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14. ABSTRACT
Among caregivers of adults with spinal cord injury (SCI), understanding factors that contribute to caregiver quality of life (QOL) is critical to providing appropriate support. This concurrent mixed-methods study aimed to understand the experiences of veteran and civilian caregivers of individuals with SCI across a diverse sample from 4 rehabilitation hospitals, including 1 VA hospital. Of the 52 dyads recruited, 39 dyads provided complete data and were included in analysis. Of the 39 caregivers, 80% were female, average age was 49.9 years, average number of years providing care was 11.9, 49% were married to/partners of the adult with SCI, and 56% were from ethnic minority groups. Adults with SCI were most commonly male (72%) with tetraplegia (72%), and half identified as white (51%). Their average age at injury was 22.3 years, current age was 39.1 years, and average injury duration was 18 years. Over a quarter of the sample were veterans (28%). Specific to risk and protective factors, overall, caregivers reported physical and mental health in normal ranges and reported experiencing low burden. Interviews highlighted a number of unmet needs but also the importance of adaptive coping and social support. Interventions aimed at bolstering effective caregiver problem solving skills and enhancing social support as well as satisfaction with social support may foster caregiver well-being.

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:** Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.

   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. Beyond the impacts of caregiving on caregiver emotional health, we know little. The current study proposed to advance the body of knowledge around caregiving and SCI by interviewing caregiver/care-recipient dyads holistically to explore the caregiving experience. Further, caregivers were 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 collected semi-structured (qualitative) and survey (quantitative) data from both caregivers and the individuals with SCI for whom they care. Caregivers were 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 were asked about their own quality of life and caregiving relationships. Taken together, the current study's goal was to fill gaps in the 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:** Provide a brief list of keywords (limit to 20 words).
   Caregivers, adults with spinal cord injuries, quality of life, mixed methods, dyads, veterans, civilians, ecological intervention development

3. **ACCOMPLISHMENTS:** The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer whenever there are significant changes in the project or its direction.

   What were the major goals of the project?
   List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project, identify these dates and show actual completion dates or the percentage of completion.

   Major Task 1: Secure necessary institutional approval from participating sites
   Subtask 1: Secure IRB and HRPO approval from the five participating sites
   Milestone Achieved: Completion 100% in Year 4. Local IRB and HRPO approval from Shriners-Chicago, Edward Hines Jr. VA Hospital, Shirley Ryan AbilityLab, Schwab Rehabilitation Hospital, and the USAMRMC HRPO. The study has been closed at all sites except at the Hines VA where the closure report was submitted on Dec. 6, 2018. (Tables 1 and 2.)

Table 1. Local IRB approval dates.

Institution	IRB Protocol Approval Date	1st Year Continuing Review Approval Date	2nd Year Continuing Review Approval Date	3rd Year Continuing Review Approval Date	Study Closure
Rush/Shriners	12/10/2014	11/2/2015	NA	NA	NA
WIRB/Shriners*	3/25/2016	3/3/2017	2/27/2018	NA	10/24/2018
Hines VA	6/8/2015	6/20/2016**	4/10/2017	4/11/2018	Submitted 12/06/2018
Marquette University	1/28/2015	1/15/2016	1/5/2017	1/10/2018	11/20/2018
Mt. Sinai Hospital/Schwab Rehabilitation Hospital	12/11/2014	12/10/2015	12/21/2016	12/7/2017	11/08/2018
Northwestern University/Shirley Ryan AbilityLab	3/16/2015	2/22/2016	2/13/2017	Study closed 2/13/2018	2/13/2018

*Shriners moved from the IRB at Rush to the IRB at WIRB
**Permission to restart study

Table 2. HRPO approval dates.

Institution	Initial HRPO Approval Date	1st Year HRPO Continuing Review Approval Date	2nd Year HRPO Continuing Review Approval Date	3rd Year HRPO Continuing Review Approval Date	Study Closure Submitted
Rush/Shriners	2/12/2015	11/13/2015	NA	NA	NA
WIRB/Shriners*	Submitted 11/8/2016	3/15/2017	3/5/2018	NA	11/14/2018
Hines VA	6/23/2015	08/31/2016	5/12/2017	4/18/2018	Expected Dec. 2018
Marquette University	2/12/2015	2/18/2016	1/25/2017	1/22/2018	11/20/2018
Mt. Sinai Hospital/Schwab Rehabilitation Hospital	2/28/2015	3/15/2016	12/28/2017	1/4/2018	12/04/2018
Northwestern University/Shirley Ryan AbilityLab	4/3/2015	5/16/2016	2/16/2017	Study closed 2/13/2018	2/16/2018

Major Task 2: Coordinate study staff for participant recruitment
Subtask 1: Hiring and training of study staff
Milestone Achieved: Completion 100% in Year 2. Research staff hired and trained.
The initial research coordinator left in May 2016; a new coordinator was hired over the summer but she left after 3 days due to a family health emergency, which re-started the hiring process. A new research coordinator, Kerry O’Rourke, was hired and began work on Sept. 1, 2016, and remained with the study through its completion

Major Task 3: Collect qualitative and quantitative data
Subtask 1: Recruit participants

Milestone Achieved: Completion 108% in Year 3. 52 dyads were recruited and consented, surpassing our minimum goal of 48 dyads.
Subtask 2: Conduct interviews with 48 caregivers and their 48 family members with SCI.
Milestone Achieved: Completion 99% in Year 3. Initial interviews were completed with 47 caregivers and 48 adults with SCI; 39 dyads completed all data collection activities (Table 3.)

Table 3. Enrollment.

Institution	Dyads referred into study	Dyads screened as eligible	Dyads enrolled (consented)		Dyads completing all data collection activities	
			# individuals	# dyads	# individuals	# dyads
Hines VA	27	26	37	18.5	22	11
Shirley Ryan	17	15	22	11	18	9
Schwab	17	15	14	7	10	5
Shriners	~300	26	32	16	28	14
Total	361	81	105	52.5	78	39

Major Task 4: Analyze data
Subtask 1: Analyze data
Milestone Achieved: Completion 100% in Year 4.
Subtask 2: Ensure credibility of data, conduct investigator triangulation, hold annual Advisory Board meetings.
Milestone Achieved: Completion 100% in Year 4. The Co-PI and research coordinator collaboratively examined memos and transcripts repeatedly throughout the research process to assess, identify and refine themes across dyads and reach consensus. Three advisory meetings were held with the latter two (06/13/2017 and 07/17/2018) focused on sharing and interpreting data (early findings and final results respectively).

Major Task 5: Disseminate study findings to appropriate audiences
Subtask 1: Present findings to scientific community
Milestone Achieved: Completion 100% in Year 4. From 2016 to 2018, we gave 6 podium presentations and 3 poster sessions at scientific meetings. One manuscript has been submitted to a scientific journal with the second one expected to be submitted in December 2018.

In addition, a Caregiver Resource Guide will be mailed to participants with a thank you letter for participating in the study, and an article aimed at a lay audience was written for a Shriners' SCI newsletter, which is circulated in the community.

Major Task 6: Suggest implications for interventions
Subtask 1: Generate list of intervention components.
Milestone Achieved: 100% in Year 4.
Over the course of this project we have gleaned learnings from the literature, a community scan of programs and services, our advisory board meetings, and research participants. We believe these learnings can inform practice and intervention development.

Results from the current study have several implications for intervention and clinical practice. Interventions aimed at bolstering effective caregiver problem-solving skills, reducing negativity and ambivalence, and enhancing social support (peer, instrumental, informational) as well as enhancing family wellness and leisure time satisfaction may foster caregiver well-being and reduce burden and health concerns. While support and resources are needed for all caregivers, some may be in need of additional supports and should be identified through screening mechanisms. Additional research with larger samples should continue to evaluate the development, implementation, and outcomes of interventions for caregivers to minimize risks and maximize protective factors.

Service delivery system reinforcements and interventions could include making available in multiple formats digests of resources particularly relative to home and vehicle modifications, local SCI providers, caregiver compensation programs, caregiver training, peer support groups for caregivers and adults with SCI, as well as quality and flexible supplemental/respite care. There also appears to be a need to advocate for more of these resources for caregivers. Interventions could also emphasize developing effective problem solving and coping mechanisms within the context of the many challenges families with SCI face including those related to economics, maximizing physical and mental health during taxing life circumstances, and maintaining important social connections beyond the caregiving relationship.

Lastly, additional research should be conducted with larger similarly diverse samples (ethnic diversity and civilian/veteran diversity) and more nuanced data collection tools and processes to better understand the nature of supplemental care (e.g., frequency, costs, referral and funding mechanisms) as well as related care nuances such as caregiver compensation, hours, and tasks as well as lost wages. Additional research among ethnic minority caregivers of adults with tetraplegia could further explore the nature of rewards, challenges, and coping with family caregiving and reception to supplemental, nonfamilial forms of caregiver support. Additional research on notions of illness and help seeking among civilian and veteran families would help better understand the common and unique stressors facing these families.

