

## Research Article

# Multiple family group intervention for spinal cord injury: Quantitative and qualitative comparison with standard education

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**Objective:** To evaluate a Multiple Family Group (MFG) education and support intervention for individuals with Spinal Cord Injury (SCI) and their primary caregivers. We hypothesized that MFG would be superior to an Education Control Group (EC) for improving patient activation and coping skills, social supports, and relationship functioning.

**Setting:** A large free-standing inpatient and outpatient rehabilitation facility.

**Participants:** Community dwelling adults with SCI and their caregivers living in the Northwest United States.

**Interventions/Methods:** Nineteen individuals with SCI who had been discharged from inpatient rehabilitation within the previous three years, and their primary caregivers participated. Patient/caregiver pairs were randomized to the MFG intervention or an active SCI EC condition in a two-armed clinical trial design. Participants were assessed pre- and post-program and 6 months post-program. Qualitative and quantitative outcomes were evaluated. Focus groups were conducted with each group to determine benefits and recommendations for improvement.

**Results:** Relative to EC, MFG reduced passive coping and increased subjective and overall social support in participants with SCI. Relative to EC, MFG also reduced passive coping in caregivers. Patient activation relative to EC was non-significantly increased. Content analysis identified four themes describing participants' experiences: enhanced sense of belonging, increased opportunities for engagement, knowledge, and team work; results that were generally congruent with quantitative measures of improved social support.

**Conclusions:** Relative to EC, MFG assisted participants with SCI and their caregivers to manage the difficult, long-term, life adjustments by improving coping and strengthening social support.

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**Keywords:** Spinal cord injury, Caregiver, Psycho-educational intervention, Multiple family group treatment

## Introduction

In the United States, an estimated 288,000 individuals currently live with spinal cord injuries (SCIs).<sup>1</sup> Most SCIs are the result of unexpected events (*i.e.* vehicular accidents, falls, acts of violence, and accidents that occur during sports and recreation) that immediately,

dramatically, and permanently change the lives of those who experience them.<sup>2</sup> Not only are those who experience SCI typically young—between the ages of 15 and 35 years—they are most frequently single young men<sup>3,4</sup> who find themselves unable to maintain employment<sup>2</sup> as a result of related disability and suddenly dependent upon others for their care<sup>5</sup> Injury related physical limitations also often limit social interaction and interfere with ability to perform social roles<sup>6-9</sup> Each of these stressors contributes to psychological

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distress and morbidity,<sup>8,9</sup> including increased risk for substance abuse,<sup>8</sup> decreased life satisfaction,<sup>9</sup> decreased social integration, and increased loneliness.<sup>6</sup>

The vast majority of those hospitalized for SCI are discharged to home.<sup>2</sup> As a result, family members often find themselves in the role of caregivers, serving as advisors, educators, advocates, and prevention/management specialists concerning health complications, as well as providing financial support.<sup>10</sup> While such support has been described as indispensable for individuals with SCI,<sup>5</sup> it significantly strains family members in these positions.<sup>11–14</sup> Caregivers often report chronic health problems, feelings of frustration, isolation, guilt, and resentment toward their injured family member;<sup>13</sup> spouses of individuals with SCI have been found to report even higher levels of distress than the person with SCI.<sup>14</sup> There is an obvious need for psychologically-based interventions aimed at improving the health status and quality of life both for individuals with SCI and their caregivers.<sup>6</sup>

Decades of research and meta-analytic reviews have demonstrated that education and support for caregivers of persons with other chronic conditions (*e.g.* severe mental illness) improves rehabilitative outcomes and community supports.<sup>15–17</sup> One such approach that engages care recipients and caregivers in co-treatment, termed multifamily group (MFG) psycho-education, has been shown to improve the management of schizophrenia and traumatic brain injury, and caregiver outcomes.<sup>18–22</sup> However, few systematic efforts have been made to involve caregivers in psycho-educational interventions designed to improve adjustment to SCI. As a result, a serious gap exists in accumulated knowledge regarding effective, family-based treatment strategies for improving outcomes for individuals with SCI and their caregivers. Building on earlier work by Dyck and colleagues,<sup>18</sup> this study sought to fill this gap by evaluating MFG for SCI.

The goal of this study was to test the effectiveness of MFG on measures of coping, patient activation, and social support in participants with SCI, and on caregiver outcomes such as burden and anger expression. The MFG intervention was compared to an active educational control (EC) condition in a two-armed clinical trial design. We hypothesized that, relative to EC, MFG would result in greater improvement in coping, patient activation, and social support among participants with SCI; secondarily it would also result in improved social support and reduced caregiver burden among caregivers, as well as improved relationship quality.

