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

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Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis: 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,

informational, appraisal and instrumental support. Mentors also reported benefits and learned from mentees' fortitude and self-management skills. The training was well-received by mentors. Their self-efficacy increased significantly after training completion. Participants' experience of peer support was informed by the unique relationship with their peer. All participants were unequivocal about the need for peer support for individuals with EIA.

Conclusions: The intervention was well-received. Training, peer support program and outcome measures were demonstrated to be feasible with modifications. Early peer support may augment current rheumatologic care.

Trial registry: NCT01054963, NCT01054131

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.

Peer support models have been successfully implemented in other chronic health issues such as cancer (10), (HIV/AIDS (11), and diabetes (12). A peer is someone who shares common characteristics (e.g., age, sex, disease status) with the individual of interest, such that the peer can relate to, and empathize with the individual on a level that a non-peer would be unable (4). Dennis defines peer support as "... the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and has similar characteristics as the target population" (13). Emotional support includes expressions of caring, empathy, encouragement and reassurance, and is generally seen to enhance self-esteem. Appraisal support involves encouraging persistence and optimism for resolving problems, affirmation of a peer's feelings and behaviours, and reassurance that frustrations can be handled. Informational support involves providing advice, suggestions, alternative actions, feedback and factual information (13). All three forms of support are based on experiential knowledge, rather than formal training (13). Peer support interventions fit within a social support model (14). Within this model, peer support could reduce feelings of isolation and loneliness, provide information about accessing available health services, and promote behaviours that positively improve personal health, well-being, and health practices (14).

Currently, the major support program that patients with EIA can access is the Arthritis Self-Management Program (ASMP) (15). While it provides emotional and appraisal support, the standardized outline is not personalizable and the group format limits one-on-one interactions.

We propose that a peer support program with trained mentors with established IA will assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA, and help them self-manage their disease. An earlier study exploring the learning and support needs of patients with IA provides a rationale for using peer support (1) and previous studies have shown that individuals with rheumatoid arthritis (RA) appear to benefit from relationships they can rely on for emotional support, information, and tangible assistance (16). Whether a peer support program may facilitate some of these benefits in patients with EIA has yet to be explored. This study examines the: 1) development and 2) feasibility and pilot phases of a peer support intervention using the 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation of Randomized Control Trials for Complex Interventions to Improve Health* (17). The primary objective is to develop a peer mentor training process and establish the feasibility and acceptability of a peer support program. Secondary objectives include measuring changes in various outcomes as a result of this intervention (Figure 1).

METHODS

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

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.

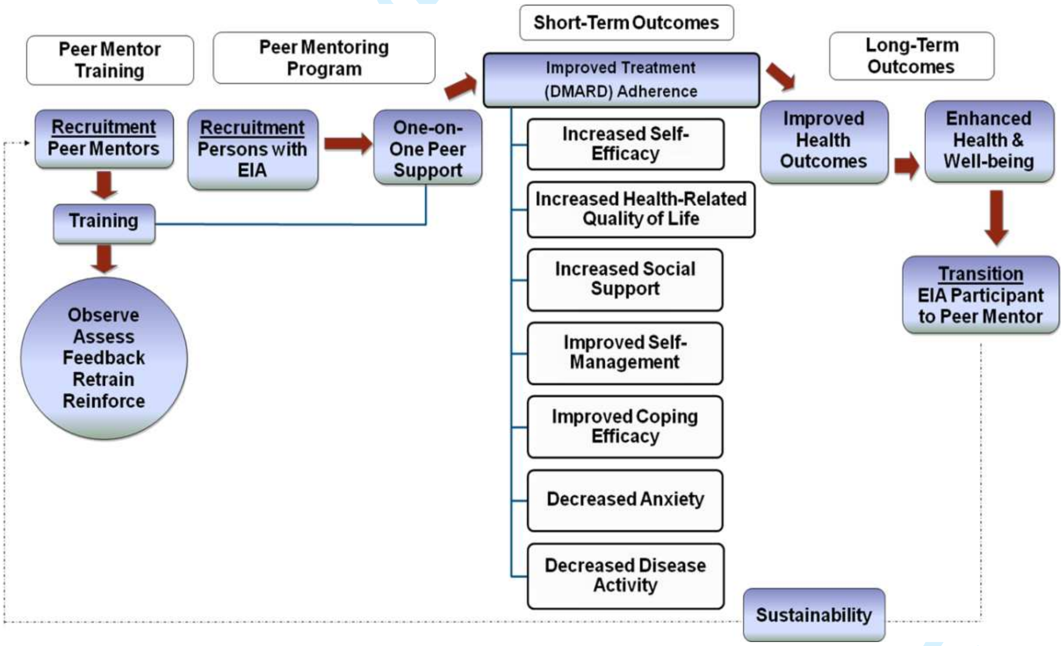

Figure 2 Flowchart outlining steps in the MRC framework.

Development Phase

Identifying the evidence base

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

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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

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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

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

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

Mentee recruitment

Patients with EIA were recruited from rheumatology clinics in two GTA teaching hospitals.

Exploratory trial

Pairing and delivery

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

Quantitative data collection

A before-and-after design was used to determine changes over time that can be attributed to the intervention. Peer mentors' self-efficacy was assessed four time points – baseline (T1), post-training (T2), immediately after program completion (T3) and three months post-program (T4). Mentee outcomes data were collected at baseline (T1), immediately 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.