What was accomplished under these goals?

The research team achieved the study goals as outlined in the protocol, resulting in findings that add to the caregiver literature and can inform intervention development, both for veteran and civilian families.

We worked with 4 participating sites—Edward Hines, Jr., VA Hospital, Schwab Rehabilitation Hospital, Shirley Ryan AbilityLab (formerly Rehabilitation Institute of Chicago), and Shriners Hospitals for Children–Chicago. This involved 6 institutional IRBs—for the 4 sites plus Marquette University and a second IRB for Shriners when Shriners moved from the Rush University IRB to Western IRB in 2016. We filed all site-specific documents with HRPO throughout the grant period. We received IRB approval from all sites during Year 1, Quarter 3. We experienced a 5-week lapse in our continuing review during Year 2 due to internal VA logistics. Permission to restart the study at Hines VA came in Year 2 (Quarter 7). In addition to the IRB requirements, all study personnel fulfilled the VA requirements to be granted Without

Compensation (WOC) appointments, and personnel were required to renew these appointments annually.

At the end of Year 1, there was a change in study leadership. The Principal Investigator, Erin Kelly resigned from her position as PI, and the Co-PI, Lawrence Vogel stepped in as the study's new PI, while Susan Ryerson Espino, the study's qualitative consultant, became the new Co-PI. Erin Kelly stayed on as a Co-Investigator.

Recruitment was challenging. In Year 2, we received approval from all sites to expand the age criteria from 25-44 years of age to 18-65 years of age. We also received approval to recruit participants from community organizations in addition to the 4 hospital sites. As noted in Table 3 above, we recruited a total of 105 individuals, or 52 complete dyads plus 1 caregiver, surpassing our minimum goal of 96 participants, or 48 complete dyads. We completed recruitment in Year 3, Quarter 10. We succeeded in enrolling a diverse sample—56% of caregivers were from ethnic minority groups; 35% of adults with SCI who were enrolled were veterans.

The study originally was designed as a longitudinal study with 2 time points—Time 1 was the first interview and a set of surveys and Time 2 was a second interview and the same set of surveys about 15 months later. Because of the IRB delays and staff changes that delayed finishing recruitment until Year 3, brief member checking interviews replaced the Time 2 interviews and focus groups, with permission from the DOD.

Methodology

This study employed purposive sampling across 4 rehabilitation hospitals in the US, including 1 VA hospital, to maximize socioeconomic and ethnic diversity. Inclusion criteria for the individuals with SCI were 18 to 65 years of age, injury duration of more than 1 year, and age 17 or older at the time of injury. The adults with SCI nominated their primary caregiver for participation, and this person was a family member or friend who had provided physical or emotional support at least weekly for at least 6 months. All participants had to speak English and have the cognitive ability to answer questionnaires and engage in conversation. Excluded from the study were caregivers with a solely financial relationship with the person with SCI. All participants consented to participate; ethical procedures were followed regarding the treatment of human subjects and reporting of all research procedures and findings.

Procedures and Instruments

Semi-structured qualitative interviews, most done by phone and a few done in community settings, were followed by structured standardized surveys and brief member checking phone interviews 15-18 months later. Data collection was centralized at Shriners–Chicago.

In our interviews with caregivers, we asked what a typical day looked like for them. We asked about the specific tasks they perform, what it was like for them when the injury occurred, the relationship dynamic they have with the person with SCI, challenges and rewards they've experienced, and needs they have that are met or unmet. We also asked them about the impact caregiving had on their physical and emotional health, how life has changed since they became a caregiver, and how caregiving impacts other activities they are involved in (such as parenting or a job), and what services or supports have been helpful to them. We collected quantitative data on demographics, QOL, leisure time satisfaction, social support, social integration, social problem-solving skills, burden, depression, and anxiety.

In the interviews with the adult with SCI, we asked about their physical and emotional health, what kind of activities they engage in regularly, what the time of their injury was like for them, about their relationship with their caregiver, and any unmet needs they thought their caregiver had. We collected quantitative data on demographics, SCI Core Measures, CHART, depression, anxiety, and PTSD.

Data Analysis

Descriptive statistics were used to assess how caregivers scored on all standardized measures. Relationships between constructs using Pearson correlation coefficients were also assessed. Multiple regression was used to assess what factors were predictive of QOL. We then integrated the qualitative and quantitative data by creating within- and across- case summaries to highlight descriptive quantitative data as well as key points from qualitative data, including caregiving tasks, unmet needs, and primary themes/highlights within families. Primary themes emerging from the qualitative data involved internal and external resources, namely coping and social support.

Additional quantitative data analyses were then used to facilitate the identification of patterns using social problem solving (a specific kind of coping) and social support scores in order to explore whether distinct profiles of caregivers could be identified and to look for any patterns in well-being. A three-cluster solution was derived to verify differences in problem solving and social support and explore if demographics and well-being varied across profiles of caregivers. Lastly, we returned to the entire mixed methods data set to summarize how coping, social support, well-being, and unmet needs varied by profile. This last step helped us better appreciate variations in coping and social support and how such factors were related to variations in unmet needs and caregiver well-being.

Results

Retained participant characteristics are shown in Table 4. Retained participants are those who completed all data collection activities.

Table 4. Retained participant characteristics.

Characteristic	Caregivers (n=39)	Participants with SCI (n=39)
Current age mean (SD, range)	49.9 years (15.2, 22-81)	39.1 years (8.1, 25-60)
Race	44% (17) white 56% (22) ethnic minority 23% (9) African American 21% (8) Latino 5% (2) Asian 5% (2) Multiracial 3% (1) Middle Eastern	51% (20) white 49% (19) ethnic minority 23% (9) African American 21% (8) Latino 3% (1) Asian 3% (1) Multiracial
Gender	80% (31) female	28% (11) female
Caregiver role	49% (19) partner 41% (16) parent 5% (2) siblings 3% (1) child 3% (1) uncle	
Mean years as a caregiver	11.9 (7.2, 1-30)	
Education	62% (24) at least some college 38% (15) high school	72% (28) at least some college 28% (11) high school or less
Marital status	54% (21) married or in a partnership	51% (20) not married or in a partnership
Compensated for caregiving (Yes)	56% (22)	
Supplemental support (visiting nurse or aide)		62% (24)
Employed	44% (17) outside of home/caregiving situation	26% employed (10) just over half in full-time positions
Poverty		21% (8) living below poverty line 69% (27) living below 200% of poverty line
Public Assistance (Yes)	31% (12)	80% (31)
Age at injury (mean, range)		22.3 years (6.4, 16-43)
Injury duration		18.0 (9.2, 4-38)
Level/nature of injury		72% (28) tetraplegia 62% (21) incomplete
Etiology		49% (19) motor vehicle 18% (7) sports/recreation 15% (6) violence 13% (5) falls 5% (2) medical
Veteran status		28% (11) veterans

The study had 4 specific aims. Here, we present our findings by each aim.

Aim 1. How does being a caregiver impact the caregiver's QOL?

Overall, caregivers reported physical and mental health in normal ranges and reported experiencing low burden. All risk and protective factors were bivariately related in expected directions to QOL. No demographic or injury characteristics were related to QOL. Caregiver burden and satisfaction with social support were the only unique significant predictors of caregiver QOL; lower reports of caregiver burden and more satisfaction with social support were predictive of more favorable perceptions of QOL. Interviews highlighted a number of unmet needs but also the importance of adaptive coping and social support.

Highlights from these themes are outlined below.

- Various unmet needs
    - Economic challenges
    - Unmet physical and mental health needs
    - Social isolation
    - Life activities put on hold
- Social support
    - Multifaceted, multigenerational family support
    - Instrumental support for caregiving, equipment, vehicles
- Adaptive coping
    - Independence striving on the part of adult with SCI
    - Family tenacity, perseverance
    - Caregiver confidence, boundaries, and self-care

Aim 2. How does the health of caregivers relate to the health of their loved ones living with SCI?

Caregiver characteristic	Person with SCI characteristic	Pearson correlation coefficient*
More physical health complaints	Older Longer duration of injury	r=.39 r=.33
Increased depression	Anxiety Urinary incontinence	r=.40 r_{pb}=.41
Greater satisfaction with social support	Younger Paraplegia	r=-.32 r_{pb}=-.32

*All p-values < 0.05.

