

PaCER REPORT: Study 2

**The Longer-term impacts of the Making it Work
Program on Working and Living with IA**

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Executive Summary

This is the report of a qualitative study of the impact of an education program designed for employees with Inflammatory Arthritis (IA), a component of the Employment Arthritis: Making it Work Study led by Dr. Dianne Mosher and funded by CIHR. The study was done to help the researchers gain an understanding of the longer term impacts of the Making it Work (MiW) program on program participants work and home lives.

This study was done by three Lead Researchers from the Patient and Community Engagement Research (PaCER) program. It used the patient-to-patient PaCER research method that has three phases: *set* (setting the direction); *collect* (collecting data); and *reflect* (confirming and expanding the data, and proposing actions) with participants from *set* and *collect*. Twenty program completers with IA (16 women and 4 men) participated in this study. Their ages ranged from the 25 to 54 and their average age was 45.5. Their work roles varied: health professionals, civil servants, library services, human resources, education, architecture, food service management, equine therapy, transportation, and millwright/mechanic.

In the *set* phase four people participated in one of two focus groups that built on emerging impacts that came from our program evaluation study. Participants emphasized the importance of considering contextual factors (e.g. family situation and severity of IA) as well as impacts, and their perspective broadened our thinking about impacts in preparation for the *collect* phase. Sixteen people were interviewed by two of the researchers in the *collect* phase. The recorded interviews were transcribed. As program impacts were deeply embedded within the complexities of living with IA our analysis focused on themes rather than the story format as was our original intent. Each researcher independently created individual documents for the first two interviews and after agreeing on a format the remaining interviews were analyzed. Through a collaborative process eighteen original themes were reduced to four (fatigue; managing at work; managing at home; and mental shift). These impacts were taken to the *reflect* focus group for validation and discussion. Five participants took part in the one of two *reflect* focus groups. Along with validating our initial analysis participants challenged assumptions about what we were hearing. Using a collaborative process the researchers came to a final set of program impacts: understanding and managing fatigue; managing and making changes at work; asking for and getting workplace accommodations; managing and making changes at work; and making a mental shift.

The *MiW* program has had an enduring impact on participants and has helped them better manage their IA at work and at home. It has impacted their ability to manage fatigue; manage work; ask for accommodations; manage at home, and it has led to a mind-shift in how they view living with IA. The extent to which participants use their learnings is affected by challenges they face across their whole lives: the pervasive and unrelenting nature of fatigue; limited energy at home; and a reticence to ask for accommodations at work and for help at home. The consequences of these challenges can lead to depression; strained family relationships and an inability to do household chores; and potentially leaving work they enjoy. These challenges take on even greater significance in changing life circumstances and worsening IA which can lead depression. These complexities lead us to believe that programs helping people manage chronic conditions such as IA would benefit from a whole-life approach that addresses both managing IA at work and home. The findings of this study should be considered in light of these limiting factors: the same impacts and factors may not hold true across all program participants, in particular, energy imbalance between work and home as well as talking about IA and asking for accommodations may be different among men program participants. Recognizing the interwoven nature of impacts and challenges and keeping with the idea of a whole-life approach, these recommendations are made: 1) throughout the program bring managing IA at home in close alignment with managing it at work; 2) include learning strategies related to distributing limited energy across all aspects of participants' lives; 3) help participants develop skills in talking to family about their IA and asking for help; 4) teach participants how to recognize depression and how to access mental health resources; and 5) work with employers to create environments where employees are able to work to their fullest capacity and are comfortable asking for workplace accommodations.

Introduction and Background

This is the report of a qualitative study of the impact of the Making it Work (*MiW*) education program designed for employees with Inflammatory Arthritis (IA), a component of the Employment Arthritis: Making it Work Study led by Dr. Dianne Mosher and funded by CIHR. This PaCER study is the second carried out as part of Dr. Mosher's research. The first study was of participants' experiences with the program components: online modules, program delivery, group learning environment, and assessments by employment specialists. This second study is an extension of the evaluation study and focuses on the longer term impacts of the *MiW* program on the lives of those who completed the program.

The purpose of the *MiW* education program is to improve the ability of people with IA to perform their work and help them remain employed as long as they choose. The program objectives are to help people develop confidence in their ability to work with their arthritis and manage the challenges they face because of their disease; identify and change things that make work difficult or put them at risk of having to stop work; and request and obtain job accommodations. This study focuses on the longer term impacts of the program: how participants' new perspectives and skills have impacted their ability to manage their IA at work and home.

This study was carried out by Jean Miller (JM), Sylvia Teare (ST), and Romita Choudhury (RC), Lead Researchers in the Patient and Community Engagement Research (PaCER) program at the University of Calgary. They were supported by the PaCER Program Director, Dr. Nancy Marlett. The PaCER program provides support in designing research projects; supervising and mentoring the PaCER researchers; and overseeing the research

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA activities to assure methodological quality and consistency with PaCER methods in the context of a particular study.