Research staff called mentors weekly for updates. One-on-one interviews with participants were conducted to determine acceptability and feasibility of procedures and outcome measures, and gain perspectives on the value of peer support. Key themes were identified from transcribed data through constant comparison. Mentees' experiences were explored using a participant diary at three time points.

Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at http://www.clinicaltrials.gov (Identification numbers: NCT01054963, NCT01054131).

RESULTS

Development phase

Identifying the evidence base

21,489 abstracts across six chronic diseases were identified. Twenty-five articles were included in the meta-ethnography. Results are reported elsewhere (20).

Key themes identified about peer mentor training were: setting boundaries around peer mentor roles, ensuring confidentiality, enhancing communication skills, providing continuing education and support for mentors, and sharing personal experiences to aid in decision-making. Literature about the delivery of peer support programs highlighted the importance of peer mentor recruitment, selection/assessment, outcome measures, and mentee recruitment.

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 basline 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 significiant effects in Disease Activity Measures Index (CDAI), Medication Adherence (Morisky) or Self-Efficacy

Scale. None of these measures showed sustained improvement three months post-program (T3) (Table 3).

Qualitative data and process measures

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

Key themes revealed from the 17 interviews are categorized below:

Mentor-specific experiences

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

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

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:

"… I found myself looking at my mentor and going, that's not me, I don't have that, I'm not going there, I'm not going to be in a wheelchair... or be badly deformed." (EIA6).

While such experiences complicated the work of providing and receiving peer support, all participants were unequivocal about the need for a peer support program for individuals with EIA. Mentees spoke about the program as "critical" (EIA1), declaring, "It can't stop. It can't" (EIA3). Mentors wished that similar peer support interventions had been available when they were first diagnosed.

DISCUSSION

In this study, we piloted a peer support program for patients with EIA using the 2008 MRC framework (17) Information from the development phase, with input from working groups and expert reviewers and a qualitative needs assessment were used to develop a pilot peer support intervention. A complementary, inductive approach helped to make additional sense of learning and support needs, how and why the intervention met (or failed to meet) these needs and to generate information and hypotheses for testing with quantitative research methods.

A peer support program could help patients with EIA navigate the issues surrounding their disease. The potential advantage of peer support relates to its focus on impacts on daily activities and functioning rather than medical information (4). Peer support encourages sharing of experiences between participants with personalized and flexible content. Our results suggested that both mentors and mentees perceived benefits from the program. Mentors described largely positive benefits including role satisfaction, and increase in their own knowledge and self-management techniques.

Few qualitative studies to date have rigorously evaluated the effect of peer support on mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores of mentors increased after training, scores decreased below baseline after 12 weeks of mentoring and three months post- program. This raises concerns that being a peer mentor could be a demanding and stressful experience (33), especially for mentors who expressed concerns with their mentees. The success of a peer support program also relies on the skills and retention of peer mentors. Our preliminary results suggest that regular training and practice sessions may be necessary to maintain mentors' self-efficacy.

Mentees showed improvements in a number of outcome measures including the Social and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a small improvement in Affect and Symptom components of AIMS2-SF.Our study did not demonstrate a significant effect of the intervention on disease activity (CDAI) and this mirrors previous quantitative studies (34), which found no significant reduction in joint counts in RA patients who received patient-education interventions. However, the main thrust behind the study was to develop an individualized support program that was responsive to the needs of each patient. Thus, improvements in the Coping Efficacy and Social Support scores are encouraging. The fact that improvements were not sustained three months post-program would suggest that three months may be insufficient for mentees to develop knowledge and skills to help them adapt to their disease. We know from education literature that "booster sessions" may be required to sustain knowledge and skill sets (35), although other studies have questioned their effectiveness (36).

Our study did not demonstrate any effect on medication adherence. This reflects previous data that interventions to increase medication adherence in chronic conditions are complex, and that a large proportion of patient education interventions in this setting have been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded null results, but participants thought they would benefit from peer support early after diagnosis (33).

A limitation is the small sample size. However, this study was designed as a feasibility and pilot study. The goal was to determine change over time in the outcome measures that can be attributed to the intervention and to obtain initial data for planning and implementing a larger scale study. As such, results from this preliminary pilot are not meant to be generalized. All trained mentors and mentees had RA, limiting the generalizability to other types of IA. Matching pairs based on personal and social characteristics was important. Unfortunately, were unable to match all pairs by gender. The two mixed gender dyads reported that this may have limited the types of conversations they had.

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 now in progress to further assess the benefits of peer support in EIA management.

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We have adhered to guidelines for Mixed Methods studies as per:
O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. J Health Serv Res Policy. 2008;13(2):92-8. PMID: 18416914.

