

AWARD NUMBER: W81XWH-14-1-0621

TITLE: The Process of Adjustment Among Caregivers of Individuals with Spinal Cord Injury:  
A Qualitative Study

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<b>14. ABSTRACT</b> This mixed-methods study aims to explore the experiences of veteran and civilian caregivers of individuals with SCI by collecting qualitative and quantitative data from 48 caregiver-care recipient dyads across four rehabilitation hospitals who together serve a diverse patient population. During our second year of funding, we have made significant progress on attaining project goals, including securing all relevant continuing institutional approvals, expanding the review of the relevant literature and existing programs and services for caregivers, and enrolling 28 participants (14 dyads) into the study bringing our overall total to 32 dyads (64 participants). We received a total of 32 referrals on additional dyads during year 2 and continue to follow up on all referrals from interested participants during year 1 and 2. We have presented early findings at our second annual advisory board meeting and at 4 conferences including 1 international conference. Caregivers are sharing a variety of unmet needs related to their emotional, physical, and social quality of life (QOL). Unmet needs are related to caregiver burden. Veteran dyads are reporting significantly more supplemental support and compensation for caregivers when compared to civilian dyads. For civilian dyads, poorer caregiver QOL and higher caregiver burden is significantly associated with higher anxiety and more pain experienced by their loved ones living with SCI. We have initiated follow-up interviews focused on deepening our understanding of support efforts and unmet needs. Taken together, we are confident that data from this study will help highlight unmet needs of caregivers and support the development of relevant and effective points of intervention for veterans and civilians across various sociodemographic groupings.					
<b>15. SUBJECT TERMS</b> Caregivers, adults with spinal cord injuries, quality of life, mixed methods, dyads, veterans, civilians, ecological intervention development					
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## 1. INTRODUCTION

Little is known about the specific process of adjustment among caregivers of individuals with spinal cord injury (SCI). Much less is known from the perspectives of caregivers themselves. While we have some information about how caregiving impacts caregivers' emotional functioning, we know little about impacts on their physical health, social integration, intimacy, and participation in meaningful activities like employment and career development. The current study proposes to advance the body of knowledge around caregiving and SCI by interviewing approximately 48 caregiver/care-recipient dyads twice over 15 months to holistically explore the caregiving experience. Further, caregivers are being recruited from four rehabilitation hospitals in the Chicagoland area in order to construct a sample of caregivers of veterans and civilians with SCI from diverse socioeconomic backgrounds. In the current study, we are collecting semi-structured (qualitative) and survey (quantitative) data from both caregivers and the individuals with SCI for whom they care. Caregivers are being asked to provide their perspectives on "adjustment," and look broadly at their emotional functioning, physical health, social integration, intimacy, and participation in meaningful life roles (including employment and career development). Individuals with SCI are being asked about their own quality of life and caregiving relationships. Taken together, the current study strives to fill gaps in existing literature in order to provide a foundation for the development of ecologically valid interventions to bolster support and quality of life among caregivers of individuals with SCI.

## 2. KEYWORDS

Caregivers, adults with spinal cord injuries, quality of life, mixed methods, dyads, veterans, civilians, ecological intervention development

## 3. ACCOMPLISHMENTS

### Major Goals

For year two, we articulated six major tasks, with associated sub-tasks for each, in our Statement of Work.

**Major Task 1:** Secure necessary institutional approval from participating sites

- Submit amendments, adverse events, and protocol deviations as needed; **As needed**
- Coordinate with sites for annual IRB and HRPO report for continuing review; **Annually**

**Major Task 2:** Coordinate study staff for participant recruitment;

- Advertise, interview, and hire for (replacement) project coordinator at MU; **Completed 09/01/2016**
- Train all staff on project expectations and responsibilities, including recruitment procedures; **Completed 9/30/2016**

**Major Task 3:** Collect qualitative and quantitative data; **Ongoing**

- Recruit 48 individuals with SCI and their 48 caregivers who meet criteria for participation; **Progress: 72% complete (69/96)**
- Conduct initial interviews with 48 caregivers and their 48 family members with SCI; **Progress: 67% complete (64/96)**
- Conduct follow-up interviews with 48 caregivers and their family members with SCI, 15 months after their initial interview; **Progress: 00% complete (00/96)**