As people with related health conditions PaCER researchers have been trained in an established protocol of qualitative inquiry to carry out patient-to-patient research that leads to a robust collective patient voice. The protocol was originally developed by Dr Marlett and Dr Emes (Marlett & Emes, 2010) from the University of Calgary for a seniors' resiliency project and further refined in an innovative collaborative project between Alberta Health Services and the University of Calgary with support from Vecova Centre for Disability Services and Research and the Arthritis Society, and funded by the Canadian Foundation for Healthcare Improvement. This collaborative project led to the PaCER program which has been shown to be successful in bringing a stronger patient voice to health care transformation (Marlett, Shklarov, Marshall, Santana, & Wasylak, 2014).

The PaCER research method has 3 phases: *set*, *collect*, and *reflect*. (See Figure 1) The *set* phase focus group clarifies the scope and direction of the study. Data is then collected (*collect* phase) from patients using focus groups, interviews, observation, or questionnaires. In the *reflect* phase patients participate in another focus group where they come to a common understanding of the *collect* findings and make recommendations including suggestions on future research directions and knowledge dissemination. This iterative approach, driven by patients working with patients, brings a collective patient voice to health system change. It results in a shared collective understanding of the issue, one that is solidly grounded in patient experience. In the study described here the *set* phase consisted of focus groups; the *collect* phase was individual interviews and the *reflect* phase was focus groups.

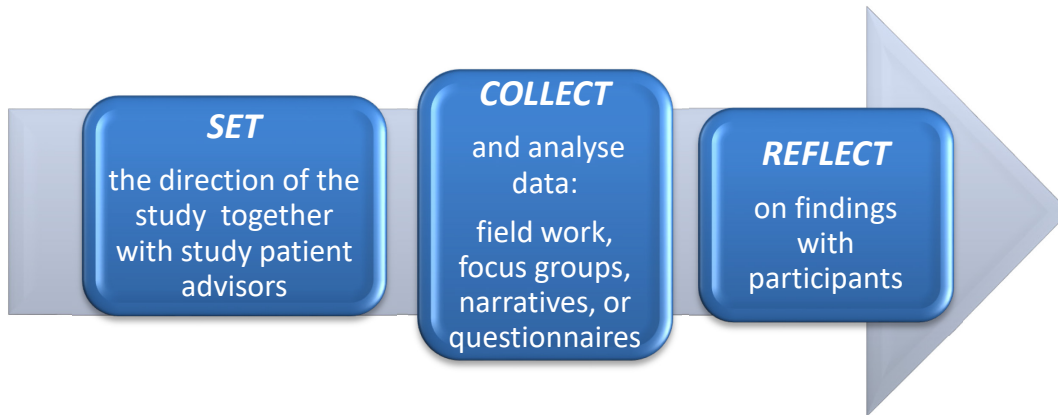


Figure 1: PaCER Research Methodology

The PaCER Research Methodology in this Study

This section begins with information about the patients who participated in this study followed by a description of the PaCER process and analysis used in this study.

Participants

Participants were recruited from 15 program cohorts who had completed the *MiW* program between January 1, 2015 and December 31, 2016. They lived in Alberta, British Columbia, Ontario, and Newfoundland. These individuals received an email from the *MiW* program leader informing them of the study. Each was given the option to indicate they did not want to be contacted for the study. Those who did not opt out were telephoned by a member of the PaCER team and those interested in participating were sent the consent and demographic forms which they completed and returned before starting the study. The inclusion criteria were people who had completed half of each of the modules, the group meetings and employment specialist assessments.

Of the 61 people who met the inclusion criteria 42 were contacted: those not contacted either declined participation or did not respond the phone calls. Twenty of the 42 took part in the study: 9 from British Columbia, 8 from Alberta, 2 from Ontario, and 1 from Newfoundland. Four

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA people took part in the *set* focus groups and 16 in the *collect* interviews. Five of the 20 also took part in the *reflect* focus groups. Ten participants had rheumatoid arthritis; 3 had systemic lupus erythematosus; 5 had psoriatic arthritis; and 3 had ankylosing spondylitis: 1 person had both psoriatic arthritis and ankylosing spondylitis. Participants were between 25 and 54 years old with an average age of 45.5. The number in each age group is in Table 1. Sixteen participants were women and 4 were men. Their work roles varied: 5 participants were in health related disciplines; 3 were civil servants; 2 people in each of human resources, library services, and education; and 1 person in each of architecture, accounting, food service management, equine therapy, transport dispatch, and millwright/mechanics.

Age Groups	Number/percentage of participants
20-30	1
31-40	2
41-50	10
51-60	7
Total	20

Table 1: Participant Age Groups

The PaCER Process and Data Analysis

This section of the report describes the *set*, *collect*, and *reflect* phases used in this PaCER study. (See Figure 2) Because of the iterative nature of PaCER research where what is learned in each of the phase informs the next phase, the section also includes data analysis.

