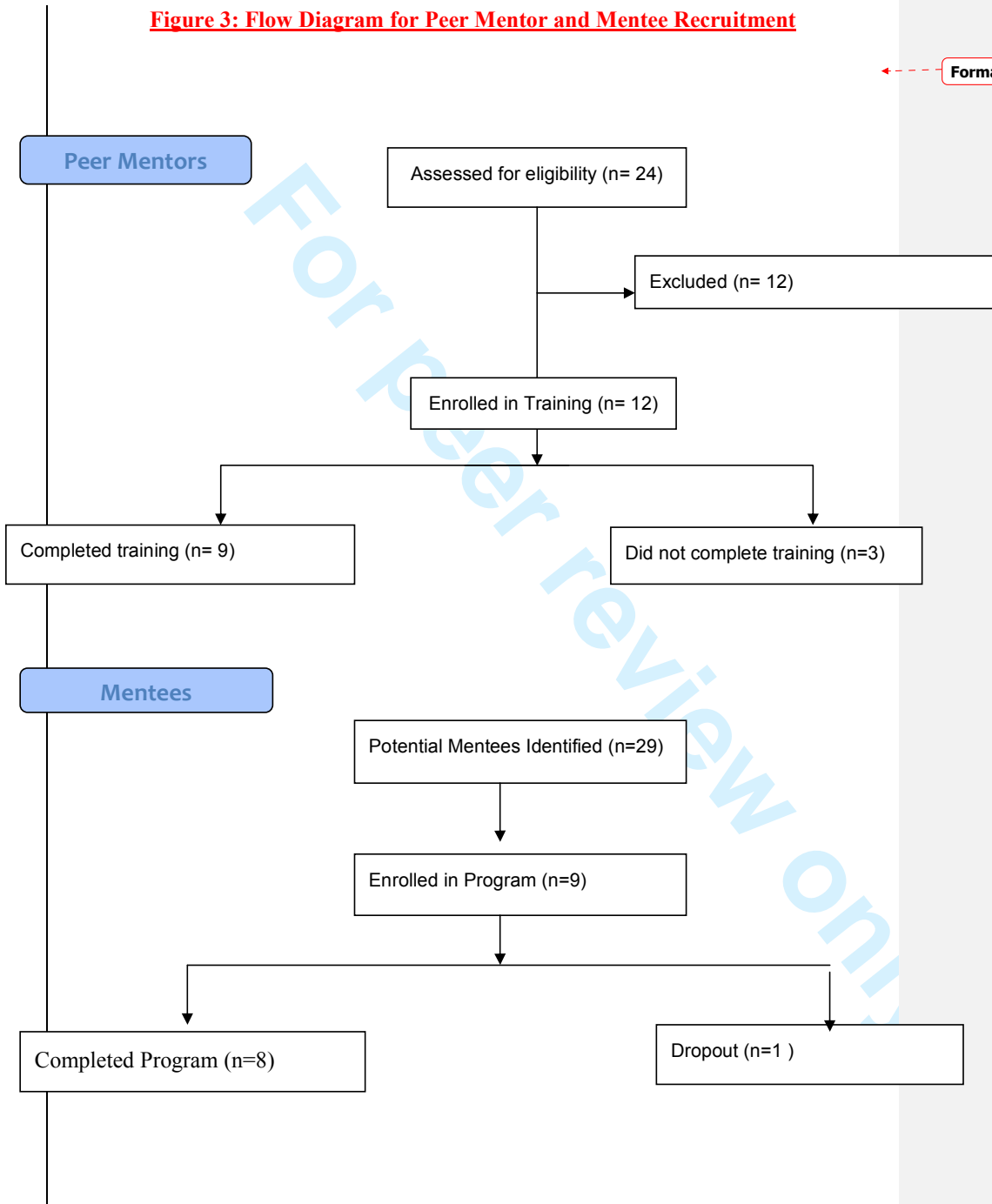
43 *Quantitative data collection*

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45 24 potential mentors were identified, of which 12 were eligible and 9 completed training.

