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

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13. SUPPLEMENTARY NOTES

14. ABSTRACT 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 third year of funding, we have made significant progress on attaining project goals, including enrolling 32 additional participants in the study. This brought our overall total to 105 participants; of these, 92 are active participants. We closed recruitment on March 31, 2017. Also in the past year, we secured all relevant continuing institutional approvals, expanded the review of the relevant literature and existing programs and services for caregivers, and conducted follow-up interviews with 44.8% of participants. We presented early findings at two conferences this year. In our preliminary analysis of 41 dyads, we found that, on average, caregivers reported low burden. They also were moderately satisfied with their leisure time, fell within normal range for depression and anxiety, and were within normal range for physical health complaints and social problem solving skills. We found a bivariate relationship between burden and these six variables; all were found to be significantly related to burden in expected directions. Multiple regression analysis showed that leisure time satisfaction and social problem solving skills together significantly predicted and accounted for 57% of the variance in caregiver burden. In analysis of the qualitative data, we saw themes emerge around successful coping strategies, effective problem solving skills, self-efficacy, and self-care. We considered these to be strengths and signs of resilience. We are continuing our mixed methods analyses to identify patterns of strengths across the caregivers. It appears that problem solving skills and social support are two variables that are driving distinct patterns.

15. SUBJECT TERMS
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

The goals and tasks referenced here are based on the revised Statement of Work that we submitted with our EWOF request to extend the study by 12 months. We revised the SOW to add months 37-48 and reference the revised SOW here in documenting our progress.

For Year 3, we articulated five major tasks, with associated sub-tasks for each.

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 3: Collect qualitative and quantitative data; **Ongoing**
- Recruit 48 individuals with SCI and their 48 caregivers who meet criteria for participation; **Progress: 109% complete (105/96)**
- Conduct initial interviews with 48 caregivers and their 48 family members with SCI; **Progress: 99% complete (95/96)**

Conduct follow-up interviews with 48 caregivers and their family members with SCI, 15 months after their initial interview; **Ongoing: 44.8% complete (43/96). We are submitting a minor protocol amendment for approval to receive feedback from participants on potential intervention components during the brief follow up/member checking interviews. This will be done in lieu of focus groups as timelines shifted (with permission from funder) due to recruitment challenges.**

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; **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 ongoing**
- Analyze quantitative data; **Progress ongoing**
- Conduct investigator-triangulation; **Progress ongoing**
- Hold annual Advisory Board meeting; **Postponed**

Major Task 5: Disseminate study findings to appropriate audiences

- Submit abstracts highlighting findings to SCI-related meetings (a minimum of two abstracts during Year 3); **Progress: 100%**
- Submit scientific manuscripts highlighting findings to SCI-related peer-reviewed journal; **Progress postponed**

Major Task 6: Suggest implications for interventions; **Progress ongoing**

- Generate ideas and strategies for intervention with Advisory Board members and participants; **Progress ongoing**

Accomplishments on Goals

We accomplished the following in Year 3 (months 25-36) 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. We are in the process of submitting amendments to all IRBs and HRPO to refine data collection during follow up interview to gather feedback on potential intervention components.

Institution	IRB Protocol Approval date	Continuing Review Approval dates	Amendment Approval dates	HRPO Approval	HRPO Continuing Review Approval dates	HRPO Amendment Approval dates
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	3/3/2017			3/15/2017	
Marquette University	01/28/2015	01/15/2016, 1/5/2017	09/25/2015	02/12/2015	2/18/2016, 1/25/2017	
Hines VA	04/27/2015	06/20/2016, 4/3/2017	02/11/2016	06/23/2015	08/31/2016, 5/12/2017	
Northwestern University/Shirley Ryan AbilityLab	03/16/2015	02/22/2016, 2/13/2017	02/22/2016	04/03/2015	5/16/2016, 2/16/2017	
Mt. Sinai Hospital/Schwab Rehabilitation Hospital	12/11/2014	12/10/2015, 12/28/2016	03/04/2016	02/28/2015	3/15/2016, 12/28/2016	

Major Task 2: Coordinate study staff for participant recruitment
Completed in Year 2

Major Task 3: Collect qualitative and quantitative data
We closed recruitment on March 31, 2017, with a total of 105 participants. This includes 32 participants from Shriners Hospitals for Children, 37 from Hines VA hospital, 22 from the Rehabilitation Institute of Chicago (now called the Shirley Ryan AbilityLab), and 14 from Schwab Rehabilitation Hospital.

