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

PRINCIPAL INVESTIGATOR: Erin H. Kelly, PhD (year one); Lawrence C. Vogel, MD (years two and three)

CONTRACTING ORGANIZATION: Marquette University
Milwaukee, WI 53233

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6. AUTHOR(S)

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5f. WORK UNIT NUMBER

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13. SUPPLEMENTARY NOTES

14. ABSTRACT

This mixed-methods study aims to understand the experiences of veteran and civilian caregivers of individuals with SCI by collecting qualitative and quantitative data from 48 caregiver-care recipient dyads across four rehabilitation hospitals who together serve a diverse patient population. During our first year of funding, we have made significant progress on attaining project goals, including securing all relevant institutional approvals, conducting a review of the relevant literature and existing programs and services for caregivers, and enrolling 44 participants into the study. We have received an additional 17 referrals from interested participants and are in the process of implementing additional recruitment strategies with those who have been hard to reach. We have also initiated data analyses and have found caregivers to be sharing a variety of unmet needs related to their emotional, physical, and social quality of life (QOL), and have found these needs to relate to caregiver burden. Finally, we have made progress in terms of developing recommendations for intervention components as we held our first annual Advisory Board meeting and are preparing an abstract highlighting caregiver QOL and social support for two 2016 scientific meetings. Taken together we are confident that data from this study will help highlight unmet needs of caregivers and support the development of relevant and effective points of intervention for veterans and civilians across various sociodemographic groupings.

15. SUBJECT TERMS

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

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
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Table of Contents

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

2. **KEYWORDS:** 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.

For year one, we articulated four major tasks, and several associated sub-tasks, in our Statement of Work.

Major Task 1: Secure necessary institutional approval from participating sites; **Target date: 12/28/14**

a. Refine eligibility criteria, exclusion criteria, screening protocol; **Completed 11/11/14**
b. Finalize consent form and human subjects protocol; **Completed 11/11/14**
c. Finalize qualitative interviews and survey instruments for caregivers and their family members with spinal cord injury (SCI); **Completed 11/11/14**
d. Secure approval of protocol and consent form from Shriners Hospitals for Children Home Office; **Completed 11/21/14**
e. Coordinate with 5 sites for Institutional Review Board (IRB) submissions; **Completed 6/8/15**
f. Secure Human Research Protection Office (HRPO) approval; **Completed 6/23/15**

Please see each site's dates of IRB submission and approval, and site-specific HRPO approval:

1. *Shriners* (IRB submission: 11/11/14 & approval: 12/10/14; HRPO approval: 2/12/15)
2. *Marquette* (IRB submission: 12/22/14 & approval: 1/28/15; HRPO approval: 2/12/15)
3. *Schwab* (IRB submission: 11/13/14 & approval: 12/19/14; HRPO approval: 2/28/15)
4. *RIC* (IRB submission: 3/2/15 & approval: 3/16/15; HRPO approval: 4/3/15)
5. *Hines* (IRB submission: 11/20/14 & approval: 6/8/15; HRPO approval: 6/23/15)

Major Task 2: Coordinate study staff for participant recruitment; **Target date: 12/28/14**

a. Advertise, interview, and hire project coordinator; **Completed 10/13/14**
b. Coordinate for space allocation for new staff; **Completed 10/13/14**
c. Identify recruitment coordinators and train all on project expectations and responsibilities, including recruitment procedures; **Completed 5/1/15**

Major Task 3: Collect qualitative and quantitative data; **Target date: 9/28/15**

a. Recruit 48 individuals with SCI and their 48 caregivers who meet criteria for participation (months 4-12); **Progress: 46% complete** (44/96)
b. Conduct initial interviews with 48 caregivers and their 48 family members with SCI (months 5-12); **Progress: 39% complete** (37/96)

Major Task 4: Analyze (Qualitative) Data; **Target date: Ongoing**

a. Code qualitative data collected during initial interviews, developing codebooks based on the first few interviews, with changes made as needed during the coding of subsequent initial interviews (months 5-16); **Progress ongoing**
b. Conduct investigator-triangulation (months 6-31); **Progress ongoing**

What was accomplished under these goals?

For this reporting period describe: 1) major activities; 2) specific objectives; 3) significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative); and/or 4) other achievements. Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.