## Methods

### Participants

We block randomized 19 outpatients with SCI and their caregivers to a 9-month MFG intervention ( $n = 10$  pairs) or EC intervention ( $n = 9$  pairs) such that groups of 3–4 dyads were assigned to either MFG or EC. A manual for each intervention was developed. To maximize treatment integrity, all clinicians implementing the interventions received weekly supervision by the principal investigator (DD). Both groups were supplied with the 4th Edition of the book titled: *Yes, you can: A guide to self-care for persons with spinal cord injury*<sup>23</sup> as reference material on SCI. All participants signed an Institutional Review Board-approved informed consent form.

Eligibility criteria for participants with SCI included having a quadriplegic or paraplegic injury with complete or incomplete lesion; discharge from inpatient rehabilitation within the previous 3 years; being age 16 years or older; having a mobility impairment as the result of the SCI; living in the community in a non-group setting after injury; and planning to remain in the geographic area for at least 12 months.

Eligibility criteria for caregivers included being the primary instrumental and/or emotional support person for a spouse, relative, partner, or friend with SCI; having a minimum of 2 h face-to-face contact per week; living with or near the participant with SCI; being over the age of 18; having a telephone; and planning to remain in the geographic area for at least 12 months.

Dyads were excluded if the primary caregiver or participant with SCI had a terminal illness with life expectancy of less than 12 months; was in active treatment for cancer; was blind or deaf; or had a moderate to severe cognitive impairment (defined at screening as a score on the Short Portable Mental Status Questionnaire > 4 errors).

### Outcome measures

Participants with SCI and their caregivers were assessed with psychometrically validated quantitative measures at baseline, at the conclusion of the 9-month intervention, and 6-months following the intervention. Qualitative focus groups were conducted with all participants at the end of the intervention period to determine participant perceptions of overall group experience, how useful it was, suggestions for improvement, and information and coping skills they learned to support rehabilitation or care giving. These were video recorded, transcribed, and the transcriptions used for qualitative analysis.

**SCI assessments**

The Patient Activation Measure (PAM) measured the degree of knowledge, confidence, and skill to participate in self-management.<sup>24</sup> A higher degree of patient activation has been associated with better health outcomes for adults with chronic conditions.<sup>25-28</sup> Two inventories were used to assess anger-expression and social support (*i.e.* change in use of adaptive social behaviors to effectively cope with SCI): the Anger Expression Scale (AXS)<sup>29</sup> measured anger management including anger-in (suppression of angry feelings), anger-out (expression of anger towards property or people), and anger control (frequency of attempts to control expressions of anger). The Abbreviated Duke Social Support Index (ADSSI)<sup>30</sup> measured both subjective support and social network interactions.

**Caregiver assessments**

The Caregiver Burden Inventory (CBI)<sup>31</sup> was used to evaluate caregiver burden in four areas: physical, social, emotional, and time dependence burden.

**Dyad functioning**

The Family Crisis Oriented Personal Evaluation Scales (F-COPES)<sup>32</sup> assessed family-level coping, including use of social/spiritual support, reframing negative events, and mobilizing the family to acquire/accept help. The F-COPES also includes a 4-item scale that assesses passive coping behaviors. Passive coping can be described as the behaviors one performs to avoid situations of conflict due to a lack of confidence in one’s ability to alter the outcomes. Disagreeing with the passive coping items is indicative of more active and effective coping, and results in a higher score on this scale. The F-COPES was administered to both dyad members.

*Overview of the MFG intervention*

MFG used a structured problem-solving and skills training approach to provide participants with SCI and their caregivers tools and information to improve coping and support through positive behavioral exchanges. **Table 1** compares the global differences between MFG and EC interventions; **Table 2** compares content between the two interventions. Two MFG health professionals with experience in management of SCI (*e.g.* physical therapists and psychologists) served as group facilitators. MFG consisted of three sequential phases: (1) a “Joining” in which MFG facilitators met with each individual dyad for 2–3 sessions to evaluate ongoing problems and define treatment goals; (2) a 2-session Educational Workshop which provided information about SCI to all dyads; (3) 12 bi-monthly MFG meetings which used a structured format for building problem-solving and communication skills while