Our goal was to maximize diversity in the sample and to have veterans represent one-third of the sample, and we achieved both of these—56% of the caregivers are ethnic minorities and 32% of the individuals with SCI are veterans.

In Year 3, we conducted 30 initial (primary) interviews with participants as well as 43 follow-up member checking interviews with participants. In Year 4, we will continue contacting participants to complete as many of remainder of follow up interviews and - pending approval of amendment - to collect their feedback on potential intervention components.

Major Task 4: Analyze data
All initial interviews have been coded in NVivo (100%), and case summaries for each dyad are updated with follow-up interview data on an ongoing basis. We created a detailed summary document with pertinent qualitative and quantitative data for each dyad to aid in analysis. Our preliminary findings are presented below.

In Year 4, in June 2018, we will hold a third Advisory Board meeting to share our findings and solicit feedback and generate ideas and strategies for intervention components to improve caregiver adjustment.

Major Task 5: Disseminate study findings to appropriate audiences
During Year 3, we presented initial findings at three SCI-related scientific meetings. Abstracts for each meeting are attached at the end of this report.

Abstract A – Ryerson Espino S, Kelly EH, Akinlose T, Harris G, Ghaffari A, Richardson M, Chen, D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. Poster at the 55th Annual International Spinal Cord Society Meeting (ISCoS). Vienna, Austria. 2016.

Abstract B – Kelly EH, Ryerson Espino S, Russell H. Caregiving Across the Lifespan of Pediatric SCI. Presentation at the 2017 Howard H. Steel Pre-course at the Annual Meeting of the American Spinal Injury Association (ASIA); Albuquerque, NM; 2017.

Abstract C – Ryerson Espino S, O'Rourke K, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Resilience among adults living with SCI and their caregivers. Presentation at Academy of Spinal Cord Injury Professionals Annual Meeting (ASCIP); Denver, CO. 2017.

In Year 4, we will present a poster at ISCoS and will submit abstracts to the ASIA and ASCIP meetings.

Also in Year 4, we will develop the following two manuscripts to submit to peer-reviewed journals and one new grant proposal to support the development of an intervention based on findings:

Journal Manuscript 1: An overarching paper examining the different clusters of caregivers (based on problem-solving skills and social support) and caregiver outcomes (mental/physical health, quality of life, and burden) and mental/physical health outcomes for the individuals with SCI.

Journal Manuscript 2: Unmet needs of caregivers of adults with SCI as seen through a framework of the caregivers' primary and secondary stressors.

Grant Proposal for the FY17 Department of Defense Spinal Cord Injury Research Program (SCIRP) Qualitative Research Award: Family Support and Skill-Building for Veterans and Civilians with SCI and Their Family Caregivers

Major Task 6: Suggest implications for interventions
During the 2016 advisory board meeting, members recommended that future interventions should emphasize skills, health promotion, knowledge development, and support to foster linkages with existing supports and services. Ongoing mixed methods analysis and results highlight the importance of social support and problem solving skills. Acting on both, in August we submitted a pre-application for the FY17 Department of Defense Spinal Cord Injury Research Program (SCIRP) Qualitative Research Award. We were invited to submit a full proposal and are currently in the process of writing it. We will propose to support the further development and validation of a family wellness intervention wherein caregivers can gain additional social support to reduce unmet needs and gain additional social problem solving skills. In Year 4, we will continue to build on recommended core intervention components based on our continued analysis.