During the first year, major activities included pursuing necessary institutional approvals, securing and training staff, preparing documents needed for data collection, processing all subaward agreements and finalizing procedures with all consultants, and beginning data collection, processing, and analyses. Specific to institutional approvals, as listed above, we secured approval from the 5 Institutional Review Boards (IRB's) associated with this project (Marquette University, Edward Hines Jr. VA Hospital, Northwestern University/Rehabilitation Institute of Chicago (RIC), Mt. Sinai Hospital/Schwab Rehabilitation Hospital, and Rush University/Shriners Hospitals for Children) and an additional institutional approval from Shriners Hospitals for Children Home Office. We similarly secured approval from the Human Research Projections Office (HRPO). Because of the unexpectedly long lag-time of some of the IRB's, the HRPO agreed to approve our sites individually, which allowed us to begin recruitment at each site once their IRB and HRPO approvals were secured. Finally, we secured additional institutional approval for our Principal Investigator (Erin H. Kelly, PhD) and Project Coordinator (Ms. Titilope Akinlose) to conduct research at Hines VA as they were both granted Without Compensation (WOC) appointments in December 2014.

Specific to training activities, Dr. Kelly and Ms. Akinlose attended a two-day training on NVIVO qualitative software (offered by QSR international) in November 2014. In addition, Dr. Ryerson-Espino, the project's Qualitative Consultant, met regularly with project staff throughout year one, to help in the preparation of data collection documents, finalize training of staff related to the collection of qualitative data, and facilitate the process of data analyses. Finally, we identified and trained recruitment coordinators at the other participating sites (Hines VA, RIC, and Schwab) as each of their sites were approved in order to begin the process of identifying eligible participants.

Specific to recruitment and data collection, to date we have consented 44 participants and have completed 37 interviews. In particular, 22 participants at Shriners have been consented and we have completed 18 participant interviews (9 dyads; 90% of goal); 10 participants have been consented at Schwab and we have completed 7 participant interviews (3 dyads and 1 person with SCI; 32% of goal); 10 participants have been consented and interviewed at RIC (4 dyads and 2 persons with SCI; 45% of goal); and 2 participants have been consented and interviewed at the Hines VA (1 dyad; 6% of goal). We have received an additional 17 referral forms from our participating sites, and are in the process of implementing additional recruitment strategies with those who have been challenging to reach. In addition to collecting data from research participants, we have also conducted a review of relevant literature, and a review of the programs and services that currently exist to support caregivers. Aim 4 of our project involves making recommendations for future caregiver interventions, and we are seeing these three data sources (participant data, literature review, and review of existing programs and services) as critical to developing relevant and effective points of intervention.

Specific to data processing and analyses, we have worked with a contracted transcription service to transcribe interviews immediately after they are conducted, and have uploaded all completed interviews into Nvivo to facilitate coding. These interviews have been coded individually by Ms. Akinlose and collectively by Ms. Akinlose and Drs. Kelly and Ryerson-Espino, and we have developed preliminary codebooks based on this first round of interviews with caregivers and individuals with SCI. We have also entered quantitative data into a database in the Statistical Package for the Social Sciences (SPSS) and have begun running preliminary analyses. In order to maximize integration of our qualitative and quantitative data, we are developing case summaries for all dyads with complete data. These case summaries have helped us to describe each participant and their caregiving relationship more holistically across qualitative and quantitative data sources. These case summaries have also helped us to identify additional questions for our follow-up interviews.

In terms of preliminary findings, we have initiated a more systematic exploration of data belonging to participants recruited from Shriners. Individuals with SCI from this subgroup are unique in that they acquired their SCI at younger ages when compared to those recruited from other sites. Qualitatively, participating caregivers have shared a variety of unmet needs related to emotional, physical, and social quality of life. Specifically, caregivers are sharing:

- Feeling emotionally drained as a result of their responsibilities
- Being physically exhausted as a result of caregiving duties on top of their regular work schedule
- Wanting to socialize more with family and friends, but being limited by a lack of accessibility in family and friends' homes
- Being too tired to be intimate with their significant other or not having access to the right resources for an intimate relationship
- Stopping participation in previous meaningful activities
- Needing more individual down time, in regards to social integration, but also self-care

In terms of structured quantitative survey data, results suggest that overall the Shriners caregivers appear very healthy and satisfied in their roles; however, 5 caregivers (62.5%) appear to have "red flags" or challenges related to at least one area of concern, including quality of life, satisfaction with leisure time, experience with physical health symptoms, depression, anxiety, or satisfaction with instrumental, emotional, or informational support. The presence of a red flag was found to significantly relate to caregiver burden such that those with at least one red flag had significantly higher caregiver burden scores when compared to those without red flags (Independent Sample Mann Whitney U Test, $p < .05$). On average, those without a red flag reported experiencing caregiver burden “never to rarely" ($M = 1$, $SD = 1.73$), whereas those with at least one red flag reported experiencing caregiver burden “rarely to sometimes” ($M = 19$, $SD = 8.75$). These relationships are intuitive and occurring in expected directions, and we will continue to evaluate relationships as our sample grows.