- Is the quantitative component feasible? Yes
- Is the qualitative component feasible? Yes
- Is the mixed methods design feasible? Yes
- Have both qualitative and quantitative components been completed? Yes
- Were some quantitative methods planned but not executed? No
- Were some qualitative methods planned but not executed? No
- Did the mixed methods design work in practice? Yes
- Is the use of mixed methods research justified? Yes
- Is the design for mixing methods described?
    - Priority Yes
    - Purpose Yes
    - Sequence Yes
    - Stage of integration Yes
- Is the design clearly communicated? Yes
- Is the design appropriate for addressing the research questions? Yes
- Has rigour of the design been considered (proposal) or adhered to (report)? Yes
- Is the role of each method clear? Yes
- Is each method described in sufficient detail? Yes
- Is each method appropriate for addressing the research question? Yes
- Is the approach to sampling and analysis appropriate for its purpose? Yes
- Is there expertise among applicants/authors? Yes
- Is there expertise on the team to undertake each method? Yes
- Have issues of validity been addressed for each method? Yes
- Has the rigour of any method been compromised? Yes
- Is each method sufficiently developed for its purpose? Yes
- Is the (intended) analysis sufficiently sophisticated? Yes
- Is the role of each method clear? Yes
- Is each method described in sufficient detail? Yes
- Did appropriate members of the team participate in integration? Yes
- Is there evidence of communication within the team? Yes
- Has rigour been compromised by the process of integration? No
- Is there clarity about which results have emerged from which methods? Yes
- Are inferences appropriate? Yes
- Are the results of all the methods considered sufficiently in the interpretation? Yes

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

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Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis: 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,

informational, appraisal and instrumental support. Mentors also reported benefits and learned from mentees' fortitude and self-management skills. The training was well-received by mentors. Their self-efficacy increased significantly after training completion. Participants' experience of peer support was informed by the unique relationship with their peer. All participants were unequivocal about the need for peer support for individuals with EIA.

Conclusions: The intervention was well-received. Training, peer support program and outcome measures were demonstrated to be feasible with modifications. Early peer support may augment current rheumatologic care.

Trial registry: NCT01054963, NCT01054131

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.

Peer support models have been successfully implemented in other chronic health issues such as cancer (10), HIV/AIDS (11), and diabetes (12). A peer is someone who shares common characteristics (e.g., age, sex, disease status) with the individual of interest, such that the peer can relate to, and empathize with the individual on a level that a non-peer would be unable (4). Dennis defines peer support as "... the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and has similar characteristics as the target population" (13). Emotional support includes expressions of caring, empathy, encouragement and reassurance, and is generally seen to enhance self-esteem. Appraisal support involves encouraging persistence and optimism for resolving problems, affirmation of a peer's feelings and behaviours, and reassurance that frustrations can be handled. Informational support involves providing advice, suggestions, alternative actions, feedback and factual information (13). All three forms of support are based on experiential knowledge, rather than formal training (13). Peer support interventions fit within a social support model (14). Within this model, peer support could reduce feelings of isolation and loneliness, provide information about accessing available health services, and promote behaviours that positively improve personal health, well-being, and health practices (14).

Currently, the major support program that patients with EIA can access is the Arthritis Self-Management Program (ASMP) (15). While it provides emotional and appraisal support, the standardized outline is not personalizable and the group format limits one-on-one interactions.

We propose that a peer support program with trained mentors with established IA will assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA, and help them self-manage their disease. An earlier study exploring the learning and support needs of patients with IA provides a rationale for using peer support (1) and previous studies have shown that individuals with rheumatoid arthritis (RA) appear to benefit from relationships they can rely on for emotional support, information, and tangible assistance (16). Whether a peer support program may facilitate some of these benefits in patients with EIA has yet to be explored. This study examines the: 1) development and 2) feasibility and pilot phases of a peer support intervention using the 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation of Randomized Control Trials for Complex Interventions to Improve Health* (17). The primary objective is to develop a peer mentor training process and establish the feasibility and acceptability of a peer support program. Secondary objectives include measuring changes in various outcomes as a result of this intervention (Figure 1). The development phase of the study has been described elsewhere (20). This paper reports on the feasibility and acceptability of the peer support program and on the secondary outcome measures.

METHODS

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

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.

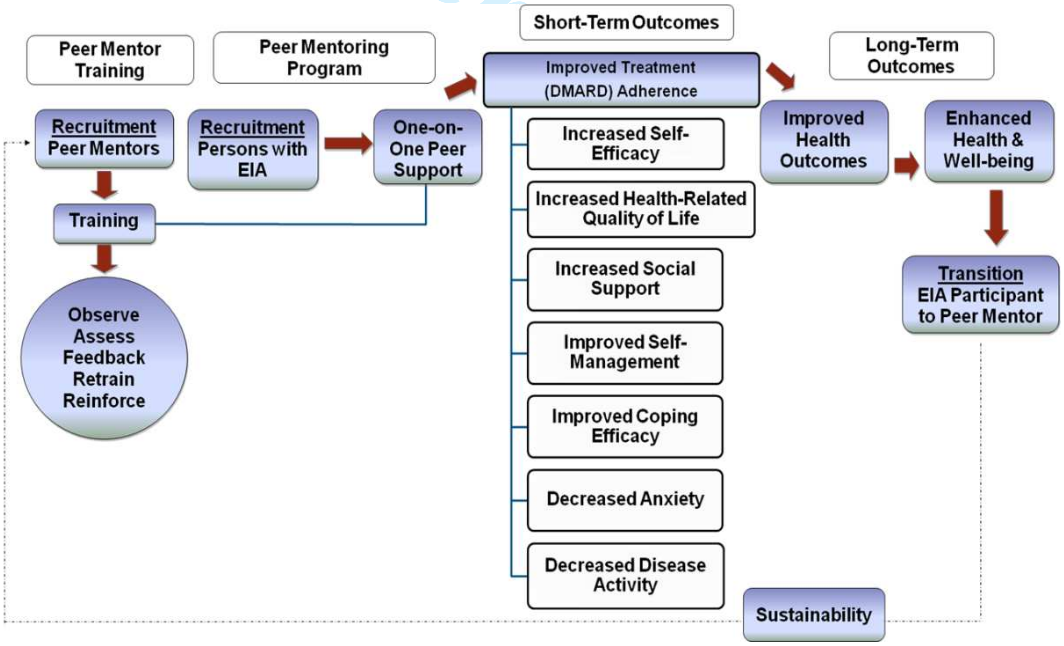


Figure 2 Flowchart outlining steps in the MRC framework.