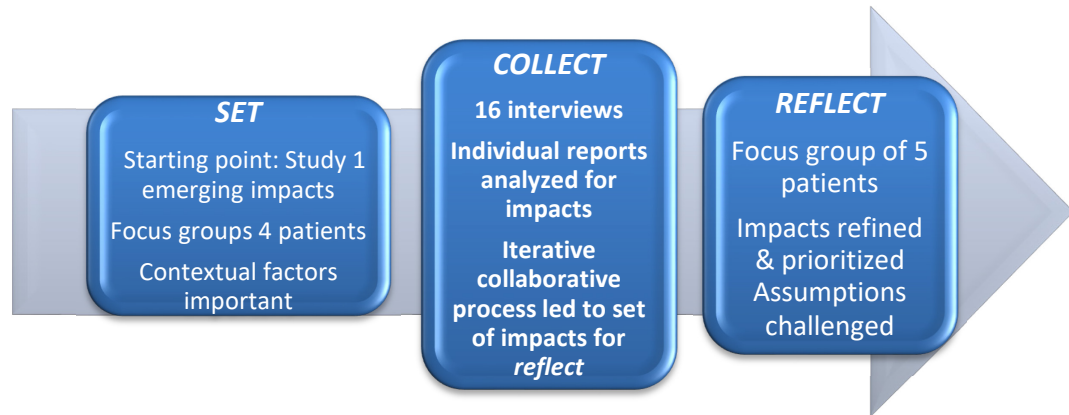
The Longer-term impacts of the *Making it Work Program* on Working and Living with IA

Figure 2: The PaCER Process in this study

Set: The *set* phase of this study built on what we heard from participants in the *MiW* evaluation study. These participants told us they had learned: how to tell their employers about their IA; how to ask for help at work and at home; changes they could make at work and at home; how to deal with fatigue; and how to set reasonable expectations. We heard how participants were beginning to use these learnings and there appeared to be value in extending this to a fuller understanding of how the program impacted participants in the longer term. These emerging impacts served as the starting point of the *set* phase for this second study. We created a pre-focus group activity where participants rated these impacts in relation to their own lives: they also had the opportunity to add their own stories to their individual responses. Participants' responses were compiled in a common document that served as the focus for the *set* activity.

Our intent was to involve 3 patients in one focus group. However, 1 of the three participants was unable to attend and it turned out that the other 2 were self-employed. In order to get an employee perspective we did a second focus group with people who weren't self-employed: 2 of 4 anticipated participants attended. In the first focus group we had intended to use OmniJoin but due to technical difficulties the Arthritis Research Canada support person connected us through Google Hangouts. In the second focus group the plan was to use Google

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA Hangouts, however due to connection difficulties with Hangouts a 3-way conference call was used.

This modified *set* phase gave us further insight into emerging program impacts and extended our thinking about impacts in preparation for the *collect* phase. It reinforced the importance of considering a range of contextual factors related to program impact: severity of their IA at the time; type of work; stage of family development; family situation; career path; and the fact that individuals respond differently to the challenges they face. These factors played out differently depending on whether they were employees or self-employed. For example, employees were concerned about how requesting adaptations might influence their employment status, while those who were self-employed could make adaptations without seeking permission. Participants in the *set* phase thought interviews would be the best way to develop a fuller understanding of the experience of program impacts and they stressed the importance of understanding individual context.

Upon completion of the *set* phase a progress report was submitted to the research team, along with the draft interview guide. After addressing feedback from the research team the interview guide was finalized: see Appendix A.

Collect: Sixteen telephone interviews were conducted for Collect. Participants were located in various parts of the country, including British Columbia, Alberta, Newfoundland, and Ontario. All of the interviews were recorded and transcribed. Although these interviews were not conducted face to face, the narrative approach of the interviewers allowed for many new themes and ideas to emerge that added depth and richness to emerging impacts from the *MiW* PaCER evaluation study.

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Our intent was to obtain stories of participants' experiences after completing the program, how the perspectives and skills they learned in the program began to make sense in the context of their individual lives, and how those learnings were now impacting their lives. This experiential research was to lead to a set of individual stories that collectively would illustrate the impacts of the *MiW* program. However, early on in the interviews we found the stories did not follow the expected pattern of a clearly described beginning, middle, and an end. Rather, program impacts were deeply embedded within the complexities of living with IA. The stories provided an array of intersecting and sometimes even contradictory and irreconcilable situations that, if cast into the mold of program components and corresponding impacts, would lose their authenticity. Thus, instead of proceeding chronologically in story form, we identified the themes that emerged most prominently in the narrative of each person: before they took the program, how things have gone since completing the program, and what has remained critical to their everyday life with IA.

After the first two interviews the researchers each created then compared individual interview documents, highlighting distinct experiences in relation to program impact both direct and indirect, various expressions of both emotional and physical effects, short and long-term observations and reflections. From then on, one of the two took the lead to create the document for each interview, with the other listening to the interview and supplementing as needed. Each created a researcher observation note at the end of the interview documents. After completing and analyzing another 14 interviews we felt we had enough stories to be able create an analysis that would be able to represent the impact of the program not as a distinct event only, but in the context of the full lives of our participants.

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The actions and events in the interviewees stories were first categorized into 18 themes. These themes reflected details in the stories of place, time, relationships, plans, processes, thoughts, and observations. Upon careful analysis of the details, we found that the impacts would be best represented in a cyclical rather than linear way so that the repetitions, interconnections, and overlaps are clearly visible. This would mean being able to draw out those themes that traverse key aspects of participants' lives and would include the full range of the experiences described by participants. The themes were thus reduced to four: fatigue; managing at work; managing at home, and mental shift. This set of four impacts was taken to participants in the *reflect* phase of the study for further validation and discussion.