Finally, we have begun the steps needed to work towards developing ecologically valid recommendations for intervention, as in June we convened our Advisory Board and held our first annual meeting. Our 17 board members included clinicians, researchers, individuals with SCI, and caregivers. During this meeting, project staff presented an overview of the study design, framework, and some preliminary findings related to a) participant assessments, b) our review of the relevant literature, and c) our review of existing services and programs. We envision all three of these data sources to be critical in terms of recommending appropriate and effective next steps for intervention. Our Advisory Board meeting was incredibly productive and included great participation from all members. After the meeting, we conducted a brief evaluation of the meeting processes in order to enhance our ability to capture all board members’ input during our meetings in years two and three.

In terms of goals that have not yet been met, while we have made significant progress regarding recruitment and data collection, we had expected to be completing recruitment by the end of year one. However, as we have communicated in the context of our quarterly reports, participant recruitment has been delayed due to several IRB-related challenges. In addition, we have learned from our site collaborators that the originally agreed upon recruitment criteria were too limiting. As a result, as explained below we are currently processing amendments at all sites to expand our recruitment criteria, and to allow for the recruitment of patients through community organizations that serve individuals with disabilities and their families. We expect this expansion to allow us to complete participant recruitment in the early part of year two of our project.

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.

As mentioned above, during the first quarter the PI and Project Coordinator attended a two-day training on NVIVO qualitative software (offered by QSR international). The training provided an in-depth look at the software and its ability to facilitate efficient qualitative analyses. In addition,

Dr. Kelly and Ms. Akinlose have had regular meetings with the project's qualitative consultant, Dr. Susan Ryerson-Espino, in order to enhance qualitative data collection and analyses techniques.

Specific to scientific meetings, Dr. Kelly attended the annual meeting of the American Spinal Injury Association (May 2015) and the Academy of Spinal Cord Injury Professionals (September 2015), and Ms. Akinlose attended the Paralyzed Veterans of America Summit (September 2015). While this year was premature for the presentation of project findings, we are currently preparing abstracts for submission to the 2016 meetings of these professional organizations.

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.

On June 10th, 2015, we held our first annual Advisory Board meeting with a group of researchers, clinicians, caregivers, and individuals with SCI to present and discuss the study design, framework, and some preliminary data and findings. Specifically, we presented results related to participant interview and survey data we had collected, our review of relevant literature, and our review of existing services and programs. As mentioned above, we are currently preparing our first round of abstracts to disseminate early findings to the scientific community. We look forward to continuing the dissemination of project findings to a variety of scientific, clinical, and consumer audiences as we continue on with data collection and analyses.

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.

As we have communicated to our Science Officer and other pertinent officials within the Department of Defense, Dr. Kelly (the project PI) has left her position at Marquette University. As a result, Dr. Lawrence C. Vogel (previously a Co-PI on this project), has taken over as PI. While Dr. Kelly will remain as a Co-Investigator on this project, Dr. Vogel will be leading all future project activities, along with Dr. Ryerson-Espino whose role has changed from Consultant to project Co-PI and Project Director.

During the next reporting period we will do the following:

1) Continue recruiting and consenting participants at Shriners, Schwab, RIC and Hines.
    a. As mentioned, we are in the process of expanding recruitment criteria and methods which we expect will positively impact recruitment efforts. We also recently met with all site Investigators and Recruitment Coordinators to talk about bolstering recruitment efforts, which allowed for problem-solving around site-specific recruitment issues. Finally, we will be instituting monthly recruitment calls with all Recruitment Coordinators to ensure progress and problem-solve barriers in an ongoing way.
2) Submit necessary amendments regarding the change in PI, participant eligibility criteria, and recruitment methods to all 5 IRB's and HRPO for final approval (we have already consulted with and received preliminary approval from the HRPO for these changes, and have received approval from the Marquette University IRB for the change in PI).
3) Continue collecting the remaining first round of qualitative and quantitative data from caregivers and the individuals with SCI for whom they care.