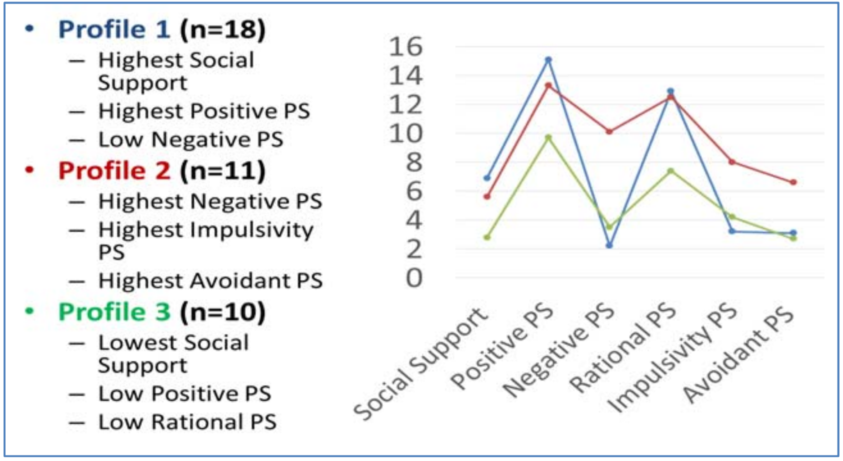
Aim 3. How does the experience of caregiving vary by certain caregiver characteristics?

Three profiles emerged from the cluster analysis and are shown in Fig. 1:

- Profile 1 caregivers were characterized by their moderate satisfaction with social support and effective problem solving (high endorsement of positive orientation and rationale strategies and low endorsements of negative orientation, impulsive/careless and avoidant strategies). Statistically, they reported more satisfaction with social support as well as more positive orientation and rational strategies than those in Profile 3 and less dysfunctional problem-solving orientation and strategies than Profile 2.

- Profile 2, labeled mixed and more negative problem solvers, were caregivers who tended to endorse all problem-solving orientations and strategies but were distinguished statistically from Profile 1 and 3 with statistically higher negative problem-solving orientation as well as impulsive/careless and avoidant strategies. They also reported higher satisfaction with social support that those in Profile 3.
- Profile 3, labeled low endorsers, tended to under-endorse all social problem solving and social support items. They reported statistically less satisfaction with social support and rationale problem solving than caregivers from both of the other profiles and lower positive problem-solving orientation than Profile 1.

Fig. 1. Three caregiver profiles derived from cluster analysis.



PS = problem solving

Then we looked for patterns of well-being that emerged in relation to the 3 profiles. Fig. 2 shows outcomes for leisure time satisfaction, social integration, and QOL; Fig. 3 depression and anxiety; and Fig. 4 physical symptoms and caregiver burden. We were not able to find any relationships between profiles and adults with SCI demographics or well-being.

Fig. 2. Caregiver outcomes by profile for leisure, social integration and QOL.

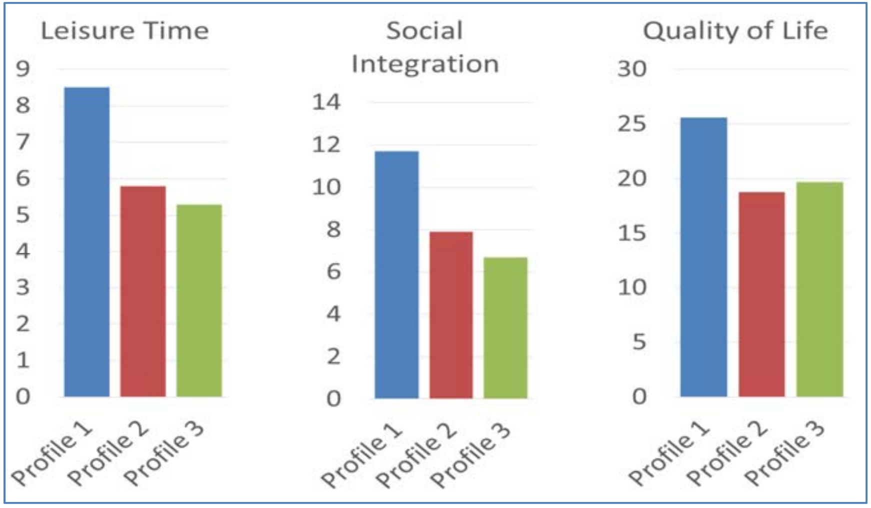


Fig. 3. Caregiver outcomes by profile for depression and anxiety.

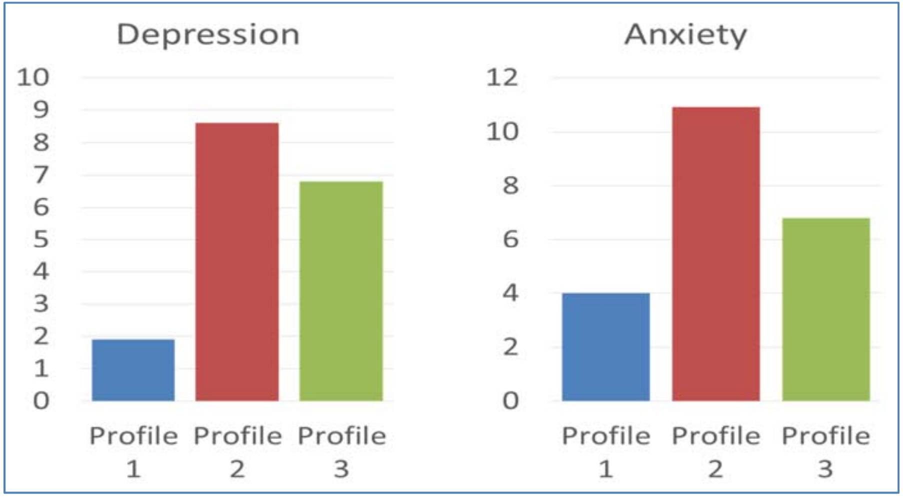
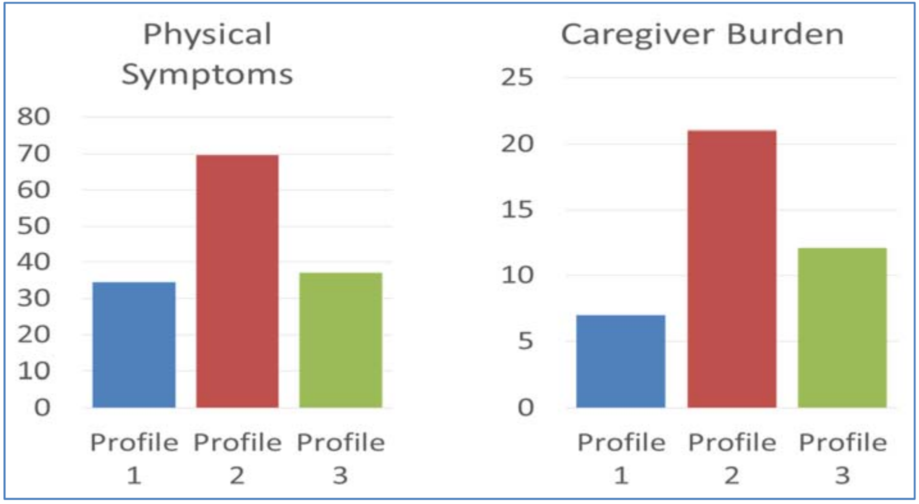


Fig. 4. Caregiver outcomes by profile for physical symptoms and burden.



Below are 3 case examples with participants' quotes to highlight the findings for each profile.

Profile 1 Case Example:

Mother/son dyad living in urban area. Both are high school graduates and seem financially stable but specifics on economics not shared. Mother receives about $800/month as caregiver. Son receives some disability and VA benefits.

Son, veteran, in mid 30s and injured over 15 years ago through motorcycle accident (tetraplegia complete injury). Son lives independently with formal and family caregiving. Caregiving entails transfers, dressing, bathing, bowel and bladder care, cooking, cleaning/household maintenance, errands with and without son, help with dog and bills. Son is able to drive independently with hand controls and uses both power and manual chairs. Mother spends night when needed (e.g., whenever he has pressure sores and needs turning). Mother reports low caregiver burden. Supplemental care through VA includes 3 visits from a nurse to monitor and assist with bowel and bladder program, daily – 1 hour activity aide, and monthly med check.

Dyad has a large extended, mixed marriage family. Mother and father were divorced prior to injury and both father and new retired step father have been helpful in supporting recovery and caregiving. Siblings have at times also been live-in caregivers. There is a strong sense of family support and family coming together to put all on hold and regroup, reprioritize, and figure out together how to move forward. Son with SCI has a positive attitude and fighting spirit.

Both mother and son report high overall quality of life and screened negative for mental health concerns. Mother was recently diagnosed with diabetes but is under regular doctor's care. Son rated his physical quality of life as lower and does report high pain intensity and frequency but it doesn't interfere with activities.

In response to a question about taking care of her own health: "I'm on it. I'm probably on it because I have to be, because I have to care for my son. I have to stay healthy. That's why. Otherwise I probably wouldn't, honestly."