Reflect: One person from the *set* phase and 4 from the *collect* phase participated in *reflect*. Our plan was to have one face-to-face focus group in a location where there was a cluster of participants and follow that up with individual interviews. As no cluster was found we held two focus groups using Google Hangouts with what we learned from the first focus group serving as a building block for the second. Three people attended the first focus group and two attended the second. Both focus groups were recorded and each PaCER researcher made individual notes.

Prior to the first *reflect* focus group participants received a document with impact categories and accompanying quotes from our *collect* analysis. Prompts were designed for each impact: does this impact ring true for you? Is there anything missing? Does it reflect your experience? What would you add or modify? Although it appeared at first that the process would lead to a retelling of the same stories, we were able to encourage participants to see their role in this stage of the research as different from their earlier participation as narrators. This revised perception yielded productive, even new results.

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The *reflect* phase provided an opportunity for us to challenge our own assumptions about what we were hearing. For example, in the first focus group we were beginning to think dealing with the fatigue was the biggest issue faced by participants and in the second focus group this bore out when participants identified dealing with fatigue as the primary impact area of the program. We also began to hear about participants being unable to follow through on what they had learned, leading us to wonder if lack of motivation was at play. When we brought this idea to the second *reflect* focus group we were told quite clearly that that was not the case; knowing but not acting was a result of fatigue, feeling depressed, and not being in a space of readiness for change.

In the last phase of analysis the three researchers examined what we learned in the *reflect* phase alongside what we learned in *collect* and through a collaborative process came to a final set of program impacts: understanding and managing fatigue; managing and making changes at work; asking for and getting workplace accommodations; managing and making changes at home; and making a mental shift.

Upon completing this iterative three-phase patient engagement research process the PaCER researchers were reasonably confident the findings are a credible representation of the longer term impacts the *MiW* program had on those who had completed the program.

Findings

The purpose of this study was to identify longer term program impacts on the lives of people with IA and our analysis led to 5 such impacts: understanding and managing fatigue; managing and making changes at work; asking for and getting accommodations; managing and making changes at home; and making a mental shift. Further, we came to see how the impacts

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA relate to each other and the totality of participants' work and home lives. Program impacts are contextualized within this context. (See Appendix B for Participant Coding)

Understanding and managing fatigue

Fatigue, as a recognized condition of IA, was one of the topics addressed in the program. As participants talked about how the program helped them deal with fatigue, its depth and pervasiveness were brought home in striking ways. One participant described the fatigue of IA this way: *"It's like walking through life with cement blocks on your feet or too much cold medicine"* (P18). She described it as a *"brain fog"* that comes on when fatigue has gotten the better of her. One lady who's IA has worsened over the past few months stated it simply as *"the fatigue kills me"* (P11).

Data collected through 16 interviews and 2 focus groups led us to believe that what they learned about living with fatigue was possibly the most significant program impact. This was borne out in the reflect phase where participants were invited to review and discuss our initial analysis of the impacts: they chose to start the discussion with fatigue. The program helped them look at their fatigue more realistically and gave them new skills for dealing with the challenges it poses in all aspects of their lives.

As a result of the program, participants came to realize that their fatigue is real and that it is intrinsic to the very nature of IA. Participants came to understand the link between inflammation and fatigue and how that relates to living with IA: prior to that they tended to think fatigue was a personal weakness which made them question its legitimacy. One person described her earlier response to fatigue this way: *"I have a tendency to go why am I so tired and not think I had any right to be tired, especially when I was in a flare-up. I just beat myself up about it all the time"* (P16). Participants also came to realize it wasn't laziness on their part: as one person

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA stated: *“It’s not just me being lazy or wimpy, it’s legitimate”* (P5). Another person said understanding gave her the *“freedom to say OK, I’m allowed to be fatigued.”* (P9). Participants’ worries about not being able to cope or being labelled as lazy were linked to others’ responses to their fatigue: a 25 year old with systemic lupus erythematosus says others think she is faking her fatigue, suggesting her situation would be much better if only she had a more positive attitude.

The program helped participants realize that ignoring their fatigue was not the way to deal with it. Prior to the program one participant would take pills to stay awake at work, resting at lunchtime, and then *“crashing”* (P4) when she got home. The program gave participants the skills to, as one person described it, *“step back a bit and list out the realities of the situation”* (P11). According to this lady this was the *“biggest gem”* of the program. Participants learned how to take the time they need to deal with fatigue and to build rest periods into their work schedules. However the demands of work and home life sometimes undid their best intentions: one lady acknowledged *“this is still a struggle as you can’t just walk away from things that need to be done”* (P11). When her best intentions slip she uses what she learned in the program to come back to a more balanced approach to the demands of her job and her need for rest.

Fatigue leaves participants with limited energy for meeting the demands of life, both at work and home. They learned about a useful concept known as spoon theory wherein a person has a finite number of spoons of energy that can be allotted to daily activities and while you can borrow some of tomorrow’s energy you must be careful not to keep using more than the allotted amount. As a result of the program they now have a better understanding of this limited energy and how to spend it wisely, for example scheduling rests during the work day and doing household chores in the morning rather than later in the day.