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47 29 potential EIA participants were identified, 9 were enrolled and 8 completed the
48 program (Figure3)
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Figure 3: Flow Diagram for Peer Mentor and Mentee Recruitment

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10 A before-and-after design was used to determine changes over time that can be attributed
11 to the intervention. Peer mentors' self-efficacy was assessed [via a self-administered](#)
12 [questionnaire at](#) four time points – baseline (T1), post-training (T2), immediately after
13 program completion (T3) and three months post-program (T4). Mentee outcomes data
14 were collected [by self-administered questionnaires and clinical assessment](#) at baseline
15 (T1), immediately after program completion (T2) and three months post-program (T3).
16 [by self-administered questionnaires and clinical assessment](#). Outcomes are below:

- 17 1) *Adherence* to DMARD/biologic treatment in EIA patients, determined indirectly
18 through the Morisky scale (22)
- 19 2) *Self-efficacy* measured by Self-Efficacy for Managing Chronic Disease 6-Item Scale (23,
20 24)
- 21 3) Change in *health-related quality of life and anxiety* measured by Arthritis Impact
22 Measurement Scales, 2nd edition (AIMS2) and dimension sub-score for anxiety,
23 respectively (25)
- 24 4) *Coping-efficacy* assessed by Gignac et al.'s method Gignac et al. (26)
- 25 5) *Clinical disease activity* assessed by a rheumatologist from the research team
26 using Clinical Disease Activity Index (CDAI) score (27)
- 27 6) *Social support* measured by Medical Outcomes Study Social Support Survey
28 (MOSSS) (28)
- 29 7) *Self-management* examined by Patient Activation Measure (PAM) (29)

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49 Descriptive statistics and effect sizes were calculated to determine clinically important
50 (>0.3) changes. Effect size, a unitless measurement of treatment effect, was used to
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8 measure the effects of the intervention. An effect size of 0.2 is considered small; 0.5
9 moderate; and 0.8 large (30).

14 *Qualitative data and process measures*

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16 Peer mentors completed a training evaluation questionnaire. Implementation process data
17 was collected to assess acceptability and feasibility. The number and nature of meetings,
18 topics discussed, and problems arising were recorded by peer mentors via activity log.

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20 Research staff called mentors weekly for updates. One-on-one interviews with
21 participants were conducted to determine acceptability and feasibility of procedures and
22 outcome measures, and gain perspectives on the value of peer support. Key themes were
23 identified from transcribed data through constant comparison. Mentees' experiences were
24 explored using a participant diary at three time points.
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33 Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences
34 Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at
35 <http://www.clinicaltrials.gov> (Identification numbers: NCT01054963, NCT01054131).
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41 **RESULTS**

42 **Development phase**

43 Identifying the evidence base

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45 21,489 abstracts across six chronic diseases were identified. Twenty-five articles were
46 included in the meta-ethnography. Results are reported elsewhere (20).
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8 Key themes identified about peer mentor training were: setting boundaries around peer
9 mentor roles, ensuring confidentiality, enhancing communication skills, providing
10 continuing education and support for mentors, and sharing personal experiences to aid in
11 decision-making. Literature about the delivery of peer support programs highlighted the
12 importance of peer mentor recruitment, selection/assessment, outcome measures, and
13 mentee recruitment.
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23 24 *Needs assessment*

25 Peer support was a well-received approach for helping individuals with EIA to cope with
26 concerns arising from their diagnosis. Participants perceived that peer mentoring, if
27 context-driven (paying attention to specific disease phases and individual circumstances)
28 and sensitive to their needs, could be valuable in managing their disease. Results are
29 reported elsewhere (1).
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37 38 *Working groups for intervention development*

39 Each of the working groups met multiple times. Additional members with specific
40 expertise were added as needed to finalize the intervention.
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45 46 *Expert review*

47 Eighteen experts (individuals with IA, HCPs, peer support researchers, representatives of
48 arthritis organizations, educators) provided input into the format/content of the peer
49 mentor training.
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Feasibility and piloting phase

Peer mentor recruitment and training

Twenty-four potential mentors were identified. Twelve were recruited. Nine completed the training and became peer mentors. Three withdrew due to personal illness and/or family issues. All mentors had RA. See Table 2.

Mentee recruitment

Twenty-nine potential mentees were identified, nine of whom were eligible and enrolled.

One mentee was lost to follow-up. All nine mentees had RA. See Table 2.

Table 2 Demographics : Peer mentors ~~s~~ ~~and~~ mentees and peer mentors who withdrew demographics

Peer mentors (N = 9)	N
Age (years)	
31-40	1
41-50	2
51-60	3
61-70	3
Sex	
Female	9
Male	0
Age at diagnosis (years)	
<18	1
18-30	3
31-40	3

	41-50	0
	51-60	1
	61-70	1
Work status	Working for pay	5
	Not working/ Homemaker	2
	Retired	2
<hr/>		
Mentees (N = 9)		N
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Age (years)	18-30	2
	31-50	2
	51-60	3
	61-70	2
Sex	Female	7
	Male	2
Marital status	Single/Never married	1
	Married	4
	Common law/Living with someone	3
	Widowed	1
Living arrangements	Living alone in house or apartment	2
	Living with family or friends in house or apartment	7
Work status	Working for pay	6