**Major Task 4:** Analyze Data; **Ongoing**

- Code qualitative data collected during initial interviews, developing codebooks based on the first few interviews, with changes made as needed during the coding of subsequent initial interviews (months 5-16); **Progress ongoing**
- Code qualitative data collected during follow-up interviews, developing codebooks based on the first few interviews, and borrowing from codebooks developed during initial interviews as appropriate, with changes made as needed during the coding of subsequent follow-up interviews; **Progress postponed**
- Analyze quantitative data (month 13); **Progress ongoing**
- Conduct investigator-triangulation (months 6-31); **Progress ongoing**
- Hold annual Advisory Board meeting (month 23); **Completed 06/13/2016.**

**Major Task 5:** Disseminate study findings to appropriate audiences; **Target date: Ongoing**

- Submit abstracts highlighting findings to SCI-related meeting (a minimum of 1 abstract during year 2); **Progress: 100%**
- Submit scientific manuscripts highlighting findings to SCI-related peer-reviewed journal (1 paper during year 2); **Progress postponed**

**Major Task 6:** Suggest implications for interventions; **Target date: Ongoing**

- Generate ideas and strategies for intervention with Advisory Board members and participants; **Progress: Initiated during 2nd annual Advisory Board meeting.**

### Accomplishments on Goals

We accomplished the following in year two regarding these goals:

#### **Major Task 1:** Secure necessary institutional approval from participating sites

IRB approvals were secured from all collaborating partners as summarized in the table below.

<b>Institution</b>	<b>IRB Protocol Approval date</b>	<b>Continuing Review Approval dates</b>	<b>Amendment Approval dates</b>	<b>HRPO Approval</b>	<b>HRPO Continuing Review Approval dates</b>	<b>HRPO Amendment Approval dates</b>
RUSH/Shriners	12/10/2014	11/02/2015	10/28/2015	02/12/2015	11/13/2015	11/09/2015, 01/04/2016
WIRB/Shriners	03/25/2016					
Marquette University	01/28/2015	01/15/2016	09/25/2015	02/12/2015		
Hines VA	04/27/2015	06/20/2016	02/11/2016	06/23/2015	08/17/16 Submitted	
Northwestern University /RIC	03/16/2015	02/22/2016	02/22/2016	04/03/2015		
Mt. Sinai Hospital/Schwab Rehabilitation Hospital	12/11/2014	12/10/2015	03/04/2016	02/28/2015		

Amendments to update study leadership and expand recruitment criteria and effort were submitted and approved during the second year of the grant. Specifically, an original Co-PI, Lawrence Vogel stepped in as the study's Principal Investigator, while Susan Ryerson Espino, the study's qualitative consultant, stepped in as the new Co-PI. Erin Kelly, the former Co-PI, remained on the study as a Co-Investigator.

In addition, we amended the protocol to expand age criteria (from 25-44 to 18-65 years of age) in an effort to bolster recruitment efforts. Lastly, we expanded our mode of recruitment to include recruitment of participants from community organizations in addition to the four originally approved recruitment rehabilitation hospitals.

Continuing reviews have been submitted and approved by all participating IRBs. Shriners recently changed IRBs (from Rush to WIRB), and WIRB reviewed and approved the protocol for this study on 03/25/2016.

Personnel amendments have been submitted to all IRBs to replace our former Research Coordinator, Titilope Akinlose, with our new Research Coordinator, Kerry O'Rourke.

**Major Task 2: Coordinator study staff for participant recruitment**

A new research coordinator, Kerry O'Rourke, was hired and began work on Sept. 1. (After the previous research coordinator left in May, a new coordinator was hired over the summer but she left after three days due to a family health emergency, which re-started the hiring process.) The Co-PI has trained the new research coordinator.