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Learning about and practising goal setting helped participants set more realistic and achievable goals. For one participant this meant getting the laundry folded by the end of the day, rather than cleaning the whole house by the end of the weekend. One person finds accomplishing short-term goals helps her self-esteem and promotes her accountability. Another said it keeps her from getting upset when she can't accomplish all she'd really like to. When she is unable to meet a goal she no longer looks for an excuse, instead considering it a choice. However, not being able to set longer term goals is frustrating: one lady would like to commit to a family reunion in the summer but her fatigue keeps her from planning that far ahead.

While these new learnings and skills are a great benefit to participants, fatigue itself sometimes gets in the way of using them. The participant whose IA has worsened said goal setting is what used to keep her going, but her extreme fatigue is making it difficult to plan anything beyond a day or two. Fatigue also makes it difficult to follow through on things participants know are important to do. One lady said that even though she is more aware, she is *"still missing the action piece"* (P6). Although she knows she should eat better and exercise more: *"Am I there yet? No, I'm in the, you should do something about this stage"* (P6). Another participant who also thinks she should exercise more said *"I know the theory behind it but it's not working"* (P10). We thought this inability to get things done might be related to motivation, something we heard from patients in our other arthritis PaCER studies. However, in the reflect phase of this study participants made it very clear that this was not about motivation, it is about fatigue.

The very experience of fatigue itself has brought some participants to the point of feeling depressed. One younger person finds she has lost motivation for life and feels she is mourning her losses. *"I have varying degrees of depression. I struggle with things not getting better and I*

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA *have a sense of hopelessness*” (P17). The lady whose IA has worsened is finding the demands of full-time work, raising a teenage son, and caring for her recently ailing mother has led her to think she is likely depressed: *“I am very very fatigued and not dealing with life well”* (P11).

The program has had a notable impact on participants’ understanding of and skills for dealing with the fatigue that accompanies IA. By understanding the link between inflammation and fatigue they now have a more realistic understanding of what they are experiencing. Knowing their fatigue is legitimate has contributed to feelings of self-worth and the ability to recognize and accept what they can and cannot do. They are using their goal-setting skills and are expending their limited energy more wisely. However, changes in the disease over time as well as life circumstances affect participants’ ability to deal with fatigue and it is clear that the constancy of fatigue itself and its consequences can lead to feelings of depression. It is likely this situation will influence the ongoing impact of what they learned about managing the fatigue of IA.

Managing and making changes at work

In this section we address the impact of the *MiW* program on the ability of patients to manage their IA while remaining productively employed. Participants worked in a variety of fields: human resources, library services, education, equine therapy, health care, transportation, and millwright/mechanic. Inherent differences in these fields including differing employer and co-worker relationships, combined with severity of their IA, and personal goals and aspirations, all played a part in how participants manage their IA at work.

Participants felt they gained both confidence and skills in managing their IA and making changes at work. One participant said she is now able to explain *“what is going on with me health-wise”* (P5), while another is able to ask coworkers for help without them thinking that *“I*

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA *am taking advantage of them*” (P14). Another person noted *“it’s important to get the skill and confidence so you can ask for modifications”* (P9). The individual guidance and help from program employment specialists also helped them understand how to resolve the specific dilemmas they faced, for example whether to quit work or go on long-term disability.

Participants developed a range of strategies to help them manage their individual work situations. Here are three examples.

- **Pacing:** The equine therapist took the program because she was worried she wouldn’t be able to keep doing her physically demanding job. She now schedules breaks when cleaning out the horse stalls and has become ambidextrous so she can keep using her heavy tools. As a result of the program *“I won’t be in a place where I’m going to be able to do this kind of work for a year or two and then I’m going to be done. I know that as long as I’m aware of what I’m doing I’m going to be able to do this a lot longer”* (P5). She also realizes she *“can tough it out”*, complete a master’s degree and contribute to the development of her field.
- **Anticipating:** A director of children’s programs has an office in a space where she is easily accessible to all who enter the church. When this happens at the end of the day she is delayed in getting home for a much-needed rest. By setting a time for leaving work she is now able to avoid this problem: after church she leaves the building by the back door. While she enjoys talking with people she realizes *“you have to take care of yourself”* (P7).
- **Self-monitoring:** A mechanic in an oil field business who describes himself as *“a mover, a shaker, and a survivor”* (P12) keeps a list of the things the occupational therapist told him to do in his Day-Timer: *you forget, and get into bad habits....(for example) keeping your wrists straight.*

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These participants from differing backgrounds and work situations are using the strategies they developed in the program to help them better manage their work environments.

In order to ensure they remain employed in their fields some participants have managed their work life by changing positions or employers. The oil field mechanic has worked himself into a position where he doesn't have to do the "*grunt work*" (P12): he now manages and supervises others. He said it's up to people "*to show their skill set*" and believes that "*if you're a good asset you can create all kinds of things*" (P12). When a nurse educator found supervising students in acute care setting too physically demanding she changed her clinical area to community and long-term-care settings: "*I have navigated around the system to be where I need to be*" (P10). She believes that if she hadn't taken control and changed employment her fitness for practice would have come in to question. Six years ago another nurse left her position on a busy urban emergency department for an urgent care facility in a rural area. She said that "*as a nurse you are either working to full capacity or you are not*" (P9). She believes that if she hadn't done this "*I would have been pushed out of the higher paced area without any place to go*". *I may have had a different outcome with respect to being able to continue to work*".