	Not working/Homemaker	2
	Retired	1
Highest level of education	Some/Completed high school	1
	Some/Completed college/university	6
	Some/Completed post graduate	2

Peer mentors who withdrew (N = 3) N

<u>Age (years)</u>	<u>41-50</u>	<u>2</u>
	<u>51-60</u>	<u>1</u>

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<u>Age at diagnosis (years)</u>	<u><18</u>	<u>1</u>
	<u>18-30</u>	<u>1</u>
	<u>41-50</u>	<u>1</u>

<u>Sex</u>	<u>Female</u>	<u>3</u>
	<u>Male</u>	<u>0</u>

<u>Diagnosis</u>	<u>RA</u>	<u>2</u>
	<u>Psoriatic Aehrthritis</u>	<u>1</u>

<u>Work</u>	<u>Working for pay</u>	<u>3</u>
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Exploratory trial

Pairing and delivery

Nine mentor-mentee pairs participated. All mentors were female resulting in two mixed-gender dyads.

Quantitative data collection

Mentors' reported self-efficacy increased significantly after training completion. However, these measures dropped below baseline upon program completion with recovery to baseline levels at three months post-program (Table 3).

Table 3 Peer mentor and mentee results

Peer mentor self-efficacy scale ratings					
Peer mentor reported self-efficacy	N	Mean	Standard Deviation	p-value	Effect Size
Baseline (T1)	12	8.00	1.18		
Post Training (T2)	9	9.13	0.55	0.008*	1.03
End of Program (T3)	8	7.29	0.62	0.16	0.42
3 Months after Program Completion (T4)	8	7.88	0.58	0.86	0.03

*-significant (p<0.05)

Mentees' mean outcome scores at baseline (T1) and program completion (T2)

	T1-T2	Effect Size

Measurement	N	T1	T2	(SD)	T1-T2 (Mean)
Medication Adherence (Morisky scale)	8	0.78	0.63	0.53	0
Self-Efficacy Scale	8	7.59	7.75	1.01	0.04
Arthritis Impact Measurement Scales (AIMS2) – Short Form (SF)					
• AIMS2-SF	5	30.26	28.96	1.33	0.39
• AIMS2-Physical (/10)	8	8.36	8.60	1.98	0.19
• AIMS2-Symptoms (/10)	8	2.59	1.56	2.23	0.28
• AIMS2-Affect (/10)	8	5.56	5.31	1.03	0.27
• AIMS2-Social (/10)	8	5.76	5.47	0.93	0.47
• AIMS2-Work (/10)	5	7.66	8.13	2.05	0.42
Coping Efficacy (Gignac et al.)	8	4.08	4.41	0.46	0.35
Clinical Disease Activity (CDAI)	6	9.94	5.68	3.91	0.19
Medical Outcomes Study Social Support Survey (MOSSS)	8	3.77	4.11	0.28	0.30
Patient Activation Measure (PAM)	8	75.80	73.11	11.75	0.22

Mentees experienced improvement in overall arthritis impact on health-related quality of life, coping, and social support. Self-reported measures at program completion (12 weeks, T2) showed significant improvements (effect size >0.3) in the overall AIMS2-SF and Social and Work subcomponents. Mentees reported improvements based on Social

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8 Support (MOSSS) and Coping Efficacy. There were no significant effects in Disease
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10 Activity Measures Index (CDAI), Medication Adherence (Morisky) or Self-Efficacy
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12 Scale. None of these measures showed sustained improvement three months post-
13
14 program (T3) (Table 3).

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18 *Qualitative data and process measures*

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20 Average number of meetings was 8.11 (range=6-12). Average length of meetings was
21
22 36.90 minutes (range=10-120 minutes). Mode of contact after initial face-to-face meeting
23
24 was telephone only for four dyads, with the remaining five dyads using a mix of
25
26 telephone and face-to-face.

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28
29 Key themes revealed from the 17 interviews are categorized below:

30
31 *Mentor-specific experiences*

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33 Peer mentors largely appreciated their training; they valued the emotional support content
34
35 of the training program and being able to work through simulated scenarios. Mentors
36
37 reported personally benefiting from the program. They reported it increased their
38
39 knowledge, provided new self-management techniques and coping strategies (PM3, PM4,
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41 PM7, PM9, PM12), reinforced self-management strategies they were familiar with, and
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43 made them realize how far they had come in their disease experience (PM12, PM8).

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47 A few mentors experienced challenges (e.g., mentee reluctant to stop consuming alcohol
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49 to take methotrexate (PM7); mentee with problems returning to work after being on long-
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8 term disability (PM8)). These mentors (PM7, PM8) also experienced challenges in
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10 arranging sessions.