**Table 1 Global comparison of Multifamily Group (MFG) and Education Control interventions (EC).**

Treatment component	MFG	EC
Therapeutic Strategy Contents	Skills training, problem solving, support	Information only
Target Group	SCI effects on the body, maximizing function, coping, living and staying healthy with SCI Persons with SCI and caregivers	SCI effects on the body, maximizing function, coping, living and staying healthy with SCI Persons with SCI and caregivers
Use of Group Dynamics/ Cohesion	<i>Social support promoted:</i> Entire group participates in problem-solving for each dyad and gives support and encouragement	<i>Social support minimized:</i> Individual health issues not discussed, education is general, group interaction minimized
Therapeutic Stance Room Set-up	Educator stance is collaborative Round table	Educator stance is didactic Lecture style (all chairs face forward)
Source of Material	Drawn from everyday problems brought in by group members	Supplied by educator
Homework	Assigned and reviewed at the start of the following session	Handouts but no homework provided

receiving social support. These 12 sessions were divided into three 4-session phases: SCI management and self-care, coping and living with SCI, and staying healthy after SCI. Through instilling a systematic approach to solving everyday problems related to SCI challenges, MFG aimed to reduce emotional distress and improve skills and supports through enlisting the caregiver’s practical and emotional support for the participant with SCI.

The facilitators “joining” with each couple co-led the group. The group sessions included 3 components: (1) A 15-minute period for socialization, unwinding, and “small talk”; (2) a 35-minute “Go Round” in which each couple reviewed how the past two weeks had gone for them, including follow-up on homework or problem-solving recommendations from previous sessions. The facilitators then amended plans or solutions which had not been successful. Based on the Go Round, a problem or goal was selected for the current week’s group exercise. (3) The facilitators then led the group in formal problem solving for approximately 35 min, using a six-step process outlined in **Table 3**. The proceedings were recorded on a whiteboard. After the problem-solving exercise, 5 min were reserved for a wind-down before ending.

This treatment approach differs from those that deliver information or develop skills in a planned

**Table 2 Content comparison between Multifamily Group (MFG) and Education Control (EC) interventions.**

Treatment component	MFG	# Sessions	EC	# Sessions
Joining	<i>Dyad-tailored Education:</i> * SWOT analysis, SCI problems identified and corrected. Formulation of management problems and coping. Recommend one or more strategies and adjustments (individual and dyad).	2(3)**	<i>Standard Dyad Intake:</i> History of person with SCI and caregiver focusing on current health, skin care, bladder management, bowel management. No skills training, interventions, or formulation of management problems and needed adjustments.	2(3)**
Group Introductory Sessions	<i>Educational Workshop:</i> ASIA classification, clinical syndromes, rehab therapy, medications, health lifestyle, the family and adjustment, family guidelines. Structure and function of multifamily group, how it can help.	2	<i>Education Introduction:</i> Structure and rationale for intervention. Rules of conduct. Overview of topics to be covered.	1
Ongoing Group Sessions	<i>Problem-solving &amp; Skills Training Sessions:</i> Problem-solving designed to address specific problems associated with SCI. Compensatory strategies for SCI problems, planning ahead.	12	<i>Education Content Provided:</i> General information provided to promote healthy living in areas relevant for persons with SCI and caregivers (bladder/bowel management, nutrition, use of alcohol, drugs, safe exercise). Personal health concerns not discussed; however, discuss referral to provider.	13
Total		16		16

\*In addition to basic intake.

\*\*The default is 2 sessions; an optional 3rd session may be used to maintain contact with group members recruited early, or where the dyads are uncertain about continued participation.

sequence. Instead, problems are identified and addressed as they occur in the course of participants' daily lives. Solutions to emergent or continuing problems are generated by the group and/or the facilitators, drawing on collective knowledge of strategies to address specific problems (e.g. pain, bladder management, pressure sores, home modifications). Solutions are then implemented as homework and reviewed during the next session. This approach has the advantage of being individually tailored to people's needs, a key aspect of rehabilitation interventions often lacking in more formulaic approaches.<sup>33</sup>

### Overview of the education control intervention

The EC condition was a 16-session, highly structured bi-monthly educational intervention that provided

information on how SCI affects the body; methods for maximizing function, coping, and living with SCI; and staying healthy with SCI. The content for these areas was based on a highly recognized self-care guide for persons with SCI.<sup>23</sup> Each EC session followed the same structure, beginning with a presentation of the objectives for the current session and a brief review of material from the previous session before introducing the session's topic and presenting information on one or two key problem areas. In order to limit opportunities for group interaction and development of group cohesion, EC utilized a traditional didactic model with information delivered by a clinician experienced with SCI treatment serving as the educator in a classroom lecture setting. The information provided was general and broad-based, rather than focused on individual participants' concerns. Individual health problems were not discussed. Instead, participants were referred to their provider as needed.