The program has had a positive impact on participants' confidence in managing their IA at work and they are using the strategies they developed while in the program to deal with the challenges they face. The light they shed on navigating through their work lives illustrates how individual perceptions and goals, along with professional identity and notions of success and self-worth are factors in how individuals manage their work life. These complexities impact participants' readiness and ability to fully practice what they learned in the program.

Asking for and getting workplace accommodations

Program participants learned about accommodation in the workplace and they practiced how to go about asking for modifications. Some had modifications done as part of the program. However, since completing the program these participants had not pursued this further. Overall participants are cautious about disclosing their IA to their employers and they consider carefully whether or not they would tell their employer they have IA, and if they do tell, they give careful consideration to how much they tell. The same degree of consideration goes into deciding whether they will ask for accommodations. At each decision point they face dilemmas that are reflected in this participant's statement: "*you don't want to talk about it too much, how much do you say to your employer: should you mention it or just bear the pain, just wish it away kind of thing*" (P19).

Some participants are comfortable telling their employers about their IA while others hold back from doing so. The severity of their IA and their relationship with their employers and coworkers are two factors that impact what they tell. A physiotherapy aide whose lupus is in remission has told her employer she has a health problem but has not specified what it is. One participant told her employer when she was first diagnosed as she felt her work was being affected. However, she has not told her current supervisor as she no longer feels her work is being affected.

Other participants were clear that telling their employers is not something they would ever choose to do. The oilfield mechanic put it most strongly: "*I never would: never, ever. It's none of his business*" (P12). He believes his employer would use it against him and he would lose his job. The nurse who transferred from an emergency department to a less busy area is selective

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA in who she tells about her IA: “*some people don’t understand and I find it best to choose my battles*” (P9).

Just as there was reticence in telling their employers about their IA, there was also a reluctance to ask for accommodations. Even though they gained confidence and skills in asking for accommodations they held back from doing so: they saw it as a skill they would draw on in the future if needed. The nurse educator who moved from acute care to long term care appreciated learning that it is within her rights to ask for modifications. However, she’s not asked for accommodations because she doesn’t “*want to be seen as the person who can’t do her job*” (P10). Participants are also wary about asking for accommodations due to possible negative reactions of fellow-employees. For example, when one person was allowed to work from home others perceived it as a privilege rather than support. One participant who was unsuccessful in getting accommodations thinks this is his “*wake-up call*” (P19) to find different employment.

While some participants had workplace modifications as a result of the program, those interviewed about longer term impacts are reticent to reveal their IA in the workplace and reluctant to ask for accommodations. There appear to be a number of reasons for this: the severity of the IA; their relationships with supervisors and coworkers; fear of job loss; and worries about their competence and professional reputation. Together these factors likely play a role in how much the program impacts participants’ ability to get workplace accommodations.

Managing and Making Changes at Home

It was natural for participants to move from talking about program impact at work to program impact at home, and many of the changes they made at work were also made at home including ergonomics, asking for help and using their energy wisely. We also learned how

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA managing IA at home is different than managing IA at work: at work it is meeting job expectations and staying employed while at home it is meeting family expectations and keeping up a home. These differences result in challenges that are important to consider with respect to program impact: getting changes done; balancing limited energy between home and work; and family relationships.

We got a sense that it takes longer to make changes at home than it does at work. The equine therapist said it took her a year and a half to actually let her housework go: *“I was a bit of a slow learner, but I did get it eventually”* (P5). She is now at the point where she will tell her family *“I can’t do it today guys and everybody’s just going to have to pitch in”*. This lady wasn’t sure why things took longer at home other than perhaps an accumulation of things over time that led to a few bad days: *“One morning you just said I have to stop doing this or I’m not going to be able to do my job for the next 7, 5, 9, years”* (P5). A working mother with two daughters suggested it can be easier to manage your IA at work than at home, especially if you have an understanding employer that makes the accommodations you need. She said that even though her children are getting better at helping, *“they are used to me doing, to having service, to do whatever I was doing before”* (P8). As with the equine therapist, she doesn’t know why things take longer at home but thought it might be because *“I put pressure on myself to do things a certain way”* (P8). It may be that making changes at home where you are asking for understanding and help from family is not as straight forward as asking for ergonomic changes at work.

The challenge of getting things done at home is compounded by the fact that participants expend most of their limited daily energy at work where they push themselves to meet job demands. One participant finds it is easier to *“prop myself up at work than at home”* (P4). By the

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA time they get home they are too tired to do household chores or activities with friends and family, spending their at-home time resting up for the next work day. This imbalance in energy expenditure adds to the challenge of managing and making changes at home.