Preliminary Study Findings

Unmet needs

Through qualitative interviewing we have identified a number of persistent unmet needs and an underutilization of community and Veteran resources. Unmet needs include financial challenges for home remodeling, accessible vehicles, and care assistants; dearth of dependable supplemental care attendants; a lack of information about caregiving strategies, support programs and self-care; and a lack of engagement with mental health professionals to support family coping with disability and interpersonal dynamics. As our participants have been living with SCI for an average of 17 years, we view these unmet needs as persistent.

Promise of Leisure and Problem Solving for Reducing Burden Among Caregivers

We presented an analysis of factors contributing to reduced burden at ASCIP 2017 for 41 active dyads.

As summarized in Table 1 below, on average, caregivers reported low burden, were moderately satisfied with their leisure time, fell within normal range for depression and anxiety, and also were within normal range for physical health complaints and social problem solving skills. However, variability was noted across all measures.

Table 1. Indicators

Variables	Descriptive Statistics Mean (SD, Range)	Pearson Correlation (bivariate relationship between burden and other variables)
Caregiver Burden	1.02 (.82, 0-3.75)	- - - -
Leisure Time Satisfaction	6.93 (2.89, 1-12)	-.69**
HADS Depression	5.15 (4.35, 0-16)	.72**
HADS Anxiety	6.84 (4.96, 0-18)	.56**
PILL (physical complaints)	44.71 (34.05, 2-169)	.57**
SPSI Total Raw Score (social problem solving)	14.17 (2.18, 6.00-17.40)	-.66**

In looking at possible relationships between caregiver burden and the other five variables in Table 1, we found these variables were significantly related to burden in expected directions. Higher scores in leisure time satisfaction and social problem solving were related to lower burden scores. Higher depression, anxiety, and physical complaints were related to higher burden scores.

No caregiver demographic characteristics were bivariately related to caregiver burden.

Next, we used multiple regression to explore multivariate relationships between these variables and burden, shown in Table 2 below. Initially, we looked at leisure time satisfaction, the HADS anxiety subscale, the PILL, and the social problem solving inventory as a group. They significantly predicted burden, but only two variables—leisure time satisfaction and social problem solving—uniquely predicted burden.

We reran the analysis with a trimmed model excluding the non-significant variables, anxiety, and the PILL. Leisure time satisfaction and social problem solving skills together significantly predicted and accounted for 57% of the variance in caregiver burden and both remained significant unique predictors. Lower leisure time satisfaction and social problem solving skills predicted higher burden, or, conversely, those caregivers reporting higher leisure time satisfaction and more effective social problem solving skills reported lower burden (see Table 2).

Table 2. Regression Predicting Burden

Variable	*B*	*SE B*	*β*
Leisure Time Satisfaction	-.16	.05	-.41**
Social Problem Solving	-.14	.03	-.48**

Adjusted R^2 = .57
F(2, 38) = 27.88**
** p < .00

Problem solving and social support patterns among family caregivers of adults with SCI

We continue to deepen the mixed methods analysis; specifically, patterns in the qualitative data led to an additional mixed methods study we are currently preparing for dissemination.

Through analysis of qualitative narratives, we have identified that satisfaction with social support and strong social problem solving skills are two areas that distinguish resilient families from those struggling to cope with the chronicity of health concerns, caregiving demands, and persistent unmet needs among families with SCI. Qualitative themes led us to explore social support and problem solving quantitatively using cluster analysis and MANOVA. Three profiles emerged distinguishing caregivers in terms of social support and problem solving and also caregiver quality of life and wellbeing.

- Profile 1 caregivers report higher social support, positive problem solving orientations, and rational problem solving compared to the caregivers in the other two profiles. These profile 1 caregivers reported higher satisfaction with leisure and social integration and fewer concerns related to depression (vs. profiles 2 and 3) as well as higher satisfaction with quality of life and lower physical complaints (vs. profile 2).
- Profile 2 caregivers reported higher negative problem solving orientations, impulsive/careless and avoidant problem solving strategies (vs. profiles 1 and 3), lower social support (vs. profile 1) and reported more burden, depression, and anxiety (vs. profiles 1 and 3), and more physical health complaints (vs. profile 1).
- Profile 3 caregivers reported lower social support and lower positive problem solving orientation (vs. profile 1) and lower rational problem solving (vs. profiles 1 and 2). Profile 3 caregivers appeared to fare slightly better than those in profile 2 with fewer reported concerns relating to depression.