### Qualitative analyses

A qualitative descriptive approach<sup>34,35</sup> with content analysis methods was used<sup>36</sup> to identify common themes associated with participants' perspectives about participating in the MFG or EC interventions. Researchers focused on identifying themes that were associated with participants' descriptions of the strengths and weaknesses of participating in the interventions.<sup>36</sup> Content analysis included combing concept- and data-driven analysis

**Table 3 Six step formal problem solving process utilized in the MFG intervention. Steps are based on brainstorming methods from organizational and business practices.**

Step	Process
1.	Define the problem or goal (MFG members & facilitators)
2.	List all possible solutions (MFG members)
3.	Discuss advantages and disadvantages of each in turn (MFG members & facilitators)
4.	Choose the solution that best fits the situation (MFG members)
5.	Plan how to carry out this solution (facilitators)
6.	Review implementation (facilitators)

approaches to the text.<sup>36</sup> Researchers used themes in the literature, their content expertise, qualitative expertise, and prior experiences to identify commonalities within the data to support themes. Once common themes were identified throughout the data they were labeled, described and supported by participants' quotes within the text.<sup>36</sup> Two of the researchers initially analyzed the data separately and then met several times to compare, refine, and further validate the themes. During the latter analysis process the entire research team met to validate findings. An audit trail was kept throughout the analysis process to document decisions and next steps.

**Quantitative analyses**

Comparison of demographic and baseline outcome measures by study group were based on chi-square tests for categorical variables or independent Student's t-tests for ratio-level variables, respectively (all ratio-level variables met the assumption of normality). There were missing values for 5 of 19 participants with SCI and caregivers at the post-treatment assessment, and 7 of 19 participants with SCI and 6 of 19 caregivers at the 6-month follow-up. The amount of missing data is likely attributable to respondent burden (in-person visits, travel time/cost, and insufficient compensation). To accommodate for missing values, we employed monotone multiple imputation for each variable with missing values using parametric regression modeling since all missing values were ratio-level data.<sup>37,38</sup> Five imputed datasets were created.<sup>39</sup> Results based on pooled imputed data are presented.<sup>40</sup> Because a large fraction of the data was imputed, sensitivity analyses compared analyses on imputed datasets to complete case analyses. Complete case analyses and imputed data set analyses were conducted with 2 x 2, group by measurement time (post-treatment, 6-month follow-up) general linear model analyses of covariance with repeated measures on the second factor. Analyses for people with SCI employed age and baseline values per measure as covariates. Analyses for caregivers employed baseline values per measure as a covariate. A 1-sided type I error rate of P < .05 (based on hypothesized superiority of MFG over EC) was used to judge statistical significance of group main effects; interactions employed a 2-sided type I error rate of P < .05. All analyses were conducted with IBM SPSS V24.0 (Chicago, IL).

**Results**

*Demographics of participants with SCI and caregivers*

Table 4 displays demographic data for participants with SCI by group to which they were assigned. The single

**Table 4 Demographic characteristics of participants with spinal cord injury assigned to each group.**

		Group	
		Multi-family group (n = 12)	Education control (n = 7)
Sex	Male	75%	57%
	Female	25%	43%
Race	African American/Black	8%	0%
	American Indian/Alaska Native	0%	14%
	White or Caucasian	92%	86%
	Some High School or Less	8%	14%
	High School Graduate/GED	42%	71%
Education Completed	Some College/Associates Degree	17%	14%
	College Graduate	33%	0%
	Yes	84%	71%
Injury Limits Employment/School	No	8%	14%
	Don't Know	8%	14%
	Cervical	50%	43%
SCI Location	Lumbar	8%	14%
	Thoracic	42%	43%
	Complete	36%	29%
SCI Completeness	Incomplete	64%	71%
	Mean CES-D Score (SD) <sup>†</sup>	9.5(5.7)	10.3(5.9)
Mean SCIM-SR Score (SD) <sup>‡</sup>	37.8(15.8)	51.4(11.8)	
Mean Age (SD) <sup>*</sup>	54.0(20.2)	33.1(20.0)	

Notes: Percentages within a variable may not add to 100% due to rounding. Asterisk denotes variable with significant difference among groups (P < .05).

<sup>†</sup>CES-D, Center for Epidemiologic Studies Depression Scale; SD, Standard Deviation.