**Major Task 3: Collect qualitative and quantitative data**

We have continued recruitment and data collection at Shriners, Schwab, RIC, and Hines. To date, 28 participants at Shriners have been consented, and we have completed 28 participant interviews, surpassing our maximum goal at Shriners (14 dyads; 117% of goal). Specific to Schwab, we have consented 10 participants and completed 9 participant interviews (4 dyads and 1 person with SCI; 36% of goal). Specific to RIC, we have consented 11 participants and completed 11 participant interviews (5 dyads and 1 persons with SCI; 45% of goal). At Hines, 17 participants have been consented and 16 participant interviews have been completed (8 dyads; 50% of goal).

In addition, we are continuing the process of data management and analysis.

By the end of Q4, we had hoped to complete our recruitment process and have all initial interviews completed for all 48 individuals with spinal cord injuries and their caregivers. However, due to several IRB-related delays, project recruitment was also delayed causing a slight set back in terms of number of participants recruited and interviewed. By the end of Q9, we aim to complete participant recruitment and data collection at Schwab, RIC, and Hines VA. During Q9 we have also begun follow-up qualitative interviews for all enrolled dyads (4 follow-up interviews have been completed to date).

**Major Task 4: Analyze data**

Sixty-four participant interviews have been transcribed and uploaded into Nvivo. We have also begun coding and analyzing all 64 interviews. Specific to the quantitative data, we have mailed out surveys to all 64 participants that have completed their initial interviews. To date, we have received 47 of those 64 surveys back and have begun analysis. During this last quarter, we expanded data collection to include electronic surveys in an effort to facilitate more convenient and timely participation for adults living with SCI and their caregivers. We piloted the online tools, received positive feedback, and have begun to share links with new recruits. They appear enthusiastic about the option to complete the surveys online.

We held our second Advisory Board Meeting on June 13, 2016, with 11 in attendance, including representatives from all recruitment sites and consumers. Our presentation of study implementation and early findings was well received.

Six of the seven advisory board members who are not research staff members responded to an online survey seeking feedback about the meeting. Overall, they felt the meeting was productive and a good use of their time and that they left with a good sense of the project goals and research design, that their role as a board member was clear, and that their contribution was valuable and well received. They also agreed that the study design is good and that the study team is making good progress toward achieving its goals. Specifically:

- 83.33% strongly agreed that the study has a good design and approach based on its aims and goals; 16.67% agreed;
- 33.33% strongly agreed that the study is making good progress toward achieving its aims and goals; 66.67% agreed.

When asked for suggestions to improve any component of the study, one advisory board member encouraged the research team to continue recruiting participants to reach the original number proposed. When asked about improving the advisory board meeting itself, two board members suggested sending out materials in advance so that attendees can better prepare for the meeting.

One board member said, “Great meeting—well planned, open and honest.” Another said, “There is definitely a positively focused direction that will lead to better results that will prove beneficial to both the civilian as well as military disabled. The ground work is well underway that will make possible the same care for both.”

**Major Task 5:** Disseminate study findings to appropriate audiences

To date, we have submitted four abstracts to scientific meetings and all four were accepted. During 2016, we presented at the following SCI-related scientific meetings:

Ryerson Espino, S., Kelly, E.H., Akinlose, T., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (2016, April). Caregivers of adults with pediatric-onset SCI: An exploration of unmet needs. Presented at the American Spinal Injury Association Scientific Meeting, Philadelphia, PA.

Ryerson Espino, S., Kelly, E.H., Akinlose, T., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (September, 2016). Burden among caregivers of adults with spinal cord injury. Presented at the Academy of Spinal Cord Injury Professionals Educational Conference, Nashville, TN.

Vogel, L.C., Akinlose, T., Ryerson Espino, S., Kelly, E.H., Ghaffari, A., Harris, G., Richardson, M., Chen, D., & Lee, R. (August, 2016). Burden among caregivers of adults with spinal cord injury. Presented at the 6<sup>th</sup> Annual Paralyzed Veterans of America Summit, Orlando, FL.

Akinlose, T., Ryerson Espino, S., Kelly, E.H., Ghaffari, A., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (September 2016). Burden among caregivers of adults with spinal cord injury. Presented at the 55th International Spinal Cord Society Meeting, Vienna, Austria.