11 12 13 14 *Mentee-specific experiences*

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16 Emotional and informational supports were most commonly reported. One mentee
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18 described his mentor as, “a book, as far as I’m concerned, she has more information than I
19
20 can absorb, really” (EIA8). Informational support was not confined to program resources,
21
22 but also included mentors’ experiential knowledge:

23
24 “I would ask her when she encountered bad weather, how were her joints? What did she
25
26 do about that? ... Can I do something prior to, when you know the weather is coming”
27
28 (EIA3).

29
30 Appraisal and instrumental support were also exchanged. One mentee said:

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32 “It was great being able to sit down and have a normal conversation, but at the same time
33
34 throw in, oh yeah, I’m thinking about switching to biologics so what’s your opinion?”
35
36 (EIA1).

37 38 39 *The inter-subjective dynamics of peer support*

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41 Participants’ experience of peer support was informed by the unique relationship they
42
43 forged with their peer. Many participants spoke of having “a connection” with his/her
44
45 peer. This was facilitated by similarities in personality, age, gender, interests, life stage,
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47 position of responsibility at work, diagnosis, disease severity, and similarity of affected
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49 joints. “My hands felt like her hands,” said one mentee (EIA4). Four participants faced
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51 challenges building rapport due to differences in gender, sexuality, political views and
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8 disease stage. Gender differences restricted the type of conversations in one mixed
9 gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-
10 bound mentor, as she was not able to cope with this:
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14 “... I found myself looking at my mentor and going, that's not me, I don't have that, I'm
15 not going there, I'm not going to be in a wheelchair... or be badly deformed.” (EIA6).
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20 While such experiences complicated the work of providing and receiving peer support,
21 all participants were unequivocal about the need for a peer support program for
22 individuals with EIA. Mentees spoke about the program as “critical” (EIA1), declaring,
23 “It can't stop. It can't” (EIA3). Mentors wished that similar peer support interventions
24 had been available when they were first diagnosed.
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30 31 **DISCUSSION**

32
33 In this study, we piloted a peer support program for patients with EIA using the 2008
34 MRC framework (17). Information from the development phase, with input from
35 working groups and expert reviewers and a qualitative needs assessment were used to
36 develop a pilot peer support intervention. A complementary, inductive approach helped
37 to make additional sense of learning and support needs, how and why the intervention
38 met (or failed to meet) these needs and to generate information and hypotheses for testing
39 with quantitative research methods.
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49 A peer support program could help patients with EIA navigate the issues surrounding
50 their disease. The potential advantage of peer support relates to its focus on impacts on
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8 daily activities and functioning rather than medical information (4). Peer support
9 encourages sharing of experiences between participants with personalized and flexible
10 content. Our results suggested that both mentors and mentees perceived benefits from the
11 program. Mentors described largely positive benefits including role satisfaction, and
12 increase in their own knowledge and self-management techniques.
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20 Few qualitative studies to date have rigorously evaluated the effect of peer support on
21 mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-
22 efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores
23 of mentors increased after training, scores decreased below baseline after 12 weeks of
24 mentoring and three months post- program. This raises concerns that being a peer mentor
25 could be a demanding and stressful experience (33), especially for mentors who
26 expressed concerns with their mentees. The success of a peer support program also relies
27 on the skills and retention of peer mentors. Our preliminary results suggest that regular
28 training and practice sessions may be necessary to maintain mentors' self-efficacy.
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39 Mentees showed improvements in a number of outcome measures including the Social
40 and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a
41 small improvement in Affect and Symptom components of AIMS2-SF. Our study did not
42 demonstrate a significant effect of the intervention on disease activity (CDAI) and this
43 mirrors previous quantitative studies (34), which found no significant reduction in joint
44 counts in RA patients who received patient-education interventions. However, the main
45 thrust behind the study was to develop an individualized support program that was
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8 responsive to the needs of each patient. Thus, improvements in the Coping Efficacy and
9 Social Support scores are encouraging. The fact that improvements were not sustained
10 three months post-program would suggest that three months may be insufficient for
11 mentees to develop knowledge and skills to help them adapt to their disease. We know
12 from education literature that “booster sessions” may be required to sustain knowledge
13 and skill sets (35), although other studies have questioned their effectiveness (36).
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21 Our study did not demonstrate any effect on medication adherence. This reflects previous
22 data that interventions to increase medication adherence in chronic conditions are
23 complex, and that a large proportion of patient education interventions in this setting have
24 been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded
25 null results, but participants thought they would benefit from peer support early after
26 diagnosis (33).
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35 A limitation is the small sample size. Also, there was no control group in this study.