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

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

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

Mentee recruitment

Patients with EIA were recruited from rheumatology clinics in two GTA teaching hospitals.

Exploratory trial

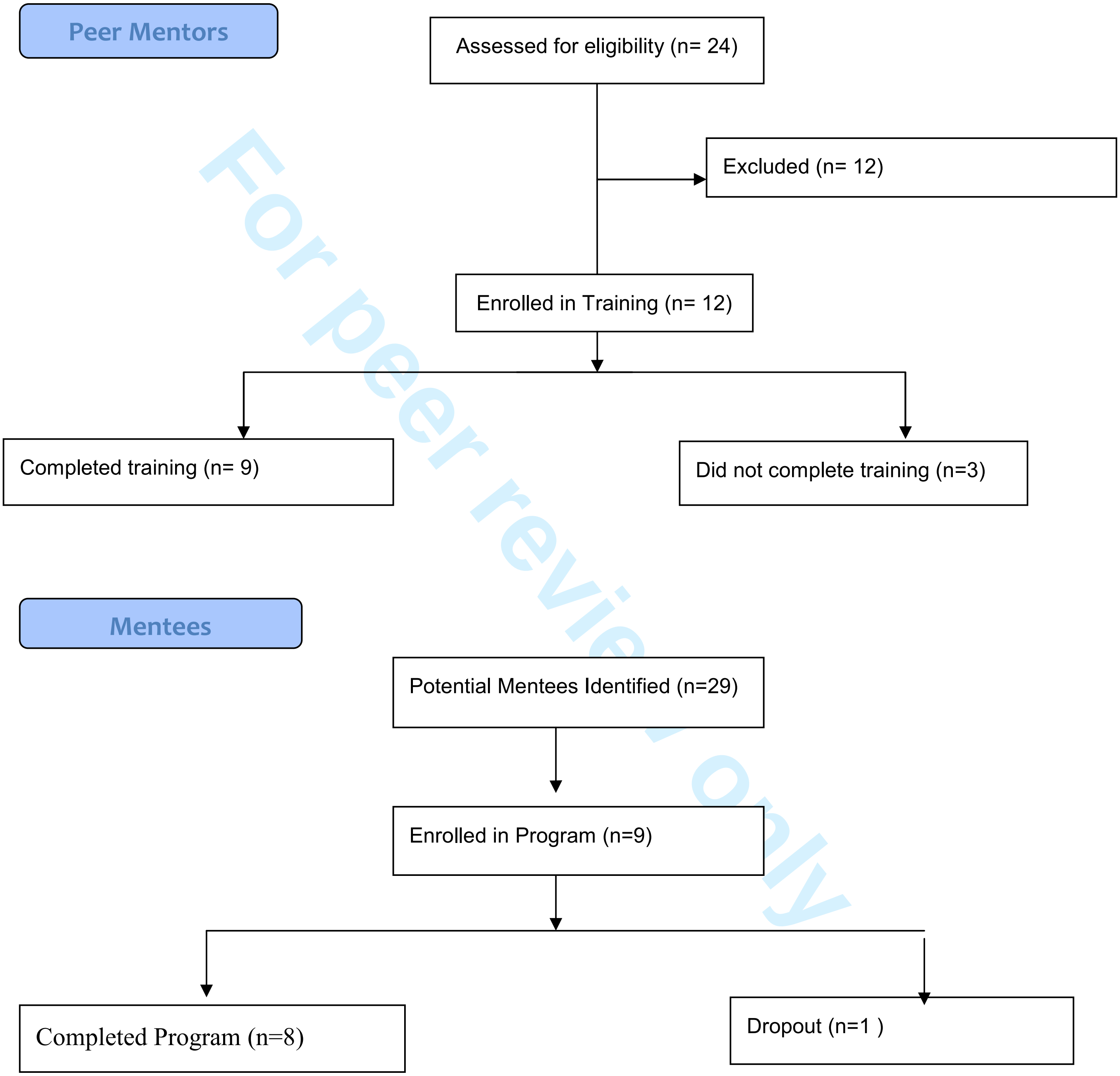
Pairing and delivery

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

Quantitative data collection

24 potential mentors were identified, of which 12 were eligible and 9 completed training. 29 potential EIA particiants were identified, 9 were enrolled and 8 completed the program (Figure3)

Figure 3: Flow Diagram for Peer Mentor and Mentee Recruitment



A before-and-after design was used to determine changes over time that can be attributed to the intervention. Peer mentors' self-efficacy was assessed via a self-administered questionnaire at four time points – baseline (T1), post-training (T2), immediately after program completion (T3) and three months post-program (T4). Mentee outcomes data were collected by self-administered questionaires and clinical assessment at baseline (T1), immediately after program completion (T2) and three months post-program (T3).. 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. Research staff called mentors weekly for updates. One-on-one interviews with participants were conducted to determine acceptability and feasibility of procedures and outcome measures, and gain perspectives on the value of peer support. Key themes were identified from transcribed data through constant comparison. Mentees' experiences were explored using a participant diary at three time points.

Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at http://www.clinicaltrials.gov (Identification numbers: NCT01054963, NCT01054131).

RESULTS

Development phase

Identifying the evidence base

21,489 abstracts across six chronic diseases were identified. Twenty-five articles were included in the meta-ethnography. Results are reported elsewhere (20).

Key themes identified about peer mentor training were: setting boundaries around peer mentor roles, ensuring confidentiality, enhancing communication skills, providing continuing education and support for mentors, and sharing personal experiences to aid in decision-making. Literature about the delivery of peer support programs highlighted the importance of peer mentor recruitment, selection/assessment, outcome measures, and mentee recruitment.

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 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 Aerhritis	1
Work	Working for pay	3

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 basline 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)	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

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, 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 significiant effects in Disease

Activity Measures Index (CDAI), Medication Adherence (Morisky) or Self-Efficacy Scale. None of these measures showed sustained improvement three months post-program (T3)..

Qualitative data and process measures

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

Key themes revealed from the 17 interviews are categorized below:

Mentor-specific experiences

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

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

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 gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-bound mentor, as she was not able to cope with this:

"… I found myself looking at my mentor and going, that's not me, I don't have that, I'm not going there, I'm not going to be in a wheelchair... or be badly deformed." (EIA6).

While such experiences complicated the work of providing and receiving peer support, all participants were unequivocal about the need for a peer support program for individuals with EIA. Mentees spoke about the program as "critical" (EIA1), declaring, "It can't stop. It can't" (EIA3). Mentors wished that similar peer support interventions had been available when they first diagnosed.

DISCUSSION

In this study, we piloted a peer support program for patients with EIA using the 2008 MRC framework (17). Information from the development phase, with input from working groups and expert reviewers and a qualitative needs assessment were used to develop a pilot peer support intervention. A complementary, inductive approach helped to make additional sense of learning and support needs, how and why the intervention met (or failed to meet) these needs and to generate information and hypotheses for testing with quantitative research methods.

A peer support program could help patients with EIA navigate the issues surrounding their disease. The potential advantage of peer support relates to its focus on impacts on daily activities and functioning rather than medical information (4). Peer support encourages sharing of experiences between participants with personalized and flexible content. Our results suggested that both mentors and mentees perceived benefits from the program. Mentors described largely positive benefits including role satisfaction, and increase in their own knowledge and self-management techniques.

Few qualitative studies to date have rigorously evaluated the effect of peer support on mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores of mentors increased after training, scores decreased below baseline after 12 weeks of mentoring and three months post- program. This raises concerns that being a peer mentor could be a demanding and stressful experience (33), especially for mentors who expressed concerns with their mentees. The success of a peer support program also relies on the skills and retention of peer mentors. Our preliminary results suggest that regular training and practice sessions may be necessary to maintain mentors' self-efficacy.

Mentees showed improvements in a number of outcome measures including the Social and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a small improvement in Affect and Symptom components of AIMS2-SF.Our study did not demonstrate a significant effect of the intervention on disease activity (CDAI) and this mirrors previous quantitative studies (34), which found no significant reduction in joint counts in RA patients who received patient-education interventions. However, the main thrust behind the study was to develop an individualized support program that was responsive to the needs of each patient. Thus, improvements in the Coping Efficacy and

Social Support scores are encouraging. The fact that improvements were not sustained three months post-program would suggest that three months may be insufficient for mentees to develop knowledge and skills to help them adapt to their disease. We know from education literature that “booster sessions” may be required to sustain knowledge and skill sets (35), although other studies have questioned their effectiveness (36).

Our study did not demonstrate any effect on medication adherence. This reflects previous data that interventions to increase medication adherence in chronic conditions are complex, and that a large proportion of patient education interventions in this setting have been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded null results, but participants thought they would benefit from peer support early after diagnosis (33).

A limitation is the small sample size. Also, there was no control group in this study. However, this study was designed as a feasibility and pilot study. The goal was to to obtain initial data for planning and implementing a larger scale study. As such, results from this preliminary pilot are not meant to be generalized. In addition, all trained mentors and mentees had RA, limiting the generalizability to other types of IA. Matching pairs based on personal and social characteristics was important but unfortunately, were unable to match all pairs by gender. The two mixed gender dyads reported that this may have limited the types of conversations they had.

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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All authors approved the final version for publication

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Peer-to-Peer Mentoring for Individuals with Early Inflammatory Arthritis: 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,

informational, appraisal and instrumental support. Mentors also reported benefits and learned from mentees' fortitude and self-management skills. The training was well-received by mentors. Their self-efficacy increased significantly after training completion. Participants' experience of peer support was informed by the unique relationship with their peer. All participants were unequivocal about the need for peer support for individuals with EIA.

Conclusions: The intervention was well-received. Training, peer support program and outcome measures were demonstrated to be feasible with modifications. Early peer support may augment current rheumatologic care.

Trial registry: NCT01054963, NCT01054131

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.