During year three, we plan to submit an abstract to the American Spinal Injury Association Scientific Meeting (April 2017 in Albuquerque, N.M.) and develop the following three manuscripts to submit to peer-reviewed journals:

1. Unmet needs of caregivers of adults with SCI
2. Support experiences and preferences of caregivers of adults with SCI
3. The relationship between caregiver burden and wellbeing of adults living with SCI

### **Major Task 6: Suggest implications for interventions**

We began generating a list of intervention components at the second annual Advisory Board meeting in June 2016. The research team asked board members whether they would recommend the following intervention components for supporting caregivers based on what they heard at the meeting (five of six responded; % refers to those who agreed):

- Skills to reinforce for caregivers—100%
- Health promotions/behaviors—60%
- Knowledge areas/educational topics—60%
- Structural kinds of supports—80%
- Other kinds of intervention components/supports—60%

### **Preliminary Study Findings**

Our preliminary analysis of qualitative and quantitative data from the 22 dyads with complete data shows that, overall, caregivers appear healthy and satisfied in their roles. However, 12 caregivers (55%) appeared to have challenges (“red flags”) related to at least one area of concern. Average caregivers appeared satisfied with their overall quality of life (QOL) and reported low caregiver burden. But, those with at least one red flag were more likely to report more caregiver burden and less satisfaction with QOL when compared to those without concerns. Further, caregiver QOL was significantly related to burden for the caregivers with red flags.

In addition, we have found significant relationships between caregiver QOL and burden and mental and physical health of individuals with SCI for civilian dyads but not for the veterans.

Our preliminary conclusions

- Caregivers who had at least one flagged concern reported higher burden and lower QOL. This suggests that a variety of factors (lack of leisure, mental health concerns, social support, physical health complaints) contribute to burden and lower QOL.
- Furthermore, burden and QOL were inversely related, in that the higher burden was associated with lower QOL.
- Specific to civilian dyads, significant relationships were found between psychosocial characteristics of caregivers and the individuals with SCI for whom they cared. In particular, increased caregiver burden and decreased caregiver QOL were found to be related to increased anxiety and increased pain of the individual living with SCI, respectively.
- Veteran dyads may be benefiting from more compensation for caregiving and supplemental care.

Next steps of this project will include examining the intersection of the quantitative and qualitative data. However, preliminary findings suggest the need to raise awareness of the importance of caregiver burden and launch initiatives to bolster caregiver QOL, such as compensating caregivers and supporting respite and supplemental caregiving initiatives.

### **Opportunities for Training and Professional Development**

Dr. Ryerson Espino attended the American Spinal Injury Association Scientific Meeting and Academy of Spinal Cord Injury Professionals Educational Conference. Dr. Vogel attended the 6<sup>th</sup> Annual Paralyzed Veterans of America Summit and 55th International Spinal Cord Society

Meeting. Ms. O'Rourke attended a 10/07/2016 Chicago Forum for Justice in Health Policy forum on ethics and injustices of giving and receiving caregiving for seniors and those with disabilities within the current long-term care system.

### **Disseminating Results to Communities of Interest**

In Year 1 and Year 2, we held Advisory Board meetings to share the study design and framework as well as preliminary data and findings with the board of researchers, clinicians, caregivers, and individuals with SCI. At both meetings, we received positive feedback about the study design and progress from the board members. As mentioned above, we disseminated early findings at four SCI-related scientific meetings in Year 2 and will begin working on three manuscripts for submission to peer-reviewed journals in Year 3.

### **Tasks During Next Reporting Period to Accomplish Goals**

During the next reporting period, we will do the following:

- 1) Continue recruiting and consenting participants at Shriners, Schwab, RIC, and Hines VA.
  - a. In Q9, we met with the site investigator and recruitment coordinator at Hines to introduce the new research coordinator and talk about bolstering recruitment efforts. We will reinstate monthly recruitment calls with recruitment coordinators at all sites to ensure progress and problem solve barriers on an ongoing basis.
- 2) Continue collecting the remaining first round of qualitative and quantitative data from the individuals with SCI and their caregivers.
- 3) Initiate conducting follow-up interviews in Q9 with persons with SCI and their caregivers and collecting quantitative data not collected during the initial round.
- 4) Continue analyzing data (qualitative and quantitative), including conducting investigator triangulation.
  - a. Further refine and add to the existing codebooks for interviews with individuals with SCI and their caregivers.
  - b. Continue systematic reviews of literature and existing services.
  - c. Review tools and literature to help inform intervention development.
- 5) Continue dissemination activities.
  - a. In Q9, we have plans to submit an abstract to the 2017 meeting of the American Spinal Injury Association.