<sup>‡</sup>SCIM-SR, Spinal Cord Independence Measure-Self Report.

significant difference among groups was for age (P = .044) with the MFG group being significantly older than the EC group. Age was therefore employed as a covariate in analyses of outcomes for participants with SCI. Table 5 displays demographic data for caregivers by group to which they were assigned. The single significant difference among groups was for relationship to participant with SCI (P = .030) with most caretakers in the MFG group being spouses, and the majority of caretakers in the EC group being parents. Attendance rates at MFG sessions averaged 84% for participants with SCI and 88% for caregivers. Attendance rates at

**Table 5** Demographic characteristics of caregivers assigned to each group. Percentages within a variable may not add to 100% due to rounding.

		Group	
		Multi-family group (n = 12)	Education control (n = 7)
Sex	Male	8%	29%
	Female	92%	71%
Race	African American/Black	0%	14%
	American Indian/Alaska Native	0%	14%
	White or Caucasian	100%	72%
	Some High School or Less	8%	29%
	High School Graduate/GED	25%	43%
Education Completed	Some College/Associates Degree	42%	29%
	College Graduate	25%	0%
	Spouse	58%	14%
	Child	17%	0%
Relationship to Person with SCI*	Parent	0%	57%
	Other Relative	8%	0%
	Friend	0%	14%
	Employed Caregiver	17%	14%
	Cervical	50%	43%
SCI Location	Lumbar	8%	14%
	Thoracic	42%	43%
	Yes	83%	71%
Living with Person with SCI	No	17%	29%
	Mean CES-D Score (SD) <sup>†</sup>	7.6(6.4)	10.5(11.0)
Mean Months Providing Care (SD)	14.2(12.3)	18.7(10.1)	
Mean Age (SD)	52.3(16.2)	51.4(21.1)	

Note: Asterisk denotes variable with significant difference among groups (P < .05).

<sup>†</sup>CES-D, Center for Epidemiologic Studies Depression Scale; SD, Standard Deviation.

EC sessions averaged 88% for participants with SCI and 92% for caregivers.

### Qualitative findings

Content analysis identified four themes describing participants' experiences about the MFG and EC interventions. These included an *enhanced sense of belonging*, *teamwork*, *increased opportunities for engagement*, and *knowledge*. Themes were similar for the two interventions, with the exception of *teamwork* being unique to the MFG group. See Table 6 for a list of themes and

examples of supporting quotes. Participants identified *belonging* as the primary strength of both MFG and EC groups, and *knowledge* as both that which was gained and ideas for how participants would like to improve the intervention experiences.

### Enhanced sense of belonging

Across both interventions, participants commonly reported reduced feelings of isolation, providing them with a sense that they were not the only one going through the experience of having SCI or caring for someone with SCI. Exposure to and engagement with others in similar situations led to the sense of belonging. There was consistent discussion surrounding belonging and social support and the positive benefit of those feelings.

Although participants found the sense of belonging, experienced through social support, in both the MFG and EC interventions, this was overwhelmingly a strength of MFG. In MFG, social support was described as spending time with other supportive participants in a relaxed and comfortable environment. New friendships were made, and the group members looked forward to seeing one another. The theme of belonging also included participants' willingness to be vulnerable and open in the group setting.

### Teamwork

Unique to the MFG group, the theme of teamwork was consistently emphasized. This theme can be described as learning from one another or problem solving as a team. Participants often described the benefit of improved problem-solving skills and this commonly stemmed from learning new ideas from the others in the group.

### Suggestions for improvement from focus groups

#### Increased opportunity for engagement

Increased opportunity for engagement was a commonly identified suggestion for improving the MFG intervention. Participants found engagement to be such a positive factor that they identified ways they could have increased it, and therefore improved the intervention. Participants also commented on how isolated they felt early in their inpatient experience. They felt that it would have been helpful to have early and frequent exposure and conversation with other persons in varying stages of recovery and rehabilitation, for example, while still inpatient. The EC group also suggested more informal interaction but also wanted more time during the groups for conversation.