And relative to their relationship, the mother stated: "The biggest thing is that I love him. It's more mental for me than anything. I just take care of all his needs. I try to make him as comfortable as possible without diminishing his spirit. … I try not to say or do things that would embarrass him in any way. So, in that respect, that's what I meant by spirit, I guess."

Unmet needs: Son is losing function in right arm. Dyad is not entirely sure about future caregiving plans. Mother limits out of town trips/vacations due to lack of backup, 24-hour care.

Profile 2 Case Example:

A 61-year-old woman caring for her son, a veteran, who was injured in a car accident 6 years ago and lives with tetraplegia. Both members of dyad are Caucasian and completed some college. They live in a small city. Son receives some disability benefits. Mother receives some compensation to provide full time caregiving a week (lifts, dressing, bowel and bladder care). They benefit from occasional supplemental caregiving support when mother has been sick/recuperating from her own hospitalizations. Combined income ($22,000) puts them at just above poverty line ($15,871 for household of 2).

Mother and son have a very small social network of extended family members who visit occasionally but are not comfortable with son's physical needs or helping out. The father passed away one year before the son's accident.

"As far as helping—I mean, they [son's brother and sister] come and visit, but as far as helping with his physical needs, helping me get him into bed or that kind of thing, they don't help with that. His brother and sister have never seemed to be comfortable with that."… It's very tiring, and it's very lonely. Of course, it's probably lonelier for me than it is for a lot of people, because I don't have my husband here either. If we could be working on this together, that would help take care of both of those things." (Mother)

They have discussed the possibility of son going to live in a residential VA facility but they haven't discussed any specific timelines. Son reports that he desires this to alleviate the burden his needs place on his mother.

Unmet needs: Both mother and son report depression and isolation. Mother reports high burden, low leisure satisfaction, and she has had physical health concerns including surgery and her own rehabilitation needs. Mother also reports low quality of life and sleep deprivation. Son also reports high quality of life but low satisfaction with activities outside of the home.

"I wake up tired because for 5 years I haven't gotten to sleep the whole night through. And it's lonely because my friends have kind of left me. One friend who has stuck close, she says that the mutual friends that we've had have talked to her and that they just—nobody knew what to do, because nobody had ever gone through a situation like that before. From my perspective, I didn't know what to do either. I never knew anybody that went through it either. But I didn't have a choice of whether… I couldn't get up and leave. So apparently, they're just not comfortable. I don't see them or hear from them much." (Mother)

Profile 3 Case Example:

Dyad is a mother/daughter. Caregiver is in her mid 60s and has been caring for her daughter, a veteran, for about 20 years and her daughter's elementary school aged son. Her daughter was injured in a hurricane and is living with tetraplegia. Both live in a suburban community and work together in a family business. Income sources include VA pension, disability, caregiver stipend, and family business. They report financial stability and are very grateful for the financial means to care for one another. "I feel like we're the luckiest people on the face of the earth because there's so many other people in the same position (daughter's) in, who have no means of living a full life…" (Mother)

Daughter requires assistance with transfers, bathing, lower body dressing, bowel and bladder care. She uses a power chair and can drive short distances with hand controls. They have a live-in care attendant but have had trouble keeping this position filled.

Mother reports fair health and below average quality of health (physical and emotional health). Her mental health screening data suggest that she is experiencing moderate anxiety. She was recently diagnosed with diabetes. She reported low burden and views her life with her daughter as a blessing. "I've got a lot of blessings but certainly that is definitely one. Let's see, how can I describe?. I would say that I get a lot of personal satisfaction in taking care of somebody else. It's very fulfilling to me. That makes me happy. No,

> it's totally not a burden." However there is also a strong sense of mom being worn out. "In my opinion, even though I did do it on my own for a long period of time, I think it is, I really think it's not … It's unrealistic for it to be one person because you kind of become enveloped in it, if you know what I mean. So I think it's more than one person….It is demanding." (Mother)
>
> Daughter has almost daily pain that interferes with sleep but reportedly not daily activities. She has had recent challenges with pressures sores that have required hospitalizations and periods of confinement to bed. Daughter screened positive for moderate PTSD.
>
> They have a large extended family, but family doesn't step in to help with care needs or emotional support. "I'll tell you, I have, like I said, this big family. We're a close family, but as strange as this is going to sound, their support has been extremely disappointing to me because I've often thought to myself, 'Wouldn't you think once in a while somebody would call you and say, 'You need a weekend away. I'm going to come over…' and I can tell you that's never happened. Or, 'Hey, why don't I stay with (daughter) tonight and you go out to dinner?' You know? Never, and you know I love my family, but that's been a real shock to me because when my parents were ill, they were all over it, coming to visit them, you know, just like you would think, but never with [my daughter], nothing. It's been very strange and isolating, you know?" (Mother)
>
> Unmet needs: Both mother and daughter report isolation and lack of satisfaction with social support. They have an ongoing challenge finding reliable personal care assistants and respite care; uncertain future care plans and significant stress for mother (caregiver) about how daughter will managed if something happens to her.

We held 3 Advisory Board meetings during the study period. Board members were caregivers, adults with SCI, a VA psychologist, a caregiver researcher, a qualitative research expert, and investigators from each of the sites. They helped us understand what issues civilian and veteran caregivers face, provided feedback on potential interventions, and helped interpret findings.

From 2016 to 2018, we gave 6 podium presentations and 3 poster sessions at scientific meetings:

- In 2016, we presented study findings in podium presentations at the annual meetings of the American Spinal Injury Association (ASIA), the Academy of Spinal Cord Injury Professionals (ASCIP) and the Paralyzed Veterans of America, and presented a poster at the International Spinal Cord Society (ISCoS) meeting.
- In 2017, we gave podium presentations at ASIA and ASCIP and presented a poster at ISCoS.
- In 2018, we gave podium presentations at ASIA and a poster presentation at ISCoS.

One manuscript titled "Quality of life among family caregivers of adults with spinal cord injury" has been submitted to a scientific journal A second one titled "Mixed-methods study of coping, social support and well-being among family caregivers of adults with SCI" will be submitted in December 2018. Both papers are being submitted to *Topics in Spinal Cord Rehabilitation* for consideration to be published in a special issue on caregivers.

For the lay audience, we published an article in a Shriner-Chicago newsletter called SCI Informer that is circulated at the hospital and in the local community. For the caregivers, we created a Caregiver Resource Guide based on the needs the caregivers expressed in their interviews. Many of the resources listed are available for free. We included a brief synopsis of our study findings.

Aim 4. To propose core intervention components to improve caregiver adjustment

- Assessment/triage
- Social support (peer, instrumental, informational)
- Skill development (problem solving, family wellness, and leisure)

What opportunities for training and professional development has the project provided?
If the project was not intended to provide training and professional development opportunities or there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe opportunities for training and professional development provided to anyone who worked on the project or anyone who was involved in the activities supported by the project. "Training" activities are those in which individuals with advanced professional skills and experience assist others in attaining greater proficiency. Training activities may include, for example, courses or one-on-one work with a mentor. "Professional development" activities result in increased knowledge or skill in one's area of expertise and may include workshops, conferences, seminars, study groups, and individual study. Include participation in conferences, workshops, and seminars not listed under major activities.

During the study period, research team members attended meetings of the American Spinal Injury Association, the Academy of Spinal Cord Injury Professionals, the International Spinal Cord Society, and the Paralyzed Veterans of America Summit. During the first quarter of the study, the PI and research coordinator attended a training on Nvivo, the qualitative software used for data analysis.

How were the results disseminated to communities of interest?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

As noted above, from 2016 to 2018, we gave 6 podium presentations and 3 poster sessions at scientific meetings. We wrote an article for a lay audience in a Shriner-Chicago newsletter that is circulated in the community, and we created a Caregivers Resource Guide for the caregivers who participated in the study.

What do you plan to do during the next reporting period to accomplish the goals?
If this is the final report, state "Nothing to Report." Describe briefly what you plan to do during the next reporting period to accomplish the goals and objectives.

Nothing to report.

4. **IMPACT:** Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:

What was the impact on the development of the principal discipline(s) of the project?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how findings, results, techniques that were developed or extended, or other products from the project made an impact or are likely to make an impact on the base of knowledge, theory, and research in the principal disciplinary field(s) of the project. Summarize using language that an intelligent lay audience can understand (Scientific American style).

Specific to the field of SCI rehabilitation, data from this study helps to 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 helps to further the conceptualization and operationalization of quantitative measures as related to caregiver QOL and SCI.

Describe how the findings, results, or techniques that were developed or improved, or other products from the project made an impact or are likely to make an impact on other disciplines.

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

What was the impact on technology transfer?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe ways in which the project made an impact, or is likely to make an impact, on commercial technology or public use, including:

- *transfer of results to entities in government or industry;*
- *instances where the research has led to the initiation of a start-up company; or*
- *adoption of new practices.*

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 formats to disseminate results and recommendations for intervention.