Peer support models have been successfully implemented in other chronic health issues such as cancer (10), HIV/AIDS (11), and diabetes (12). A peer is someone who shares common characteristics (e.g., age, sex, disease status) with the individual of interest, such that the peer can relate to, and empathize with the individual on a level that a non-peer would be unable (4). Dennis defines peer support as "... the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and has similar characteristics as the target population" (13). Emotional support includes expressions of caring, empathy, encouragement and reassurance, and is generally seen to enhance self-esteem. Appraisal support involves encouraging persistence and optimism for resolving problems, affirmation of a peer's feelings and behaviours, and reassurance that frustrations can be handled. Informational support involves providing advice, suggestions, alternative actions, feedback and factual information (13). All three forms of support are based on experiential knowledge, rather than formal training (13). Peer support interventions fit within a social support model (14). Within this model, peer support could reduce feelings of isolation and loneliness, provide information about accessing available health services, and promote behaviours that positively improve personal health, well-being, and health practices (14).

Currently, the major support program that patients with EIA can access is the Arthritis Self-Management Program (ASMP) (15). While it provides emotional and appraisal support, the standardized outline is not personalizable and the group format limits one-on-one interactions.

We propose that a peer support program with trained mentors with established IA will assist those with EIA to navigate the diverse set of issues and challenges inherent in EIA, and help them self-manage their disease. An earlier study exploring the learning and support needs of patients with IA provides a rationale for using peer support (1) and previous studies have shown that individuals with rheumatoid arthritis (RA) appear to benefit from relationships they can rely on for emotional support, information, and tangible assistance (16). Whether a peer support program may facilitate some of these benefits in patients with EIA has yet to be explored. This study examines the: 1) development and 2) feasibility and pilot phases of a peer support intervention using the 2008 Medical Research Council (MRC) *Framework for the Development and Evaluation of Randomized Control Trials for Complex Interventions to Improve Health* (17). The primary objective is to develop a peer mentor training process and establish the feasibility and acceptability of a peer support program. Secondary objectives include measuring changes in various outcomes as a result of this intervention (Figure 1). The development phase of the study has been described elsewhere (20). This paper reports on the feasibility and acceptability of the peer support program and on the secondary outcome measures.

METHODS

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

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.

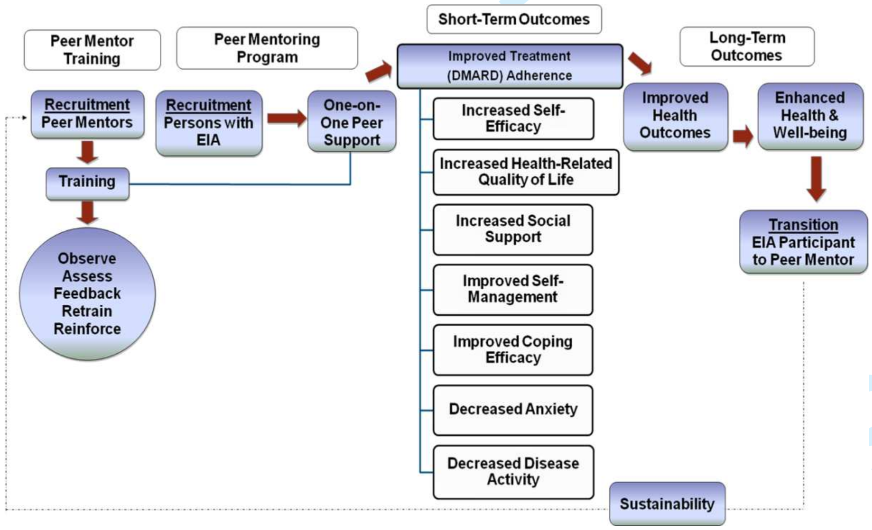

Figure 2 Flowchart outlining steps in the MRC framework.

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

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

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

Mentee recruitment

Patients with EIA were recruited from rheumatology clinics in two GTA teaching hospitals.

Exploratory trial

Pairing and delivery

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

Quantitative data collection

24 potential mentors were identified, of which 12 were eligible and 9 completed training. 29 potential EIA particiants were identified, 9 were enrolled and 8 completed the program (Figure3)