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37 However, this study was designed as a feasibility and pilot study. The goal was to
38 ~~determine change over time in the outcome measures that can be attributed to the~~
39 ~~intervention and~~ to obtain initial data for planning and implementing a larger scale study.
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43 As such, results from this preliminary pilot are not meant to be generalized. In addition, A
44 all trained mentors and mentees had RA, limiting the generalizability to other types of IA.

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46 Matching pairs based on personal and social characteristics was important but-
47 Unfortunately, were unable to match all pairs by gender. The two mixed gender dyads
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49 reported that this may have limited the types of conversations they had.
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10 In summary, this study showed that developing and delivering a peer support program
11 was acceptable, feasible with modifications, and well-received by peer mentors and
12 mentees. Peers can be instrumental in promoting self-management and improving one's
13 ability to cope with the diagnosis of a chronic disease. Peers also facilitate social support
14 and may be a useful adjunct to standard rheumatologic care. The information gleaned
15 from this study has been incorporated into a randomized, wait-list controlled study
16 [comparing the "peer support program" with a "standard care" control group now in](#)
17 [progress](#) to further assess the benefits of peer support in EIA management.
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39 **Author Contributions**

40 Mary Bell – Principal Investigator, intervention development, implementation and
41 evaluation, data analysis, manuscript writing
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44 Sharron Sandhu – Co-investigator, intervention development and implementation, data
45 analysis, manuscript writing
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48 Paula Veinot - ~~Project Manager,~~ Intervention development, implementation and
49 evaluation, data analysis, manuscript writing
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8 Gayathri Embuldeniya - ~~Research Assistant~~, ~~i~~Intervention development, implementation
9 and evaluation, data analysis, manuscript writing
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11 Sydney Brooks – Co-investigator, intervention development, implementation and
12 evaluation, data analysis, manuscript writing
13

14 Joanna Sale – Co-investigator, intervention development, evaluation, manuscript writing
15

16 Sicong Huang – ~~Medical student~~, ~~d~~Data analysis, manuscript writing
17

18 Alex Zhao - ~~Medical student~~, ~~d~~Data analysis, manuscript writing
19

20 Dawn Richards - ~~Research team member/consumer collaborator~~, ~~i~~Intervention
21 development, implementation and evaluation, manuscript writing
22
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26 **All authors approved the final version for publication**
27

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29
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35 **Data sharing statement** No additional data available
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39 **Competing interests** The authors have no competing interests to declare.
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3 We have adhered to guidelines for Mixed Methods studies as per:
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- 8 • Is the quantitative component feasible? Yes
- 9 • Is the qualitative component feasible? Yes
- 10 • Is the mixed methods design feasible? Yes
- 11 • Have both qualitative and quantitative components been completed? Yes
- 12 • Were some quantitative methods planned but not executed? No
- 13 • Were some qualitative methods planned but not executed? No
- 14 • Did the mixed methods design work in practice? Yes
- 15 • Is the use of mixed methods research justified? Yes
- 16 • Is the design for mixing methods described?
 - 17 ○ Priority Yes
 - 18 ○ Purpose Yes
 - 19 ○ Sequence Yes
 - 20 ○ Stage of integration Yes
- 21 • Is the design clearly communicated? Yes
- 22 • Is the design appropriate for addressing the research questions? Yes
- 23 • Has rigour of the design been considered (proposal) or adhered to (report)? Yes
- 24 • Is the role of each method clear? Yes
- 25 • Is each method described in sufficient detail? Yes
- 26 • Is each method appropriate for addressing the research question? Yes
- 27 • Is the approach to sampling and analysis appropriate for its purpose? Yes
- 28 • Is there expertise among applicants/authors? Yes
- 29 • Is there expertise on the team to undertake each method? Yes
- 30 • Have issues of validity been addressed for each method? Yes
- 31 • Has the rigour of any method been compromised? Yes
- 32 • Is each method sufficiently developed for its purpose? Yes
- 33 • Is the (intended) analysis sufficiently sophisticated? Yes
- 34 • Is the role of each method clear? Yes
- 35 • Is each method described in sufficient detail? Yes
- 36 • Did appropriate members of the team participate in integration? Yes
- 37 • Is there evidence of communication within the team? Yes
- 38 • Has rigour been compromised by the process of integration? No
- 39 • Is there clarity about which results have emerged from which methods? Yes
- 40 • Are inferences appropriate? Yes
- 41 • Are the results of all the methods considered sufficiently in the interpretation? Yes
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