**Table 6 Themes and supporting quotes.**

Theme	Multi-family group quotes	Classroom education group quotes
Enhanced Sense of Belonging	<p>[...] knowing that other people were also having that same issue was again and again and again. Hearing that it wasn't just one person's problem. We all had the same problems. That was really comforting because when you are isolated you feel like you are the only one who has that issue. So that has been really helpful. Essential contact with other people who are going through the same thing that I was going through was very supportive in this format. I don't think I would have gotten it if I had been sitting in a room with somebody there lecturing.</p> <p>And you just don't see people like us out and about. I thought I might bump into somebody on occasion cruising along in their motorized chair, but it's just so rare to have anybody to even talk to about it because they're not out. So a setting like this is about the only way you're going to be able to share with anybody in a similar situation.</p>	<p>[One participant enjoyed] having other people in the wheelchair, like, in the classroom environment ... the ability to talk with them and relate to things.</p> <p>I think if you could make a connection with people, and you can't – I didn't feel that that could be done if you're reading a computer and looking at the board. [...] I think that makes a big, huge difference to connect.</p> <p>We just started enjoying and getting to know each other.</p>
Teamwork	<p>Even when I was not the focus of a problem it was highly beneficial in seeing how to throw ideas out there and how to apply them and how to figure out the pros and cons of the different ideas ... picking two or three of them to apply to yourself and even when it was someone else at the center of the focus, you could still apply that to yourself and it was a great refresher in problem.</p> <p>I would agree with having that problem-solving technique has really been helpful and before the group, I would find myself getting really emotional and unable to think straight and having the input of the group with ideas that I haven't thought of because my brain was clogged up with stress and emotion. It was really helpful.</p>	<p>I guess putting a little more time allowing more time in each session to be able to let people somehow express themselves whether it's just chatting or, how was your week? Did you have a good week this week?</p> <p>[One participant disliked the] Limited time for conversations.</p>
Increased Opportunities for Engagement	<p>More informal socializations before we even start so we can get to know each other ... It took a few weeks to even do that ... It would have broke the ice sooner.</p> <p>I would like to have had something like this when we were in-patient, because you get no social contact there at all ... we kind of talked to some of the therapists when we were in and maybe when you all were in there was group therapy or something. I used to have my groups of people, but there was no social contact at all for the month and a half that we were in.</p> <p>Like, you know, have somebody who's been in the group do a little video blurb that they could show that says, here's some of the stuff that we ran into x, y, z. ... Have them come in and talk during one of the sessions. Somebody from the past or someone, you know. Somebody who's gone through it all. Maybe somebody who's totally recovered, and then somebody else who isn't going to recover. And how does he cope with life. And then how did the other guy– how long did it take him for everything?</p> <p>You know, there's a lot of stuff out there. That's another thing. You know, there's not really any communication as far as what's available. Like when you're at a certain stage what might work for you and what might not. Bring in someone who is familiar with getting the assistance that is needed once you make the rapid transition from an injury, from being capable, and to being needy. What resources are available in the community? Paying their caregiver through the state, getting qualified for social security, they haven't done that yet, those kinds of speakers would be extremely informative.</p>	<p>I would suggest having it even more kind of where you're more active in the learning as opposed to just sitting and watching a slide show. That can get kind of repetitive and boring after a while.</p> <p>Having more time to share tricks and just habits and things like that because that really helps hearing other people's tricks and stuff that they do on a daily basis that you never really thought of helps.</p> <p>She knows now, and I know now, that we can go to the book and look up things if we have questions. But a lot of it was very helpful.</p> <p>Some things didn't apply to my specific injury. [...] maybe they could be more tailored.</p>
Knowledge		

## Knowledge

Participants from both intervention groups discussed an ongoing quest for knowledge to cope with the dynamic changes and adjustments to the complications of spinal cord injury. Participants desired more pharmacological knowledge about medications and their side effects, as well as nutritional knowledge. Both groups had suggestions for speakers or specialists they would like to see present during the groups; some of these included a pharmacist, psychiatrist, dietician, elder law specialist, and nurse.

## Quantitative outcome analyses

Several significant group main effects observed in the pooled imputed analyses were also detected in the complete case analyses. Participants with SCI in the MFG group had significantly higher disagreement scores on the F-COPES passivity scale at post-treatment and at the 6-month follow-up in pooled imputed analyses ( $P = .047$ ) and complete case analyses ( $P = .036$ ). Likewise, caregivers in the MFG group had significantly higher disagreement scores on the F-COPES passivity scale at post-treatment and at the 6-month follow-up in pooled imputed analyses ( $P = .018$ ) and complete case analyses ( $P = .038$ ). Participants with SCI in the MFG group had significantly higher scores on the ADSSI subjective social support scale at post-treatment and at the 6-month follow-up in pooled imputed analyses ( $P = .037$ ) and complete case analyses ( $P = .007$ ). Participants with SCI in the MFG group also had significantly higher total ADSSI scores at post-treatment and at the 6-month follow-up in pooled imputed analyses ( $P = .050$ ) and complete case analyses ( $P = .006$ ). Table 7 displays descriptive statistics for significant main effects and standardized mean difference effect size estimates. Effect sizes indicated the magnitude of the effect of MFG relative to EC to be substantial for each of these outcomes. No other significant group main effects were detected in other outcome measures. Table 8 displays means and standard deviations for nonsignificant group outcomes.