As was true in the workplace, participants were reticent to talk about their IA with their families. One person acknowledged that although there had been some discussion in the program about dealing with family relationships, *“it’s not as easy to talk to them as it might sound”* (P8). She finds herself apologizing to her family about the things she can’t do and she feels she shouldn’t have to do that: *“it gets old”*. Another lady doesn’t often talk about her IA with her family: *“as a mother you don’t want them to be scared”* (P7). So although she knows she could get them to help her more, she doesn’t. One participant knows she could ask her son for help but due to his reluctance and her extreme fatigue she does not: *“you have to choose your battles and ask yourself it is worth pursuing or explaining”* (P11). While a reticence to talk about their IA with family was the norm for this group, the oil field mechanic took a more pro-active approach. When he was first diagnosed he held family meetings to plan how to handle his worsening arthritis. As a result he and his wife and kids put in place a 2-year plan to move from an acreage to town. He said they were tough times but *“we made it happen”* (P12). Rather than talk about how he is feeling with his family his approach is *“to figure out what’s wrong. – root cause analysis, and make sure it doesn’t happen again”*.

There appear to be a number of challenges that are impacting participants’ ability to make changes at home. There is a high degree of personal investment in being part of a family and these participants have set high expectations for their individual contributions to that relationship. Participants also want to live up to the expectations their family members have of

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA them. Additionally there is a sense of wanting to protect family members from any burden their IA would place on them. Participants face these challenges when their energy is low having expended most of it at work. Understanding this helped us realize that managing life with IA at work and home go hand-in-hand.

Making a Mental Shift

The final impact has to do with a change in how participants view IA in the context of their whole lives, what one participant referred to as a “*mental shift*” (P6). They began to shift their thinking from denial and hoping it would magically go away, to recognizing and dealing with the reality of it. One lady said the program helped her “*normalize the arthritis, made it real*” ...*That was the big take-away – that this wasn’t going to go away and I need to deal with it*” (P5). Another participant said the program helped her see her arthritis “*from a practical, but also very much from an emotional and cognitive point of view*” (P10). This mental shift helped participants realize that while IA is part of them, it is not all of who they are. Much of this shift in thinking came from hearing others’ experiences in living and working with IA: those who had IA for a shorter time found it encouraging to hear from others who have been able to keep working 10 years and longer. While this mental shift helped participants see their future in a different light, it is likely this change in perspective is one that evolves over time: as one lady noted, that although she is coming to accept IA as part of who she is, she continues to need help in changing the way she thinks about it.

In summary, the program has had an enduring impact on participants and has helped them better manage their IA at work and home. They also face a number of challenges that affect the extent to which they are able to use what they learned in the program. While participants have a better

The Longer-term impacts of the *Making it Work Program* on Working and Living with IA understanding of their fatigue and have developed skills to manage their limited energy, the pervasive and unrelenting nature of fatigue and changing life circumstances affect their ongoing ability to manage their fatigue, potentially leading to depression. Participants now have greater confidence in managing their IA at work and are using the strategies they developed to meet their individual challenges. The extent to which they continue to use these learnings is impacted by the nature of their work and their personal situations and goals. While participants believe that what they learned about asking for workplace accommodations will stand them in good stead in the future, they appear to see this as a last resort. There was an overall reluctance to talk about their IA and ask for modifications both at work and at home. Their reluctance at work stems from concerns about competence and about job loss. At home it stems from expectations in emotionally invested relationships and depleted energy at the end of the work day. It is likely these challenges will continue to influence the ongoing impact of the program on participants' ability to manage their work and home lives.



Figure 3: Impacts and Challenges Experienced by Participants

Discussion

The findings of this study show that the *MiW* program has had a positive impact on participants' ability to manage their IA. It has impacted their ability to manage fatigue; manage work; ask for accommodations; manage at home, and it has led to a mind-shift in how they view living with IA. It also became apparent that these impacts are interwoven with challenges that affect the extent to which participants are able to use what they learned in the program: pervasive fatigue; limited energy at home; and a reticence to ask for accommodations at work and ask for help at home. (See Figure 2) These complexities lead us to believe that programs helping people manage chronic conditions such as IA would benefit from a whole-life approach that addresses managing IA at work and home.

In this study we saw how fatigue affects all aspects of participants' lives and how this can lead to feeling of hopelessness and depression. On reflection, we think we just got a glimmer of the depression and its consequences experienced by the participants. While most participants did not talk about depression at length, the pervasive and persistent nature of fatigue and changing life circumstances suggest this may be an area for further attention.

Participants in this study expended a disproportionate amount of their limited energy at work with little left for home. This affected their relationships with family and friends, and their ability to do household chores. For some this became a vicious circle: over expending energy at work and doing as little as possible at home so they could rest up for work. The consequences of this were evident in feeling depressed and extreme fatigue which in the end affects how they manage their IA across all aspects of their lives. While in this instance managing at work got most of their energy, it may be that others with IA expend most of their energy at home. Either

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way we believe it is important that programs such as the *MiW* program help participants find the right balance of energy expenditure across all aspects of their lives.