## **4. IMPACT**

### **Impact on the Principle Discipline**

Specific to the field of SCI rehabilitation, data from this study will help highlight unmet needs of caregivers as well as how interventions can be developed to support caregivers of veterans and civilians across various sociodemographic groupings. Lastly, examining our qualitative and quantitative data together will help to further the conceptualization and operationalization of quantitative measures as related to caregiver quality of life and SCI.

### **Impact on Other Disciplines**

Findings from the present study also have implications for the general field of rehabilitation, as well as the literatures related to caregiver health across a variety of chronic illness and disability groups.

### **Impact on Technology Transfer**

We have made connections with a number of community organizations including the Spinal Cord Injury Association of Illinois, the Paralyzed Veterans of America, Access Living, Progress Center for Independent Living, and Center for Disability Services, as well as the team who runs the online community, [facingdisability.com](http://facingdisability.com). We expect our project findings to have broad relevance for a variety of audiences including scientists, practitioners, and consumers, and will use multiple media forms to disseminate results and recommendations for intervention.

### **Impact on Society Beyond Science and Technology**

As mentioned above, we have made connections with a number of community organizations including the Spinal Cord Injury Association of Illinois, Paralyzed Veterans of America, Access Living, Progress Center for Independent Living, and Center for Disability Services, as well as the team who runs the online community, [facingdisability.com](http://facingdisability.com). We expect our project findings to have broad relevance for a variety of audiences including scientists, practitioners, and consumers, and will use multiple media forms to disseminate results and recommendations for intervention.

## **5. CHANGES/PROBLEMS**

The only change from our last report, as was mentioned above, is that a new researcher coordinator, Kerry O'Rourke, began work on Sept. 1, 2016.

Because of the significant IRB-related delays that have affected our ability to meet our target number for participant recruitment as well as the expansion of our recruitment criteria in order to meet recruitment goals, we would like to explore the possibility with the Science Officer of a no-cost extension.

## **6. PRODUCTS**

Nothing to Report.

## **7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS**

### **Individuals Who Have Worked on the Project (PDs/PIs and those who worked one person month or more)**

Name:	Lawrence C. Vogel, MD
Project Role:	Principal Investigator

Nearest person month worked: 0.6 calendar months  
Contribution to Project: Took over as PI at beginning of year 2

Name: Susan Ryerson Espino, PhD  
Project Role: Co-Principal Investigator  
Nearest person month worked: 2.4 calendar months  
Contribution to Project: Became Co-PI at beginning of year 2

Name: Titilope Akinlose, MPH  
Project Role: Research Coordinator  
Nearest person month worked: 8 calendar months  
Contribution to Project: Left project in May 2016

Name: Kerry O'Rourke, MPH  
Project Role: Research Coordinator  
Nearest person month worked: 1 calendar month  
Contribution to Project: Began work Sept. 1, 2016

### **Changes in Key Personnel**

- Dr. Vogel replaced Dr. Kelly as the PI; Dr. Kelly now is a Co-Investigator.
- Dr. Ryerson Espino, who had been the qualitative research consultant, now is the Co-PI.
- Research Coordinator Titilope Akinlose left and was replaced by Research Coordinator Kerry O'Rourke.

### **Other Organizations Involved as Partners**

Organization: Shriners Hospitals for Children – Chicago  
Location: 2211 N. Oak Park Ave  
Chicago, IL 60707

Contribution: Drs. Vogel and Ryerson Espino and Ms. O'Rourke use Shriners Hospital's facilities for project activities. In addition, Shriners serves as a site of participant recruitment for individuals with SCI and their caregivers.

Organization: Edward Hines, Jr. VA Hospital  
Location: 5000 S. 5th Ave  
Hines, IL 60141

Contribution: Hines is one of the project's collaborating partners and serves as the site of recruitment for veterans with SCI and their caregivers.