## Discussion

There is a clear need to provide coping skills as well as supports for persons living with SCI and their caregivers. While educational curricula have been developed, these have often not been individualized for persons with SCI and their caregivers. This project compared an individualized and tailored education and support intervention delivered in a multifamily group format to a standard education intervention. Of note, MFG used a structured problem-solving and skills training approach to provide participants with SCI and their

**Table 7 Means (standard deviations) per group for significant group main effects in the outcome measures ( $P < .05$ ).**

Analysis	Group		Effect size	
	Multi-family group	Education control		
<i>Participants with SCI</i>				
F-COPES passive appraisal scale <sup>†</sup>	Pooled	17.7(2.7)	14.9(3.1)	0.9
	Imputed			
ADSSI subjective social support scale <sup>‡</sup>	Complete Case	18.6(2.1)	15.5(2.2)	1.4
	Pooled	19.3(1.5)	15.8(1.7)	2.1
ADSSI total score	Imputed			
	Complete Case	19.4(1.9)	15.4(2.0)	2.0
F-COPES passive appraisal scale	Pooled	27.1(1.8)	24.0(2.1)	1.5
	Imputed			
ADSSI total score	Complete Case	28.1(2.2)	23.2(2.3)	2.1
	Pooled			
F-COPES passive appraisal scale	Pooled	18.3(2.4)	13.9(2.7)	1.6
	Imputed			
ADSSI total score	Complete Case	18.0(2.5)	14.7(2.6)	1.3
	Pooled			

<sup>†</sup>F-COPES, Family Crisis Oriented Personal Evaluation Scales.

Higher scores represent lower passive appraisal.

<sup>‡</sup>ADSSI, Abbreviated Duke Social Support Index.

caregivers tools and information to improve coping and support through positive behavioral exchanges. Participants were taught self-care strategies related to SCI, given practice in solving problems related to SCI, and provided the opportunity to exchange experiences and coping strategies with other care dyads over an eight to nine-month period. While the content of the sessions was guided by set topics, the identified problems and problem-solving suggestions were provided collaboratively by the participants, caregivers, and MFG facilitators.

MFG was associated with greater disagreement with negative passive coping statements (e.g. “believing if we wait long enough, the problem will go away”) and improved social support in participants with SCI and their caregivers. These quantitative outcomes were largely congruent with themes identified in the qualitative results in which MFG participants emphasized the important benefits of an enhanced sense of belonging and teamwork. The focus groups also provided the opportunity for participants to provide suggestions for improvement of the interventions. Of note, the method of instruction in the EC group was disliked by most of the participants as they felt it was overly structured



**Table 8 Means (standard deviations) per group for nonsignificant group main effects (P > .05).**

	Analysis	Group	
		Multi-family group	Education control
<i>Participants with SCI</i>			
Patient Activation Measure	Pooled Imputed	75.5(13.4)	68.9(13.8)
	Complete Case	75.4(16.5)	65.1(17.4)
F-COPES acquiring social support scale <sup>†</sup>	Pooled Imputed	32.6(6.3)	28.6(6.5)
	Complete Case	31.5(7.2)	27.6(7.6)
F-COPES reframing scale	Pooled Imputed	33.5(3.2)	31.2(3.3)
	Complete Case	32.7(3.9)	30.4(4.1)
F-COPES seeking spiritual support scale	Pooled Imputed	13.5(2.2)	11.7(2.3)
	Complete Case	13.8(2.9)	11.7(3.1)
F-COPES mobilizing family to acquire/accept help scale	Pooled Imputed	15.3(2.4)	13.2(2.4)
	Complete Case	16.4(3.0)	13.1(3.2)
F-COPES total score	Pooled Imputed	111.2(10.1)	104.1(10.2)
	Complete Case	113.4(12.7)	105.4(12.8)
ADSSI social interaction scale <sup>‡</sup>	Pooled Imputed	16.0(5.1)	14.8(5.2)
	Complete Case	16.0(5.2)	14.7(5.5)
AX anger in scale*	Pooled Imputed	16.4(1.4)	16.0(1.5)
	Complete Case	16.2(2.2)	15.0(2.9)
AX anger out scale	Pooled Imputed	17.0(1.8)	18.3(1.9)
	Complete Case	16.5(2.0)	18.5(2.6)
AX anger control scale	Pooled Imputed	7.2(1.0)	7.9(1.1)
	Complete Case	7.4(1.1)	9.0(1.5)
AX total score	Pooled Imputed	51.9(4.3)	52.9(4.4)
	Complete Case	51.9(4.2)	54.3(5.5)
<i>Caregivers</i>			
F-COPES acquiring social support scale	Pooled Imputed	29.1(6.6)	27.7(6.5)
	Complete Case	28.1(5.3)	28.1(5.3)
F-COPES reframing scale	Pooled Imputed	34.0(4.6)	31.6(4.7)
	Complete Case	32.1(3.8)	30.5(3.9)
F-COPES seeking spiritual support scale	Pooled Imputed	10.5(2.4)	10.8(2.9)
	Complete Case	10.9(2.6)	12.2(2.5)
F-COPES mobilizing family to acquire/accept help scale	Pooled Imputed	15.5(2.6)	14.6(2.6)
	Complete Case	15.5(2.0)	15.9(1.9)
F-COPES total score	Pooled Imputed	106.9(8.8)	104.5(6.8)
	Complete Case	106.5(10.1)	105.8(9.9)
Caregiver Burden Inventory	Pooled Imputed	29.6(7.7)	31.5(7.8)
	Complete Case	30.9(9.6)	32.6(9.0)