Qualitative data shed additional light on differences between profiles in terms of poverty, adjustment to disability, family support, and coping. Profile 2 caregivers experienced greater poverty and challenges with disability adjustment. Profile 1 caregivers most commonly talked about the importance of family support and active coping. Taken together, effective problem solving and strong social support may be protective factors offsetting stressors associated with caregiving and bolstering caregiver well-being. These findings are additive to the research on the power of effective problem solving. Engaging caregivers in interventions designed to increase problem solving and social support may hold promise for the prevention of physical and mental health distress in caregivers.

Opportunities for Training and Professional Development

Drs. Ryerson Espino, Kelly, and Vogel attended the American Spinal Injury Association Scientific Meeting. Dr. Vogel attended the annual International Spinal Cord Society meeting. Ms. O’Rourke attended the Academy of Spinal Cord Injury Professionals Educational Conference.

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. We have disseminated early findings at a total of six SCI-related scientific meetings in Years 2 and 3. We have begun work on two manuscripts for submission to peer-reviewed journals in Year 4.

Tasks During Next Reporting Period to Accomplish Goals

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

1) 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.
2) Continue dissemination activities.
    In Q13, we will present a poster at the ISCoS meeting; submit an abstract to the 2018 ASIA meeting; and submit an invited proposal for the FY17 Department of Defense Spinal Cord Injury Research Program (SCIRP) Qualitative Research Award

1. 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 at www.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. We expect our project findings to have broad relevance for a variety of audiences including scientists, practitioners, and consumers, and we will use multiple media forms to disseminate results and recommendations for intervention.

2. CHANGES/PROBLEMS

Nothing to report.

3. PRODUCTS

Nothing to report.

4. 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: Shirley Ryan AbilityLab
Location: 355 East Erie Street
Chicago, IL 60611
Contribution: The AbilityLab 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.

5. SPECIAL REPORTING REQUIREMENTS

None Required.

6. APPENDICES

Abstracts from Three Presentations in Year 3:

Appendix A Burden among caregivers of adults with spinal cord injury

Appendix B Caregiving across the lifespan of pediatric spinal cord injury

Appendix C Resilience among adults living with SCI and their caregivers

Appendix A

ISCoS 2016
Abstract

Title: Burden among caregivers of adults with spinal cord injury

Titilope Akinlose, MPH[1]; Susan Ryerson Espino, PhD[1,2]; Erin H. Kelly, PhD[1,2,3]; Azadeh Ghaffari, PhD[4]; Gerald Harris, PhD[1,2]; Michael Richardson, MD[4]; David Chen, MD[5]; Ray Lee, MD[6]; and Lawrence C. Vogel, MD[1, 2, 7]
[1]Marquette University, Milwaukee, WI; [2] Shriners Hospitals for Children, Chicago, IL; [3]American Academy of Pediatrics, Elk Grove Village, IL; [4]Hines Veteran Administration, Hines, IL; [5]Rehabilitation Institute of Chicago, Chicago, IL; [6]Schwab Rehabilitation Hospital, Chicago, IL; [7]Rush University, Chicago, IL.

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.
Support: Department of Defense (Grant #SC130279)

Appendix B

ASIA 2017
Pediatric Steel Pre-Course
Instructional Course Proposal

Title: Caregiving Across the Lifespan of Pediatric Spinal Cord Injury

Type: Instructional Course

Educational Objectives:
At the conclusion of this course, participants will be able to:

1. Articulate why it is important to assess and attend to caregiver wellbeing.
2. Describe psychosocial and medical impacts that are associated with unmet caregiver needs.
3. Summarize at least 3 points of intervention development within their practice settings to improve support for caregivers.