Organization: Rehabilitation Institute of Chicago  
Location: 345 E. Superior St.  
Chicago, IL 60611

Contribution: RIC serves as another site of participant recruitment for individuals with SCI and their caregivers.

Organization: Schwab Rehabilitation Hospital

Location: 1401 S. California Ave  
Chicago, IL 60608

Contribution: Schwab serves as another site of participant recruitment for individuals with SCI and their caregivers.

Organization: Paralyzed Veterans of America, Vaughan Chapter

Location: 2235 Enterprise Drive, Suite 3501  
Westchester, IL 60154

Contribution: The Vaughan Chapter of the PVA provides valuable information on program and services that the organization offers to paralyzed veterans and serves as an additional recruitment site.

Organization: Spinal Cord Injury Association of Illinois

Location: 1032 South La Grange Road #5  
La Grange, IL 60525

Contribution: Provides valuable information on program and services the organization offers to persons living with SCI and their families and serves as an additional recruitment site.

Organization: Access Living

Location: 115 W Chicago Ave  
Chicago, IL 60654

Contribution: Provided valuable information on program and services this Center for Independent Living offers to persons living with SCI.

Organization: Progress Center for Independent Living

Location: 7521 Madison St  
Forest Park, IL 60130

Contribution: Provided valuable information on program and services they offer to persons living with SCI, specifically related to independent living.

Organization: Center for Disability Services

Location: 311 South Reed Street  
Joliet, IL 60436

Contribution: Provided valuable information on program and services organization offers to persons living with SCI.

Organization: American Academy of Pediatrics

Location: 141 Northwest Point Blvd  
Elk Grove Village, IL 60007

Contribution: Erin Hayes Kelly, PhD through American Academy of Pediatrics will serve as a source of investigator triangulation and an inquiry auditor. Dr. Kelly was the initial PI for this project and has been retained as an advisor and Spinal Cord Injury (SCI) Research Specialist. She is a community psychologist with extensive experience conducting research with families living with SCI and mixed methods research. She

will provide guidance on the analysis process including qualitative coding and interpretations, quantitative analyses, and manuscripts in development for publication.

## **8. SPECIAL REPORTING REQUIREMENTS**

None Required.

## **9. APPENDICES**

### **Abstracts from Four Presentations in Year 2**

**Appendix A:** Ryerson Espino, S., Kelly, E.H., Akinlose, T., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (2016, April). Caregivers of adults with pediatric-onset SCI: An exploration of unmet needs. Presented at the American Spinal Injury Association Scientific Meeting, Philadelphia, PA.

**Appendix B:** Ryerson Espino, S., Kelly, E.H., Akinlose, T., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (September, 2016). Burden among caregivers of adults with spinal cord injury. Presented at the Academy of Spinal Cord Injury Professionals Educational Conference, Nashville, TN.

**Appendix C:** Vogel, L.C., Akinlose, T., Ryerson Espino, S., Kelly, E.H., Ghaffari, A., Harris, G., Richardson, M., Chen, D., & Lee, R. (August, 2016). Burden among caregivers of adults with spinal cord injury. Presented at the 6<sup>th</sup> Annual Paralyzed Veterans of America Summit, Orlando, FL.

**Appendix D:** Akinlose, T., Ryerson Espino, S., Kelly, E.H., Ghaffari, A., Harris, G., Richardson, M., Chen, D., Lee, R., & Vogel, L.C. (September 2016). Burden among caregivers of adults with spinal cord injury. Presented at the 55th International Spinal Cord Society Meeting, Vienna, Austria.

## Appendix A

### Abstract

**Title:** Caregivers of Adults with Pediatric-Onset SCI: An exploration of unmet needs

Susan Ryerson Espino, PhD<sup>1</sup>; Erin H. Kelly, PhD<sup>1,2,3</sup>; Titilope Akinlose, MPH<sup>1</sup>; Gerald Harris, PhD<sup>1,2</sup>; Michael Richardson, MD<sup>4</sup>; David Chen, MD<sup>5</sup>; Ray Lee, MD<sup>6</sup>; and Lawrence C. Vogel, MD<sup>1,2,7</sup>

<sup>1</sup>Marquette University, Milwaukee, WI; <sup>2</sup>Shriners Hospitals for Children, Chicago, IL; <sup>3</sup>American Academy of Pediatrics, Elk Grove, IL; <sup>4</sup>Hines Veteran Administration, Hines, IL; <sup>5</sup>Rehabilitation Institute of Chicago, Chicago, IL; <sup>6</sup>Schwab Rehabilitation Hospital, Chicago, IL; <sup>7</sup>Rush University, Chicago, IL.