<sup>†</sup>F-COPES, Family Crisis Oriented Personal Evaluation Scales.

<sup>‡</sup>ADSSI, Abbreviated Duke Social Support Index.

\*AX, Anger Expression Scale.

and lacked focus on individual needs. In fact, several comments from the EC group suggested that it would be improved if each participant could talk, share, and teach others in the group. Thus, without knowing the tenets of an MFG approach, EC participants identified that such an approach would be more valuable than a traditional educational approach.

With a few exceptions, the results were generally consistent with those of a previous single-arm pilot study. In that MFG intervention development study<sup>18</sup> participants with SCI reported an increase in life satisfaction, decrease in depressive symptoms and anger-expression, and described learning a variety of coping strategies. Similar to the current study, caregivers in the development study reported a significant reduction in burden and reported learning a variety of coping strategies that improved patience and reduced feelings of guilt and burden. The present study represents a more methodologically rigorous comparison of MFG to an active educational control intervention. Both interventions were helpful in affecting change in several of the outcomes as noted by non-significant findings in several outcome measures. Yet, despite the power of an educational intervention, MFG was able to significantly improve several outcomes beyond that experienced by EC participants.

The current study is generally supportive of earlier findings on MFG and adds a significant dimension to our evaluation efforts to adapt and implement multi-family group for persons with SCI and their caregivers. Consistent with previous work, group members valued the knowledge and support from group facilitators. Two of the most significant impacts of SCI are the abrupt and sudden loss of normality in the patient's life and the isolation that typically follows the initial injury.<sup>41</sup> The MFG format and experience led participants to recognize that they were not alone. Both participants with SCI and their caregivers described the benefit of connecting with others, which reduced isolation and improved communication and understanding. Participants in the MFG group also valued the team-based approach to managing everyday problems. While it is possible that the greater number of couples in the MFG group may have contributed to the opportunity to experience working as a team, similar results have been reported by Elliot *et al.*<sup>42</sup> using a problem-solving intervention for family caregivers of persons with SCI. Finally, similar to our findings, Routasalo *et al.*<sup>43</sup> found that psychosocial groups improved social functioning, loneliness, and well-being in older lonely people.

Several study limitations need to be acknowledged. The sample was small and self-selected, with difficulties in recruitment and retention. The high cost of commitment to an intensive intervention with time and travel demands contributed to these challenges. The design could also have benefitted from adding a treatment as usual comparison, such as participants that did not attend any program. Such a comparison would have

made it possible to better determine the impact of both MFG and EC interventions. It must also be acknowledged that both interventions were manualized, which may provide both strengths (improved internal validity) and limitations (decreased external validity and flexibility). Finally, it should also be acknowledged that providing these interventions is costly for providers, unlikely to be paid for by insurers, and challenging to implement. Advocacy and downscaled alternatives should be evaluated in the future.

## Conclusion

This study illustrates that MFG can be successfully implemented with an SCI population, and is superior on some measures of psychological and social functioning relative to receiving structured education about SCI. In addition, the qualitative findings are encouraging in that participants uniformly viewed the MFG intervention experience as acceptable and helpful; a notion not generally expressed about the education control intervention.

## Abbreviations

MFG: multifamily group; SCI: spinal cord injury; EC: education control; TBI: traumatic brain injury.

## Disclaimer statements

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**Ethics approval and consent to participate** This study and the informed consent form were reviewed and approved by the Institutional Review Board-Spokane as IRB1923.

**Availability of data and materials** Data supporting findings from the study will be available upon request from the corresponding author.

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