What was the impact on society beyond science and technology?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how results from the project made an impact, or are likely to make an impact, beyond the bounds of science, engineering, and the academic world on areas such as:

- *improving public knowledge, attitudes, skills, and abilities;*
- *changing behavior, practices, decision making, policies (including regulatory policies), or social actions; or*
- *improving social, economic, civic, or environmental conditions.*

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 formats to disseminate results and recommendations for intervention. Our findings add to the knowledge base of caregiver tasks and unmet needs, which could help clinicians in rehabilitation hospitals better prepare caregivers to provide care after a loved one's injury. Our findings may also help social workers design programs to help caregivers adjust to their new role.

5. **CHANGES/PROBLEMS:** The Project Director/Principal Investigator (PD/PI) is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer whenever there are significant changes in the project or its direction. If not previously reported in writing, provide the following additional information or state, "Nothing to Report," if applicable:

Changes in approach and reasons for change
Describe any changes in approach during the reporting period and reasons for these changes. Remember that significant changes in objectives and scope require prior approval of the agency.

As noted above, the study originally was designed as a longitudinal study with 2 time points—Time 1 was the first interview and a set of surveys and Time 2 was a second interview and the same set of surveys about 15 months later. Because of the IRB delays and staff changes that delayed finishing recruitment until Year 3, brief member checking interviews replaced the Time 2 interviews and focus groups, with permission from the sponsor.

Actual or anticipated problems or delays and actions or plans to resolve them
Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

Our collaborators found our initial participant eligibility requirements to be too restrictive so the protocol was amended to broaden the age range from 25 to 44 years and only traumatic SCI to 18 to 65 years with either traumatic or non-traumatic SCI. We also expanded our mode of recruitment to include participants from community organizations, such as the Spinal Cord Injury Association of Illinois and the Paralyzed Veterans of America, in addition to the four rehabilitation hospitals.

It was challenging and time consuming to work with six IRBs. Reporting requirements and timing were different at each institution. In Year 3, we requested an extension without funds (EWOF) because of IRB delays, staff changes, and additional time needed to reach minimum recruitment goals. Specifically, we underestimated the time it would take to seek approval of the multiple IRBs associated with this project (a total of 6 IRBs to account for 5 partner organizations, including the lead institution that transitioned to a new IRB mid-grant, along with submissions for each IRB to HRPO). VA IRB delays significantly hampered veteran recruitment. The original approval took 8 months and then we experienced a 5-week lapse in our continuing review during Year 2 due to internal VA logistics. In addition, the requirement each year that all study personnel fulfill the same VA requirements that employees do in order to be granted Without Compensation (WOC) status was time consuming and onerous.

Staffing modifications also impacted recruitment and data collection and analysis progress. The original PI of this study, Erin Kelly, resigned from her position at Marquette University and therefore from her position as PI of this study, to take on a new role at the American Academy of Pediatrics. 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. Dr. Kelly remained on the study as a Co-Investigator. Titilope Akinlose left her position as Research Coordinator in June 2016 to pursue an overseas fellowship. A second research coordinator was hired over the summer but she left after three days due to a family health emergency, which re-started the hiring process. Our current research coordinator, Kerry O'Rourke, was hired and began work on Sept. 1, 2016.

Recruitment also was challenging because the adults with SCI often told their providers at the rehabilitation hospitals that they were interested in participating in the study but were more reluctant to agree to the study when talking with the research coordinator from Shriners.
We collected limited data from the four participating sites regarding individuals who refused participation or initially accepted but then dropped. Future collaborative endeavors should consider ways to support and incentivize more complete referral data.

We provided caregivers a $40 stipend and adults with SCI a $30 stipend for each interview. In the future, we would recommend larger stipends to better compensate them for their time.
budget.

Changes that had a significant impact on expenditures

Describe changes during the reporting period that may have had a significant impact on expenditures, for example, delays in hiring staff or favorable developments that enable meeting objectives at less cost than anticipated.

Despite a one-year extension, we did not exceed our budget.

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Describe significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period. If required, were these changes approved by the applicable institution *committee (or equivalent) and reported to the agency? Also specify the applicable Institutional Review Board/Institutional Animal Care and Use Committee approval dates.*

Significant changes in use or care of human subjects

Nothing to report.

Significant changes in use or care of vertebrate animals

Nothing to report

Significant changes in use of biohazards and/or select agents

Nothing to report.

6. **PRODUCTS:** List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state “Nothing to Report.”

- **Publications, conference papers, and presentations**
  Report only the major publication(s) resulting from the work under this award.

  Journal publications. *List peer-reviewed articles or papers appearing in scientific, technical, or professional journals. Identify for each publication: Author(s); title; journal; volume: year; page numbers; status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

  O’Rourke K, Ryerson Espino SL, Kelly EH, Vogel LC. Quality of Life Among Family Caregivers of Adults with Spinal Cord Injury. Submitted for publication.

  Ryerson Espino SL, O’Rourke K, Kelly EH, January A, Vogel LC. Mixed-Methods Study of Coping, Social Support, and Well-being among Family Caregivers of Adults with SCI. Expected submission in December 2018.

  Books or other non-periodical, one-time publications. *Report any book, monograph, dissertation, abstract, or the like published as or in a separate publication, rather than a periodical or series. Include any significant publication in the proceedings of a one-time conference or in the report of a one-time study, commission, or the like. Identify for each one-time publication: Author(s); title; editor; title of collection, if applicable;*

bibliographic information; year; type of publication (e.g., book, thesis or dissertation); status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).

2016 Citations
Ryerson Espino S, Kelly EH, Akinlose T, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Caregivers of Adults with Pediatric-Onset SCI: An exploration of unmet needs. *Top Spinal Cord Injury Rehabil*. 2016; 22:S28 (Suppl 1).

Akinlose T, Ryerson Espino S, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. Presentation at Paralyzed Veterans of America 2016 Summit & Expo; Aug. 31, 2016; Orlando, FL.

Ryerson Espino S, Kelly EH, Akinlose T, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. *J Spinal Cord Med*. 2016; 39:549-550.

Akinlose T, Ryerson Espino S, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. Poster presentation at International Spinal Cord Society 2016 Annual Scientific Meeting; Sept. 14, 2016; Vienna, Austria.

2017 Citations
Kelly EH, Ryerson Espino S, Russell H, Zebracki K. Caregiving along the lifespan of pediatric spinal cord injury. Course presented at Howard H. Steel Pre-Course on Pediatric Spinal Cord Injury/Dysfunction at the American Spinal Injury Association 2017 Annual Scientific Meeting; April 26, 2017; Albuquerque, NM.

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 the 2017 Annual meeting of the Academy of Spinal Cord Injury Professionals. *J Spinal Cord Med*. 2017; 40:5, 579-604, DOI: 10.1080/10790268.2017.1351703.

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. Poster at the annual meeting of the International Spinal Cord Society, Dublin, Ireland. 2017.

2018 Citations
Ryerson Espino S, O'Rourke K, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Problem solving and social support patterns among family caregivers of adults with SCI. Presented at American Spinal Injury Association 2018 Scientific Meeting; May 3, 2018; Rochester, MN.

Ryerson Espino S, O'Rourke K, Kelly EH, January A, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Problem solving and social support patterns among family caregivers of adults with SCI. Poster to be presented at International Spinal Cord Society 2018 Annual Scientific Meeting; September 13, 2018; Sydney, Australia.

Other publications, conference papers, and presentations. *Identify any other publications, conference papers and/or presentations not reported above. Specify the status of the publication as noted above. List presentations made during the last year (international, national, local societies, military meetings, etc.). Use an asterisk (*) if presentation produced a manuscript.*

Nothing to report.

- **Website(s) or other Internet site(s)**
  List the URL for any Internet site(s) that disseminates the results of the research activities. A short description of each site should be provided. It is not necessary to include the publications already specified above in this section.

Nothing to report.

- **Technologies or techniques**
  Identify technologies or techniques that resulted from the research activities. In addition to a description of the technologies or techniques, describe how they will be shared.

Nothing to report.

- **Inventions, patent applications, and/or licenses**
  Identify inventions, patent applications with date, and/or licenses that have resulted from the research. State whether an application is provisional or non-provisional and indicate the application number. Submission of this information as part of an interim research performance progress report is not a substitute for any other invention reporting required under the terms and conditions of an award.

Nothing to report.

- **Other Products**
  Identify any other reportable outcomes that were developed under this project. Reportable outcomes are defined as a research result that is or relates to a product, scientific advance, or research tool that makes a meaningful contribution toward the understanding, prevention, diagnosis, prognosis, treatment, and/or rehabilitation of a disease, injury or condition, or to improve the quality of life. Examples include:
  - *data or databases;*
  - *biospecimen collections;*

- *audio or video products;*
- *software;*
- *models;*
- *educational aids or curricula;*
- *instruments or equipment;*
- *research material (e.g., Germplasm; cell lines, DNA probes, animal models);*
- *clinical interventions;*
- *new business creation; and*
- *other.*

Nothing to report.