**Objective:** Enhance our understanding of the caregiver experience by exploring caregiver quality of life (QOL) in the context of caring for adults with spinal cord injury (SCI).

**Design/Method:** The current study combined the strength of standardized quantitative measures of caregiver burden, QOL, and social support with in-depth interviewing about the caregiving relationship and caregiver's role, preparation and support for caregiving, QOL and unmet needs.

**Results:** Eight dyads were enrolled (8 adults with SCI and their 8 caregivers). Adults with SCI were injured when 17-18 years old and had a current mean age of 36.41 years old (SD=2.87, Range=33-41); 75% had tetraplegia. Caregivers were an average of 46.61 years old (SD=13.09, Range=34-65), largely Caucasian (75%), female (75%), high school educated or higher (75%), and were a spouse or significant other (62.5%) or parent (37.5%) to the adult with SCI. Overall, caregivers appeared healthy and satisfied in their roles. However, quantitative measures indicated that five caregivers (62.5%) appeared to have "red flags" or challenges related to at least one area of concern (QOL, amount of leisure time, physical health, mental health, or social support). Those flagged with such concerns had significantly higher caregiver burden scores than those without red flags (Independent Samples Mann-Whitney U Test,  $p < 0.05$ ). In addition, all caregivers qualitatively shared a variety of unmet needs related to physical and emotional stamina, self-care and socialization. For instance, caregivers reported feeling emotionally and physically exhausted as a result of caregiving on top of their regular work schedule and other family responsibilities. They also reported restricted social lives due to lack of time, accessibility, and resources.

**Conclusion:** These data suggest the need to raise awareness of the importance of caregiver QOL and launch initiatives to bolster caregiver physical and emotional health including self-care and connections with others.

**Support:** Department of Defense (Grant #SC130279)

## Appendix B

### Abstract

**Title:** Burden among caregivers of adults with spinal cord injury

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**Design/Method:** Cross-sectional mixed methods (qualitative and quantitative) study.

**Participants and Setting:** Twenty dyads were enrolled from four rehabilitation hospitals in or around one large urban area (20 adults with SCI; 20 caregivers; three adults with SCI were veterans (15%)). Adults with SCI were injured at an average age of 21 years (Range 17-37), were currently between 26-53 years of age (M=37.12 years, SD=6.47); 75% had tetraplegia; 60% were injured in transportation accidents. Caregivers were an average of 49.23 years old (SD=16.35, Range=22-77); were mostly Caucasian (55%), female (75%), high school educated or higher (80%); and were a spouse or significant other (40%), parent (45%), sibling (10%), or other relative (5%) to the adult with SCI.

**Materials/Methods:** The current study combined the strength of standardized quantitative measures of caregiver burden, QOL, and social support with in-depth interviewing about the caregiving relationship and caregiver's role, preparation and support for caregiving, QOL and unmet needs.

**Results:** Overall, caregivers appeared healthy and satisfied in their roles. However, quantitative measures indicated that ten caregivers (55%) appeared to have "red flags" or challenges related to at least one area of concern (amount of leisure time, physical health, mental health, or social support) and such flags were related to lower QOL ( $r=-.51$   $p<.05$ ) and higher caregiver burden scores ( $r=.47$   $p<.05$ ). In addition, adults with SCI were more likely to report higher anxiety from dyads with higher caregiver burden scores ( $r=.45$ ,  $p <.05$ ). All caregivers qualitatively shared a variety of unmet needs related to physical and emotional stamina, self-care and socialization.

**Conclusion:** These data suggest the need to raise awareness of the importance of caregiver burden and launch initiatives to bolster caregiver physical and emotional health including self-care and connections with others.