Synopsis:
The purpose of this course is to highlight the importance of caregiving across the lifespan in the context of pediatric spinal cord injury (SCI), and to discuss intervention possibilities to support caregivers and families. Research has identified relationships between the well-being of parental caregivers and their children with SCI. The course will include three sections and discussion. First, a brief literature overview of the importance of caregiving will be presented, including a review of research on caregiving and pediatric SCI (Dr. Russell). Second, we will present evaluation findings from a pilot intervention developed to meet the needs of caregivers of youth with SCI (Dr. Kelly). Third, we will highlight qualitative data on unmet caregiver needs across the lifespan, including focus groups with caregivers of youth with SCI, and a qualitative study of adults with pediatric-onset SCI and their caregivers (Dr. Ryerson Espino). Data across these studies highlight the importance of caregiver wellbeing and the ongoing need to launch additional initiatives to bolster caregiver physical and emotional health. The course will end with questions and a discussion around intervention development to support caregivers over time (Dr. Zebracki).

Course Chair:
Erin Kelly, PhD
Senior Research Associate
American Academy of Pediatrics, Elk Grove Village, IL, USA
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Shriners Hospitals for Children
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The Department of Defense

Appendix C

ASCIP 2017
Abstract

Title: Resilience among adults living with SCI and their caregivers

Susan Ryerson Espino, PhD[1,2]; Kerry O'Rourke, MPH[1]**;** Erin H. Kelly, PhD[2,3]; Azadeh Ghaffari, PhD[4]; Gerald Harris, PhD[1,2]; Michael Richardson, MD[4]; David Chen, MD[5]; Ray Lee, MD[6]; and Lawrence C. Vogel, MD[1, 2, 7]
[1]Marquette University, Milwaukee, WI; [2] Shriners Hospitals for Children, Chicago, IL; [3]American Academy of Pediatrics, Elk Grove Village, IL; [4]Hines Veteran Administration, Hines, IL; [5]Rehabilitation Institute of Chicago, Chicago, IL; [6]Schwab Rehabilitation Hospital, Chicago, IL; [7]Rush University, Chicago, IL.

Background: Studies addressing caregivers commonly emphasize negative outcomes. This study explored promising facilitators of well-being for caregivers of civilians and veterans with spinal cord injury (SCI).
Design: Longitudinal mixed methods study of 32 civilian and veteran dyads from three USA rehabilitation hospitals and one Veterans Administration hospital.
Methods: Members of dyads participated in qualitative interviews guided by a semi-structured protocol. Quantitative data included standardized surveys on caregiver burden, problem solving, and satisfaction with leisure time, along with surveys on mental health and well-being for both members of the dyad. Follow-up qualitative interviews were conducted approximately 15 months later to clarify and deepen understandings of well-being. Participants with SCI were injured on average at age 22 years (17-37) and interviewed on average at 37 years (26-53); 71% had tetraplegia; 52% were injured in transportation incidents; 68% were male; and 23% were veterans. Caregivers were an average of 50 years old (22-77); mostly female (81%); ethnic minorities (52%); high school educated or higher (87%); and were a parent (48%), spouse/significant other (42%), sibling (7%), or other relative (3%) to the adult with SCI.
Results: Qualitative narratives spoke to the important facilitators of dyad well-being including family cooperation, positive interpersonal relations, self-care, and collaboration with paid non-family caregivers and personal care assistants. In quantitative data, caregivers demonstrating fewer challenges with problem solving and greater leisure time satisfaction experienced lower burden ($p<0.01$); together these accounted for 65% of the variance in caregiver burden. Importantly, caregiver burden and challenges with problem solving were associated with mental distress among civilians (not veterans) with SCI.
Conclusion: Findings suggest the importance of caregiver self-care, leisure time satisfaction, skills development (including problem solving and interpersonal communication), and collaboration with other family members and personal care assistants. For instance, problem solving training aiming to reduce the tendency to view problems as insurmountable and reduce reliance on strategies such as avoidance and applying hurried/incomplete solutions has promise to contribute to the well-being of caregivers and adults living with SCI.
Support: Department of Defense (Grant #SC130279)

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

SC130279 and Y3Q2

W81XWH-14-1-0621

PI: Lawrence C. Vogel, MD **Org:** Marquette University/Shriners Hospital for Children Chicago **Award Amount:** $496,000

Study/Product Aim(s)

- To study how caring for someone else impacts all facets of the caregiver’s life and how this changes over time.
- To study the specific experiences of caregivers of veterans and civilians with SCI across a variety of socioeconomic groups.
- To examine how the health of individuals with SCI relates to the health of their caregivers and how this relationship changes over time.
- To propose a set of key intervention components to improve caregiver adjustment.