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?
Provide the following information for: (1) PDs/PIs; and (2) each person who has worked at least one person month per year on the project during the reporting period, regardless of the source of compensation (a person month equals approximately 160 hours of effort). If information is unchanged from a previous submission, provide the name only and indicate "no change."

Name: Lawrence C. Vogel, MD
Project Role: Principal Investigator
Nearest person month worked: 0.2 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: Erin H. Kelly, PhD
Project Role: Co-Investigator
Nearest person month worked: 0 calendar months
Contribution to Project: Initial PI through end of Year 1

Name: Titilope Akinlose, MPH
Project Role: Research Coordinator
Nearest person month worked: 0 calendar months
Contribution to Project: Left project in Year 2, Quarter 7

Name: Kerry O'Rourke, MPH
Project Role: Research Coordinator
Nearest person month worked: 6 calendar months
Contribution to Project: Began work in Year 2, Quarter 8

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

If the active support has changed for the PD/PI(s) or senior/key personnel, then describe what the change has been. Changes may occur, for example, if a previously active grant has closed and/or if a previously pending grant is now active. Annotate this information so it is clear what has changed from the previous submission. Submission of other support information is not necessary for pending changes or for changes in the level of effort for active support reported previously. The awarding agency may require prior written approval if a change in active other support significantly impacts the effort on the project that is the subject of the project report.

Nothing to report.

What other organizations were involved as partners?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe partner organizations – academic institutions, other nonprofits, industrial or commercial firms, state or local governments, schools or school systems, or other organizations (foreign or domestic) – that were involved with the project. Partner organizations may have provided financial or in-kind support, supplied facilities or equipment, collaborated in the research, exchanged personnel, or otherwise contributed.
Provide the following information for each partnership:
<u>Organization Name:</u>
<u>Location of Organization: (if foreign location list country)</u>
<u>Partner's contribution to the project</u> (identify one or more)

- *Financial support;*
- *In-kind support (e.g., partner makes software, computers, equipment, etc., available to project staff);*
- *Facilities (e.g., project staff use the partner's facilities for project activities);*
- *Collaboration (e.g., partner's staff work with project staff on the project);*
- *Personnel exchanges (e.g., project staff and/or partner's staff use each other's facilities, work at each other's site); and*
- *Other.*

<u>Other Organizations Involved as Partners</u>

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 served 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 St.
Chicago, IL 60611
Contribution: The AbilityLab served 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 served 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 served 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 the American Academy of Pediatrics served 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

COLLABORATIVE AWARDS: For collaborative awards, independent reports are required from BOTH the Initiating PI and the Collaborating/Partnering PI. A duplicative report is acceptable; however, tasks shall be clearly marked with the responsible PI and research site. A report shall be submitted to **https://ers.amedd.army.mil** for each unique award.

QUAD CHARTS: If applicable, the Quad Chart (available on https://www.usamraa.army.mil) should be updated and submitted with attachments.

9. APPENDICES: Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc.

Appendix A Caregiver Project Abstracts 2016-2018

DOD Caregiver Project Abstracts 2016

Presentation at the 42nd Annual Scientific Meeting of the American Spinal Injury Association, Philadelphia.

Citation:
Ryerson Espino S, Kelly EH, Akinlose T, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Caregivers of Adults with Pediatric-Onset SCI: An exploration of unmet needs. *Top Spinal Cord Injury Rehabil*. 2016; 22:S28 (Suppl 1).

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

Susan Ryerson Espino, PhD[1]; Erin H. Kelly, PhD[1,2,3]; Titilope Akinlose, MPH[1]; 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, 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.

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)

Presentation at Academy of Spinal Cord Injury Professionals Annual Meeting 2016; Nashville, TN.

Citation:
Ryerson Espino S, Kelly EH, Akinlose T, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. *J Spinal Cord Med*. 2016; 39:549-550.

Title: Burden among caregivers of adults with spinal cord injury

Susan Ryerson Espino, PhD[12]; Erin H. Kelly, PhD[1,2,3]; Titilope Akinlose, MPH[1]; 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.

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)

Presentation at Paralyzed Veterans of America 2016 Summit & Expo; Aug. 31, 2016; Orlando, FL.

Citation:

Akinlose T, Ryerson Espino S, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. Presentation at Paralyzed Veterans of America 2016 Summit & Expo; Aug. 31, 2016; Orlando, FL.

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.

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)

Poster presentation at International Spinal Cord Society 2016 Annual Scientific Meeting; Sept. 14, 2016; Vienna, Austria.

Citation:
Akinlose T, Ryerson Espino S, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Burden among caregivers of adults with spinal cord injury. Poster presentation at International Spinal Cord Society 2016 Annual Scientific Meeting; Sept. 14, 2016; Vienna, Austria.

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)

DOD Caregiver Project Abstracts 2017

Presentation at Howard H. Steel Pre-Course on Pediatric Spinal Cord Injury/Dysfunction at the American Spinal Injury Association 2017 Annual Scientific Meeting, Albuquerque, NM.

Citation:
Kelly EH, Ryerson Espino S, Russell H, Zebracki K. Caregiving along the lifespan of pediatric spinal cord injury. Course presented at Howard H. Steel Pre-Course on Pediatric Spinal Cord Injury/Dysfunction at the American Spinal Injury Association 2017 Annual Scientific Meeting; April 26, 2017; Albuquerque, NM.

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).

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Funding Sources
Shriners Hospitals for Children
The Craig H. Neilsen Foundation
The Department of Defense

Presentation at the 2017 Annual meeting of the Academy of Spinal Cord Injury Professionals.

Citation:
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 the 2017 Annual meeting of the Academy of Spinal Cord Injury Professionals. *J Spinal Cord Med*. 2017; 40:5, 579-604, DOI: 10.1080/10790268.2017.1351703

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)

Poster presentation at the annual meeting of the International Spinal Cord Society, Dublin, Ireland.

Citation:
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. Poster at the annual meeting of the International Spinal Cord Society, Dublin, Ireland. 2017.

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.

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Design: Mixed methods study of 32 civilian and veteran dyads.
Methods: Qualitative interviews were guided by a semi-structured protocol. Quantitative data included standardized surveys on caregiver burden, problem solving, and leisure time

satisfaction, mental health and well-being surveys. Average injury age of SCI participants was 22 years (17-37); average age of interview was 37 years (26-53); 71% tetraplegia; 68% male; 23% veterans. Average age of caregivers was 50 years (22-77); female (81%); and were a parent (48%), spouse/significant other (42%), sibling (7%), or other relative (3%).

Results: Qualitative narratives spoke to important facilitators of dyad well-being including family cooperation, positive interpersonal relations, self-care, and collaboration with paid non-family caregivers. Caregivers who demonstrated fewer challenges with problem solving and greater leisure time satisfaction experienced lower burden ($p<0.01$); together these accounted for 65% of variance in caregiver burden. Caregiver burden and challenges with problem solving were associated with mental distress among civilians (but not veterans) with SCI.

Conclusion: Findings suggest importance of caregiver self-care, leisure time satisfaction, skills development (problem solving and interpersonal communication), and collaboration with other family members and personal care assistants. Training to reduce tendency to view problems as insurmountable and reduce reliance on avoidance and applying hurried/incomplete solutions may contribute to well-being of caregivers and adults living with SCI.

Support: Department of Defense (Grant #SC130279)

DOD Caregiver Project Abstracts 2018

Presented at American Spinal Injury Association 2018 Scientific Meeting; Rochester, MN.

Citation:

January AM, Ryerson Espino S, O'Rourke K, Kelly EH, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Problem solving and social support patterns among family caregivers of adults with SCI. Presented at American Spinal Injury Association 2018 Scientific Meeting; May 3, 2018; Rochester, MN.

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

Ali January, PhD[2,7]; 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; Purdue University Northwest, Hammond, IN

Objective: To assess social problem solving (PS) skills and social support profiles and explore associations between profiles, demographics, caregiving press, and caregiver outcomes.

Design: Longitudinal mixed methods study of 41 civilian and veteran dyads from three USA rehabilitation hospitals and one Veterans Administration hospital.

Participants/methods: Members of dyads participated in qualitative interviews guided by a semi-structured protocol that explored the nature of caregiving, impacts on other areas of life, and wellbeing. Quantitative data included standardized surveys on PS, social support, as well as measures on the caregiving press (independence of adult with SCI, caregiver burden, commitment to future care), other areas of life (satisfaction with leisure time and social integration), along with outcomes relating to perceptions of quality of life and physical and mental health assessments. Follow-up qualitative interviews were conducted approximately 15 months later to clarify and deepen understandings of well-being. Cluster analysis was used to explore patterns in social PS skills and social support. MANOVA was used to explore specific variations of PS and social support across the profiles of caregivers. Then, MANOVA and qualitative analyses were used to explore if profiles distinguished caregivers in terms of caregiving context, impacts on others areas of life, and outcomes.