**Support:** Department of Defense (Grant #SC130279)

## Appendix C

### Abstract

**Title:** Burden among caregivers of adults with spinal cord injury

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**Learning Objectives:** Enhance our understanding of the relationships between quality of life (QOL) of caregivers, caregiver burden, and QOL of veterans and other adults living with spinal cord injury (SCI). Explore unmet needs of caregivers. Generate initiatives to bolster caregiver physical and emotional health including self-care and connections with others.

**Design/Method:** Cross-sectional mixed-methods (qualitative and quantitative) study.

**Participants and Setting:** Twenty-two caregiver-care recipient dyads were enrolled from four rehabilitation hospitals in or around Chicago, IL (5 of the 22 adults with SCI were veterans, 23%). Adults with SCI were injured at an average age of 21 years (Range 17-37, SD=4.99), were currently between 26-53 years of age (M=37.11 years, SD=6.16); 77% had tetraplegia; 59% were injured in vehicular crashes. Caregivers were an average of 50 years old (SD=15.83, Range=22-77); were mostly Caucasian (59%), female (77%), high school educated or higher (82%); and were a spouse or significant other (36%), parent (50%), sibling (9%), or other relative (5%) to the adult with SCI.

**Materials/Methods:** The current study combined the strength of standardized quantitative measures of caregiver burden, QOL, leisure time satisfaction, physical health and mental health, and social support with in-depth interviewing about the caregiving relationship and caregiver's role, preparation and support for caregiving, QOL and unmet needs.

**Results:** Overall, caregivers appeared healthy and satisfied in their roles. However, quantitative measures indicated that twelve caregivers (55%; caregivers of veterans (n=3), caregivers of civilians (n=9)) appeared to have "red flags" or challenges related to at least one area of concern (QOL, amount of leisure time, physical health, mental health, or social support). Overall, such flags were related to higher caregiver burden scores (Mann Whitney U Test  $p < .01$ ). Although sample sizes are very small, when exploring subgroups, the relationship between red flags and caregiver burden was maintained for civilian (n=17) but not veteran (n=5) dyads. Qualitatively both groups of caregivers shared a variety of unmet needs related to their physical and emotional stamina, and the need for better self-care and social integration. However, veteran dyads appeared to be more likely to report receiving compensation for their primary caregiver and/or additional caregiving support from patient care assistants (Spearman's rho,  $p < .05$ ).

**Conclusion:** These data suggest the need to raise awareness of the importance of caregiver burden and launch initiatives to bolster caregiver QOL. Services such as those offered under the Veterans Health Administration Directive 1176 provide possible models for how to compensate caregivers and fund respite and supplemental caregiving.

**Support:** Department of Defense (Grant #SC130279)

## Appendix D

**Title:** Burden among caregivers of adults with spinal cord injury

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**Introduction:** A better understanding of the relationships between caregiver's quality of life (QOL) and caregiver burden and QOL of adults with spinal cord injury (SCI) will help improve outcomes of adults with SCI.

**Methods:** Cross-sectional mixed methods (qualitative and quantitative) study of 22 dyads from four USA rehabilitation hospitals. Average age of injury was 21 years (17-37), current age between 26-53 years of age (M=37.11); 77% had tetraplegia; 59% were injured in transportation incidents. Caregivers were an average of 50 years old (22-77); were mostly Caucasian (59%), female (77%), high school educated or higher (82%); and were a spouse or significant other (36%), parent (50%), sibling (9%), or other relative (5%) to the adult with SCI.

**Results:** Overall, caregivers appeared healthy and satisfied in their roles. However, quantitative measures indicated that twelve caregivers (55%) appeared to have challenges related to at least one area of concern (QOL, amount of leisure time, physical health, mental health, or social support) and were related to higher caregiver burden scores (Mann Whitney U Test  $p < .01$ ). Qualitatively, caregivers shared a variety of unmet needs related to physical and emotional stamina, a need for better self-care and social integration.

**Conclusion:** These data suggest the need to raise awareness of the importance of caregiver burden and launch initiatives to bolster caregiver quality of life, such as compensating caregivers and supporting respite and supplemental caregiving initiatives.

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