Figure 3: Flow Diagram for Peer Mentor and Mentee Recruitment

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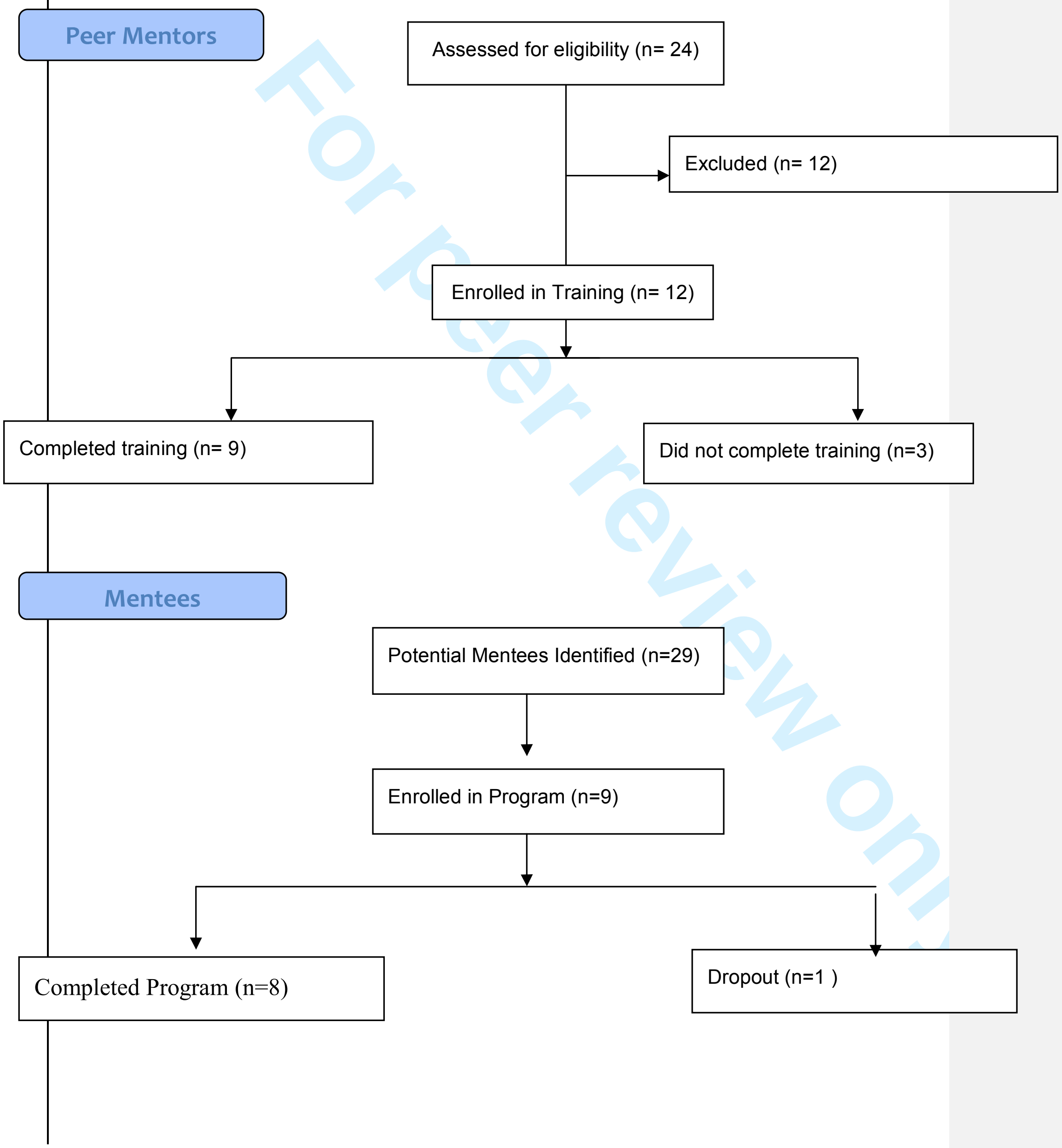

A before-and-after design was used to determine changes over time that can be attributed to the intervention. Peer mentors' self-efficacy was assessed via a self-administered questionnaire at four time points – baseline (T1), post-training (T2), immediately after program completion (T3) and three months post-program (T4). Mentee outcomes data were collected by self-administered questionaires and clinical assessment at baseline (T1), immediately 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. Research staff called mentors weekly for updates. One-on-one interviews with participants were conducted to determine acceptability and feasibility of procedures and outcome measures, and gain perspectives on the value of peer support. Key themes were identified from transcribed data through constant comparison. Mentees' experiences were explored using a participant diary at three time points.

Ethics approval was obtained from research ethics boards at Sunnybrook Health Sciences Centre and Mount Sinai Hospital, Toronto, Canada. The study was registered at http://www.clinicaltrials.gov (Identification numbers: NCT01054963, NCT01054131).

RESULTS

Development phase

Identifying the evidence base

21,489 abstracts across six chronic diseases were identified. Twenty-five articles were included in the meta-ethnography. Results are reported elsewhere (20).

Key themes identified about peer mentor training were: setting boundaries around peer mentor roles, ensuring confidentiality, enhancing communication skills, providing continuing education and support for mentors, and sharing personal experiences to aid in decision-making. Literature about the delivery of peer support programs highlighted the importance of peer mentor recruitment, selection/assessment, outcome measures, and mentee recruitment.

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 Demographics : Peer mentors~~, 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
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 Aerhritis	1
Work	Working for pay	3

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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 basline 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~~9	~~8.0093~~7.91	~~1.4122~~1.18		
Post Training (T2)	9	~~9.1358~~9.14	~~0.5577~~0.56	~~.008~~0.01*	~~1.03~~ 1.04
End of Program (T3)	~~8~~9	~~7.2917~~7.55	~~0.6220~~0.97	~~.161~~0.26	~~0.42~~ -0.31
3 Months after Program Completion (T4)	~~8~~9	~~7.8818~~7.88	~~0.5898~~0.59	~~.859~~0.86	~~0.03~~ -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

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

Qualitative data and process measures

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

Key themes revealed from the 17 interviews are categorized below:

Mentor-specific experiences

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

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

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 gender dyad. In another dyad, a mentee found herself disassociating from her wheelchair-bound mentor, as she was not able to cope with this:

"… I found myself looking at my mentor and going, that's not me, I don't have that, I'm not going there, I'm not going to be in a wheelchair... or be badly deformed." (EIA6).