Results:

Cluster analysis revealed 3 profiles of caregivers: 1) high perception of social support and high reports of positive problem solving orientation; 2) high negative problem solving orientation and high reports of avoidant and impulsive/compulsive PS strategies; 3) low perception of social support and significantly lower reports in rationale PS strategies.

The 3 group typology distinguished caregivers in terms of press, impacts on other areas of life, and outcomes. Relative to caregiving press, caregivers in profile 2, vs. other caregivers, cared for individuals with less reported cognitive, mobility, and social integration independence. No associations were found between caregiver profiles and level of injury or physical independence. Profile 2 caregivers also reported significantly more burden than other caregivers as well as a lower commitment to provide future care. Caregivers in profile 1 reported higher satisfaction

with leisure and social integration compared to other caregivers. Caregivers in profile 2 tended to report less work outside of the home although this was not statistically significant (86% of profile 2 caregivers *did not* work outside the home vs. 53% of others *did not* work outside of the home). Caregivers in profile 1 reported higher quality of life and fewer concerns related to depression compared to other caregivers. Caregivers in profile 1 reported fewer concerns related to anxiety than those in profile 2. Profile 2 caregivers reported significantly more complaints related to physical health. Profile 2 caregivers appear to be most at risk for adverse outcomes putting in jeopardy as well the future care of their family members with SCI.

Discussion: Correlation is not causation however patterns in findings suggest that effective problem solving and social support, such as those exhibited by caregivers in profile 1, may be protective factors offsetting stressors associated with caregiving and bolstering caregiver wellbeing and quality of life. Triaging at risk caregivers, like those in profile 2 reporting less independence on part of adults with SCI, more burden, less leisure and involvement in roles and relationships outside of the home, into interventions aimed at increasing effective problem solving and social support holds promise for enhancing their quality of life and wellbeing.

Support: Department of Defense, Qualitative Research Award

Poster presented at International Spinal Cord Society 2018 Annual Scientific Meeting; Sydney, Australia.

Citation:

Ryerson Espino S, O'Rourke K, Kelly EH, January A, Ghaffari A, Harris G, Richardson M, Chen D, Lee R, Vogel LC. Problem solving and social support patterns among family caregivers of adults with SCI. Poster to be presented at International Spinal Cord Society 2018 Annual Scientific Meeting; September 13, 2018; Sydney, Australia.

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

Susan Ryerson Espino, PhD[1,2]; Kerry O'Rourke, MPH, MA[1,2]; Erin H. Kelly, PhD[2,3]; Ali January, PhD[2]; 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] Shirley Ryan AbilityLab, Chicago, IL; [6]Schwab Rehabilitation Hospital, Chicago, IL; [7]Rush University, Chicago, IL.

Objective: Assess profiles based on social problem solving (PS) skills and social support among caregivers of adults with SCI and associations between profiles and caregiver quality of life and well-being.

Design: Mixed-methods study of 41 dyads of U.S. caregivers and adults with SCI from 3 rehabilitation hospitals and one Veterans Administration hospital.

Methods: Dyad members participated in qualitative interviews exploring caregiver quality of life and well-being and standardized surveys exploring caregiver PS, social support, quality of life, and well-being. Qualitative patterns were identified involving social support and PS, leading us to explore these constructs quantitatively using cluster analysis and MANOVA. Caregiver PS included: positive problem orientation (PPO), negative problem orientation (NPO), rational style (RS), impulsive/compulsive style (ICS), and avoidant style (AS). Adults with SCI were most commonly male (73%) and had tetraplegia (68%); mean age at injury was 22 years (range=17-37), and current age was 39 years (range=25-57); 51% reported being white; and 34% were veterans. Caregivers were most commonly female (81%), ethnic minority (56%), with post-secondary education (61%); and mean current age was 50 years (range 22-81). Just under half of caregivers were partners (46%), 39% parents, and <5% siblings, close friends, or extended relatives.

Results: Cluster analysis revealed 3 profiles distinguishing caregivers in terms of PS skills and social support (F (12,66)=10.48, p<0.01; Wilk's lambda=0.12, partial eta squared=0.66): Profile 1 – higher social support (vs. profiles 2 and 3) higher PPO and RS (vs. profile 3); Profile 2 – higher NPO, ICS, and AS (vs. profiles 1 and 3) and lower social support (vs. profile 1); Profile 3 – lower social support and PPO (vs. profile 1) and lower RS (vs. profiles 1 and 2). The 3 profiles also distinguished dyads by caregiver quality of life and well-being. Profile 1 reported fewer challenges and higher well-being (vs. profiles 2 and 3). Specifically, caregivers in profile 1 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 more burden, depression, and anxiety (vs. profiles 1 and 3) and more physical health complaints (vs. profile 1). Profile 3 appeared to fare slightly better than those in profile 2 with fewer reported concerns relating to depression. Qualitative data sheds additional light on differences between profiles in terms of poverty, adjustment to disability, family support, and coping. Qualitative data further demonstrated that 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.

Discussion: Findings suggest that effective problem solving and strong social support may be protective factors offsetting stressors associated with caregiving and bolstering caregiver well-being. Assessing PS, social support, and caregiving challenges and triaging caregivers into supportive interventions when depicting risk may hold promise for the prevention of physical and mental health distress in caregivers.

Support: Department of Defense, Qualitative Research Award (Grant #SC130279)

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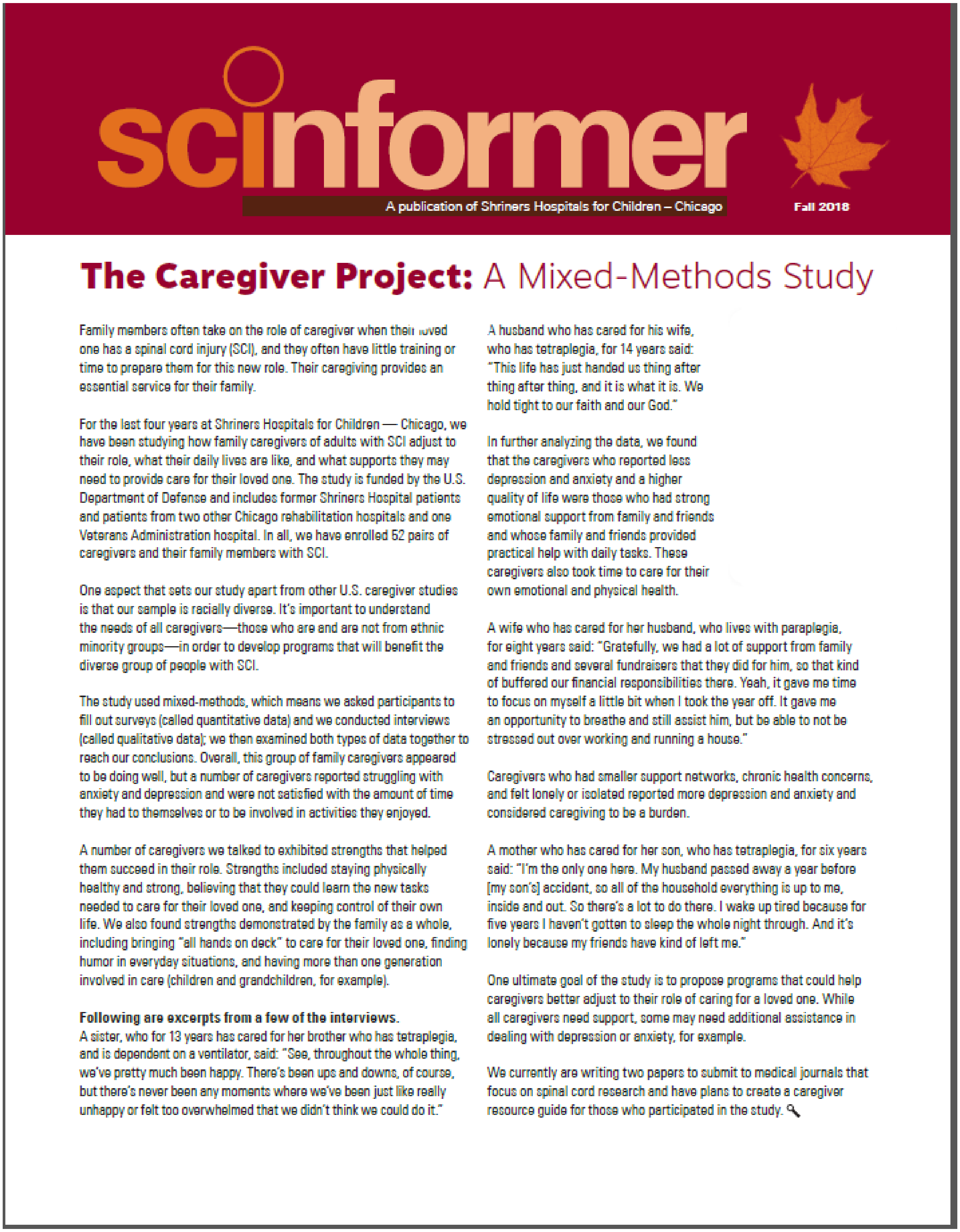
Smith EM, Boucher N, Miller WC. Caregiving services in spinal cord injury: a systematic review of the literature. *Spinal Cord.* 2016;54(8):562-569. doi: 10.1038/sc.2016.8

Parashar D. The trajectory of hope: pathways to find meaning and reconstructing the self after a spinal cord injury. *Spinal Cord.* 2015;53(7):565-568. ISSN: 13624393.