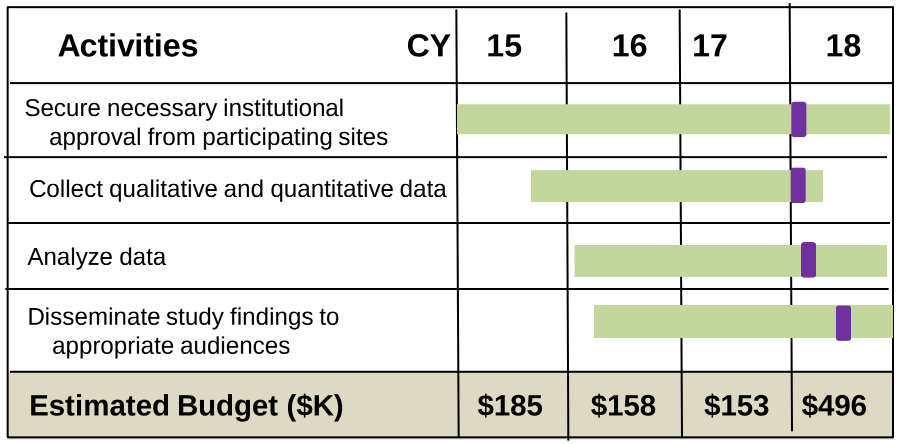
Approach

This study takes a mixed-methods approach. We are collecting semi-structured interviews (qualitative) and survey (quantitative) data from both caregivers and the individuals with SCI.

Variables	Descriptive Statistics Mean (SD, Range)	Pearson Correlation (bivariate relationship between burden and other variables)
Caregiver Burden	1.02 (.82, 0-3.75)	- - - -
Leisure Time Satisfaction	6.93 (2.89, 1-12)	-.69**
HADS Depression	5.15 (4.35, 0-16)	.72**
HADS Anxiety	6.84 (4.96, 0-18)	.56**
PILL (physical complaints)	44.71 (34.05, 2-169)	.57**
SPSI Total Raw Score (social problem solving)	14.17 (2.18, 6.00-17.40)	-.66**

These 5 variables were significantly related to burden in expected directions. Higher scores in leisure time satisfaction and social problem solving were related to lower burden scores. Higher depression, anxiety, and physical complaints were related to higher burden scores.

Timeline and Cost



Activities CY	**15**	**16**	**17**	**18**
Secure necessary institutional approval from participating sites	🟩	🟩	🟩	🟩
Collect qualitative and quantitative data	🟩	🟩	🟩	🟩
Analyze data		🟩	🟩	🟩
Disseminate study findings to appropriate audiences		🟩	🟩	🟩
Estimated Budget ($K)	**$185**	**$158**	**$153**	**$496**

Updated: October 25, 2017

Goals/Milestones (all in progress)

CY15 Goal – Securing institutional approval

☑ Coordinating sites for annual IRB and HRPO submissions

CY16 Goals – Collecting qualitative and quantitative data

☑ Recruit participants from 4 sites

☑ Conduct 2 interviews with each caregiver and person w/ SCI

☑ Disseminate study findings to appropriate audiences

CY17 Goal – Suggest implications for interventions

☑ Generate list of intervention components

Comments/Challenges/Issues/Concerns

- Significant IRB-related delays impacted recruitment and thus lower than projected expenses relating to transcription and stipends for participants.
- Initial research coordinator left the program 6/2016. We were able to replace by 9/2016 but this gap led to lower than projected personnel expenses.

Budget Expenditure through 9/29/2017

Projected Expenditure: $496,000

Actual Expenditure: $379,342