While such experiences complicated the work of providing and receiving peer support, all participants were unequivocal about the need for a peer support program for individuals with EIA. Mentees spoke about the program as "critical" (EIA1), declaring, "It can't stop. It can't" (EIA3). Mentors wished that similar peer support interventions had been available when they were first diagnosed.

DISCUSSION

In this study, we piloted a peer support program for patients with EIA using the 2008 MRC framework (17). Information from the development phase, with input from working groups and expert reviewers and a qualitative needs assessment were used to develop a pilot peer support intervention. A complementary, inductive approach helped to make additional sense of learning and support needs, how and why the intervention met (or failed to meet) these needs and to generate information and hypotheses for testing with quantitative research methods.

A peer support program could help patients with EIA navigate the issues surrounding their disease. The potential advantage of peer support relates to its focus on impacts on daily activities and functioning rather than medical information (4). Peer support encourages sharing of experiences between participants with personalized and flexible content. Our results suggested that both mentors and mentees perceived benefits from the program. Mentors described largely positive benefits including role satisfaction, and increase in their own knowledge and self-management techniques.

Few qualitative studies to date have rigorously evaluated the effect of peer support on mentors themselves (31). Our study assessed the self-efficacy of peer mentors. Self-efficacy is the belief in one's own ability to perform well (32). While self-efficacy scores of mentors increased after training, scores decreased below baseline after 12 weeks of mentoring and three months post- program. This raises concerns that being a peer mentor could be a demanding and stressful experience (33), especially for mentors who expressed concerns with their mentees. The success of a peer support program also relies on the skills and retention of peer mentors. Our preliminary results suggest that regular training and practice sessions may be necessary to maintain mentors' self-efficacy.

Mentees showed improvements in a number of outcome measures including the Social and Work components of AIMS2-SF, Coping Efficacy and Social Support. There was a small improvement in Affect and Symptom components of AIMS2-SF.Our study did not demonstrate a significant effect of the intervention on disease activity (CDAI) and this mirrors previous quantitative studies (34), which found no significant reduction in joint counts in RA patients who received patient-education interventions. However, the main thrust behind the study was to develop an individualized support program that was responsive to the needs of each patient. Thus,~~-~~ improvements in the Coping Efficacy and Social Support scores are encouraging. The fact that improvements were not sustained three months post-program would suggest that three months may be insufficient for mentees to develop knowledge and skills to help them adapt to their disease. We know from education literature that “booster sessions” may be required to sustain knowledge and skill sets (35), although other studies have questioned their effectiveness (36).

Our study did not demonstrate any effect on medication adherence. This reflects previous data that interventions to increase medication adherence in chronic conditions are complex, and that a large proportion of patient education interventions in this setting have been ineffective (37). A recent peer-support intervention for type 2 diabetes also yielded null results, but participants thought they would benefit from peer support early after diagnosis (33).

A limitation is the small sample size. Also, there was no control group in this study. However, this study was designed as a feasibility and pilot study. The goal was to ~~determine change over time in the outcome measures that can be attributed to the intervention and~~ to obtain initial data for planning and implementing a larger scale study. As such, results from this preliminary pilot are not meant to be generalized. In addition,~~A~~ all trained mentors and mentees had RA, limiting the generalizability to other types of IA. Matching pairs based on personal and social characteristics was important but ~~.~~ ~~U~~unfortunately, were unable to match all pairs by gender. The two mixed gender dyads reported that this may have limited the types of conversations they had.

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 ~~now in progress~~ to further assess the benefits of peer support in EIA management.

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

Dawn Richards - ~~Research team member/consumer collaborator, i~~Intervention development, implementation and evaluation, manuscript writing

All authors approved the final version for publication

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We have adhered to guidelines for Mixed Methods studies as per:
O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. J Health Serv Res Policy. 2008;13(2):92-8. PMID: 18416914.

- Is the quantitative component feasible? Yes
- Is the qualitative component feasible? Yes
- Is the mixed methods design feasible? Yes
- Have both qualitative and quantitative components been completed? Yes
- Were some quantitative methods planned but not executed? No
- Were some qualitative methods planned but not executed? No
- Did the mixed methods design work in practice? Yes
- Is the use of mixed methods research justified? Yes
- Is the design for mixing methods described?
  - Priority Yes
  - Purpose Yes
  - Sequence Yes
  - Stage of integration Yes
- Is the design clearly communicated? Yes
- Is the design appropriate for addressing the research questions? Yes
- Has rigour of the design been considered (proposal) or adhered to (report)? Yes
- Is the role of each method clear? Yes
- Is each method described in sufficient detail? Yes
- Is each method appropriate for addressing the research question? Yes
- Is the approach to sampling and analysis appropriate for its purpose? Yes
- Is there expertise among applicants/authors? Yes
- Is there expertise on the team to undertake each method? Yes
- Have issues of validity been addressed for each method? Yes
- Has the rigour of any method been compromised? Yes
- Is each method sufficiently developed for its purpose? Yes
- Is the (intended) analysis sufficiently sophisticated? Yes
- Is the role of each method clear? Yes
- Is each method described in sufficient detail? Yes
- Did appropriate members of the team participate in integration? Yes
- Is there evidence of communication within the team? Yes
- Has rigour been compromised by the process of integration? No
- Is there clarity about which results have emerged from which methods? Yes
- Are inferences appropriate? Yes
- Are the results of all the methods considered sufficiently in the interpretation? Yes