Appendix B Shriners SCI Informer Caregiver Project Article



scinformer

A publication of Shriners Hospitals for Children – Chicago

Fall 2018

The Caregiver Project: A Mixed-Methods Study

Family members often take on the role of caregiver when their loved one has a spinal cord injury (SCI), and they often have little training or time to prepare them for this new role. Their caregiving provides an essential service for their family.

For the last four years at Shriners Hospitals for Children — Chicago, we have been studying how family caregivers of adults with SCI adjust to their role, what their daily lives are like, and what supports they may need to provide care for their loved one. The study is funded by the U.S. Department of Defense and includes former Shriners Hospital patients and patients from two other Chicago rehabilitation hospitals and one Veterans Administration hospital. In all, we have enrolled 52 pairs of caregivers and their family members with SCI.

One aspect that sets our study apart from other U.S. caregiver studies is that our sample is racially diverse. It's important to understand the needs of all caregivers—those who are and are not from ethnic minority groups—in order to develop programs that will benefit the diverse group of people with SCI.

The study used mixed-methods, which means we asked participants to fill out surveys (called quantitative data) and we conducted interviews (called qualitative data); we then examined both types of data together to reach our conclusions. Overall, this group of family caregivers appeared to be doing well, but a number of caregivers reported struggling with anxiety and depression and were not satisfied with the amount of time they had to themselves or to be involved in activities they enjoyed.

A number of caregivers we talked to exhibited strengths that helped them succeed in their role. Strengths included staying physically healthy and strong, believing that they could learn the new tasks needed to care for their loved one, and keeping control of their own life. We also found strengths demonstrated by the family as a whole, including bringing "all hands on deck" to care for their loved one, finding humor in everyday situations, and having more than one generation involved in care (children and grandchildren, for example).

Following are excerpts from a few of the interviews.
A sister, who for 13 years has cared for her brother who has tetraplegia, and is dependent on a ventilator, said: "See, throughout the whole thing, we've pretty much been happy. There's been ups and downs, of course, but there's never been any moments where we've been just like really unhappy or felt too overwhelmed that we didn't think we could do it."

A husband who has cared for his wife, who has tetraplegia, for 14 years said: "This life has just handed us thing after thing after thing, and it is what it is. We hold tight to our faith and our God."

In further analyzing the data, we found that the caregivers who reported less depression and anxiety and a higher quality of life were those who had strong emotional support from family and friends and whose family and friends provided practical help with daily tasks. These caregivers also took time to care for their own emotional and physical health.

A wife who has cared for her husband, who lives with paraplegia, for eight years said: "Gratefully, we had a lot of support from family and friends and several fundraisers that they did for him, so that kind of buffered our financial responsibilities there. Yeah, it gave me time to focus on myself a little bit when I took the year off. It gave me an opportunity to breathe and still assist him, but be able to not be stressed out over working and running a house."

Caregivers who had smaller support networks, chronic health concerns, and felt lonely or isolated reported more depression and anxiety and considered caregiving to be a burden.

A mother who has cared for her son, who has tetraplegia, for six years said: "I'm the only one here. My husband passed away a year before [my son's] accident, so all of the household everything is up to me, inside and out. So there's a lot to do there. I wake up tired because for five years I haven't gotten to sleep the whole night through. And it's lonely because my friends have kind of left me."

One ultimate goal of the study is to propose programs that could help caregivers better adjust to their role of caring for a loved one. While all caregivers need support, some may need additional assistance in dealing with depression or anxiety, for example.

We currently are writing two papers to submit to medical journals that focus on spinal cord research and have plans to create a caregiver resource guide for those who participated in the study.

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

SC130279 and 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)

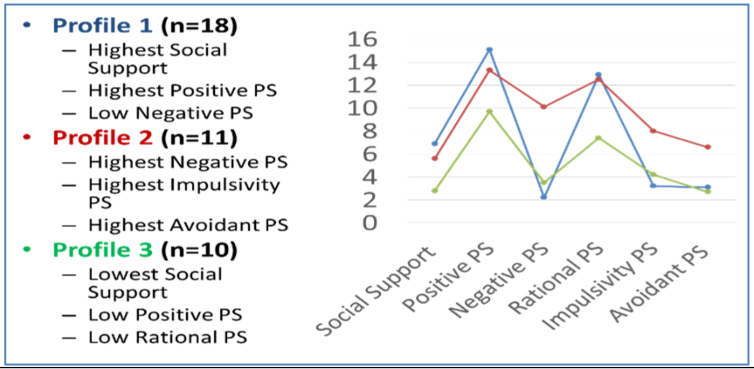
Aim 1. How does being a caregiver impact the caregiver's QOL?
Aim 2. How does the health of caregivers relate to the health of their loved ones living with SCI?
Aim 3. How does the experience of caregiving vary by certain caregiver characteristics?
Aim 4. To propose core intervention components to improve caregiver adjustment.

Approach

This mixed-methods study employed purposive sampling across 4 rehabilitation hospitals in the US, including 1 VA hospital, to maximize socioeconomic and ethnic diversity. Semi-structured qualitative interviews, most done by phone and a few done in community settings, were followed by structured standardized surveys and brief member checking phone interviews 15-18 months later.

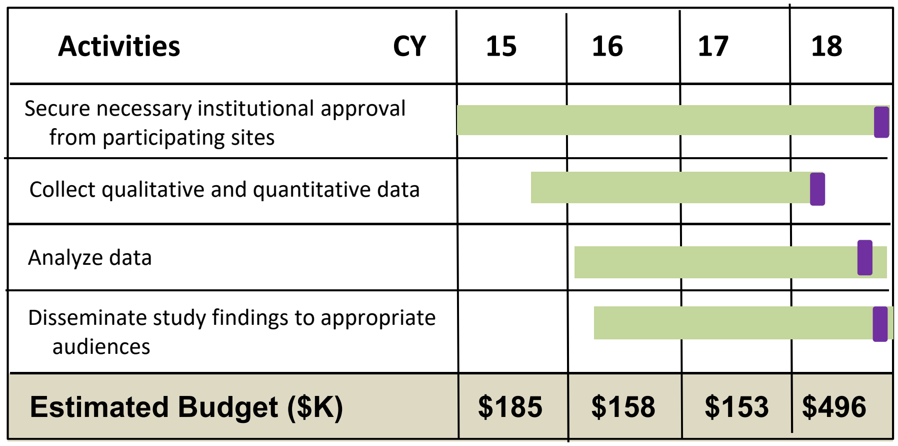
General Overview

Overall, caregivers were doing well (e.g., fair QOL, low burden and mental health symptoms); lower reports of caregiver burden and more satisfaction with social support were predictive of greater QOL in multivariate analyses. Duration of injury and age appear to play a role in caregiver wellbeing, with age of caregiver and duration of injury related to more physical health complaints.



Three profiles of caregivers were discovered using mixed methods analysis and social problem solving (PS) and social support scores. Profile 1 caregivers were more likely to report fewer concerns and more effective problem solving as well as satisfaction with social support *and* wellbeing. Profile 3 caregivers appeared to be doing better than profile 2 (less burden and trends toward less physical complaints and anxiety); however, narratives from both these profiles featured isolation, unmet needs, and less satisfaction with wellbeing relative to those in profile 1.

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: December 13, 2018

Goals/Milestones

Major Task 1: Secure necessary institutional approval from participating sites
☑ Milestone Achieved: Completion in Year 4.
Major Task 2: Coordinate study staff for participant recruitment
☑ Milestone Achieved: Completion in Year 2.
Major Task 3: Collect qualitative and quantitative data
☑ Milestone Achieved: Completion in Year 3.
Major Task 4: Analyze data
☑ Milestone Achieved: Completion in Year 4.
Major Task 5: Disseminate study findings to appropriate audiences
☑ Milestone Achieved: Completion in Year 4.
Major Task 6: Suggest implications for interventions
☑ Milestone Achieved: Completion in Year 4.

Budget Expenditure through 12/13/2018

Projected Expenditure:	$496,000
Actual Expenditure:	$496,000