The participants in this study were reluctant to talk about their IA with their employers and to ask them for workplace accommodations. This is in spite of the fact they had learned specific skills for approaching their employers. They were also reluctant to talk to their family and it and ask for their help. With respect to work this reluctance may mean people leave jobs they enjoy and that benefit from their skills: a loss for both employee and employer. At home it can lead to strained relationships and not coping with household chores. Within a whole-life context these consequences are not separate from each other: leaving work impacts families and stress at home impacts work. Based on what we learned from participants we believe it is important that programs for people with chronic illnesses help people develop skills for talking about and asking for help from both their employers and their families. Our findings suggest this should take into account that their reasons for holding back at work won't be the same as their reasons for holding back at home and that their adoption of these skills will depend on their individual whole-life situation.

There are a number of factors to keep in mind when considering how this study can inform both the *MiW* program and potentially similar programs for people with chronic illness. The impacts and challenges experienced by these participants may be different for others, for example people new to the workforce or those in remote areas. In particular, what we learned about fatigue and energy balance from a predominantly female group could be quite different had most of the group been men. It is also possible that gender was a factor in talking about IA and asking for accommodations and help. While type of employment could bring about different experiences we were not able to get a sense of that because of the variety of jobs they held. In

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spite of these limitations we believe that what we learned from these participants goes some
distance in informing the *MiW* program about its impact on people with IA.

Conclusion and Recommendations

The *MiW* program has had a notable positive impact on the ability of participants to manage their IA at home as well as at work: several years after completing the program they continue to use what they learned about managing work and home life with IA. However, there also appears to be room for potentially greater impact with respect to overwhelming fatigue that leads to depression; managing limited energy; and talking about and asking for help at work and at home. Further, what we learned about the interwoven nature of program impacts and the challenges participants face across all aspects of their lives leads us to believe that a whole-life approach to programs such as the *MiW* program would greatly enhance their impact on the lives of those with chronic illness. With that in mind we offer the following recommendations that we believe will enhance this whole-person focus of the program and ultimately lead to even greater impacts on the lives of people with IA.

Recommendation 1: Throughout the program bring managing IA at home in close alignment with managing it at work.

Recommendation 2: Include learning strategies related to distributing limited energy across all aspects of participants' lives.

Recommendation 3: Help participants develop skills in talking to family about their IA and asking for help

Recommendation 4: Teach participants how to recognize depression and how to access mental health resources.

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Recommendation 5: Work with employers to create environments where employees are able to work to their fullest capacity and are comfortable asking for workplace accommodations.

Respectfully submitted,

Jean Miller, Sylvia Teare and Romita Choudhury

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Appendix A: The Interview Guide Questions and Prompts

Thank you for agreeing to participate in this optional study called “Your experience with the *Making it Work* program – The voice of program participants”: Study 2. The research team is interested in knowing how the program has impacted participants’ lives and to find that out they have asked us to talk to people like you who completed the program more than 6 months ago.

I am Sylvia Teare/Jean Miller a patient with arthritis, trained as a Patient and Community Engagement Researcher from the University of Calgary

We have received your signed consent form: do you have any questions about it? (The form will be reviewed).

Do you have any questions about this project?

- To start, tell us about yourself:
 - how long you’ve had inflammatory arthritis
 - how is your IA now
 - type of work
 - when you completed the program
- Tell us about your life since completing the program?
 - How things are going
 (Let them start without us specifying work or home life)

Prompts:

- Tell us how things are going at work.
- Tell us how things are going at home
- Are there changes in your life as a result of completing the program?
- How have you used what you learned in the program?

Approach: “and then”; “how was that”; “what happened next”; tell us more about.

Keep these things in mind from *set* and study 1:

- Work life: daily activities, fatigue, stresses; place in career development
- Family life; stage of family development
- **At the end of the interview:**
 - Do you have any insights/thoughts you’d like to share with us as you’ve told us your story today.
 - It sounds to us like.....
- Is there anything else you would like to tell us?

Thank you for taking the time to talk with us today.

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Appendix B: Participant Coding

Participant # & occupation	Type of IA	Set	Collect	Reflect	Province	Age
1. Architect	RA	X			BC	45 Male
2. Accountant /book keeping	AS	X			BC	50 Female
3. Safeway manager	RA	X			BC	42 Male
4. Library Tech	RA	X		X	BC	52 Female
5. Equine therapist	RA		X		BC	54 Female
6. Human resources	PsA		X		AB	43 Female
7. Education director	SLE		X		BC	40 Female
8. Transport officer/dispatch	PsA		X	X	AB	44 Female
9. Nurse	PsA		X	X	AB	53 Female
10. Nurse educator	RA		X		BC	50 Female
11. Human Resources	RA		X	X	NFL	52 Female
12. Millwright/mechanic	PsA		X		AB	52 Male
13. Civil servant	RA		X		BC	31 Male
14. Education resource	RA		X		ON	52 Female
15. Civil servant	RA		X		AB	45 Female
16. Personal trainer	RA		X		ON	41 Female
17. Librarian	SLE		X	X	AB	25 Female
18. Dental hygienist	AS/PsA		X		BC	51 Female
19. Civil servant	AS		X		AB	44 Female
20. Physiotherapy Assistant	SLE		X		AB	44 Female

RA: Rheumatoid arthritis

SLE: Systemic lupus erythematosus

AS: Ankylosing spondylitis

PsA: Psoriatic arthritis