4) Continue analyzing data (qualitative and quantitative), including conducting investigator triangulation.
    a. Further refine and add to the existing codebooks for interviews conducted with a) individuals with SCI and b) caregivers.
    b. Continue systematic reviews of literature and existing services.
    c. Review tools and literature to help inform intervention development.
5) Initiate dissemination activities with abstract submission to the 2016 meeting of the American Spinal Injury Association and the 2016 Paralyzed Veterans of America Summit highlighting caregiver quality of life and social support.

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

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

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

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

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.*

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

5. CHANGES/PROBLEMS: The 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.

Due to the slower than expected pace of recruitment, as communicated to our Science Officer and the HRPO, we are seeking to make changes to the study protocol concerning participant eligibility criteria. Our current criteria for persons with SCI include individuals between the age of 25-44, with a traumatic SCI who sustained their injury at 17 years of age or older, and were injured at least one year prior to the time of their first interview. In response to feedback from our collaborators, we are proposing the following changes to the eligibility criteria for persons with SCI: a) Expand the requirement for current age to 18-65, and b) Expand etiology of the SCI to include both traumatic and non-traumatic, but stable (i.e., non-progressive), etiologies (e.g., transverse myelitis). As mentioned above, these changes are being made in response to feedback from collaborators, who found our previously agreed-upon criteria too strict. This, in combination with the IRB delays we experienced, have contributed to a slower-than-expected recruitment rate. We believe that these changes will increase participant recruitment and ensure that we meet our recruitment goals for the study.

In addition, we are proposing to expand our mode of recruitment. We are currently recruiting participants from four hospitals in or around Chicago that serve a diverse group of individuals with SCI: the Edward Hines, Jr. VA hospital (Hines), the Rehabilitation Institute of Chicago (RIC), Schwab Rehabilitation Hospital (Schwab), and Shriners Hospitals for Children (Shriners). While we will still recruit individuals with SCI who received care at one of these four sites, we would like to add the ability to recruit participants through local community organizations (e.g., the Spinal Cord Injury Association of Illinois and local chapter of the Paralyzed Veterans of America). This will involve posting information about the study within organizational newsletters and websites. In addition to recruiting individuals directly from our participating sites, we are hoping this will provide another effective way to reach out to individuals who have received care at our four participating hospitals.

Lastly, there will be a change in leadership regarding the study. As mentioned above, the original PI of this study, Dr. Erin Kelly has resigned from her position at Marquette University, and therefore from her position as PI of this study. While Dr. Kelly will remain on the study as a Co-Investigator, Dr. Lawrence Vogel, previously a Co-PI on this project, will be assuming the role as study PI, and Dr. Susan Ryerson Espino, the study's Qualitative Consultant, will be stepping in as the new Co-PI. We have secured approval from the Department of Defense to make these changes, and this has also been approved by the Marquette University IRB. We are currently in the process of submitting amendments to all other IRBs to reflect these leadership changes as well.

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.

We have experienced significant IRB-related delays. This has pushed back our anticipated start-dates for recruitment and data collection at all hospital sites, which in turn has affected our ability to reach our target number for participant recruitment and completed interviews in year one. However, we are now actively recruiting participants at all 4 clinical sites and are in the process of expanding our participant eligibility criteria. As a result we expect to see a significant improvement in participant recruitment rates during year two.

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.

Participant qualitative interviews were targeted to be between 1 hour and 1.5 hours for individuals with SCI and between 1.5 hours and 2 hours for caregivers. However, these interviews have been shorter than originally targeted, reducing the anticipated cost for transcribing participant interviews. We will continue to monitor expenditures (including transcription costs) as time goes on, as we expect to see the second round of interviews to be longer than the first round now that initial rapport has been established.

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

None to Report

Significant changes in use or care of vertebrate animals

None to Report

Significant changes in use of biohazards and/or select agents

None 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).*

None to Report

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).*

None to Report

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.

We are currently preparing an abstract for submission to the 2016 meeting of the American Spinal Injury Association and the 2016 Paralyzed Veterans of America Summit.

- **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.

  None 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.

  None 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.

  None 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.*

None 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."

Example:

Name: *Mary Smith*
Project Role: *Graduate Student*
Researcher Identifier (e.g. ORCID ID): 1234567
Nearest person month worked: *5*
Contribution to Project: *Ms. Smith has performed work in the area of combined error-control and constrained coding.*
Funding Support: *The Ford Foundation (Complete only if the funding support is provided from other than this award).*

**Please note this reflects what occurred during year one. Dr. Vogel took over as PI at the start of year two, and our Q5 report will reflect the new changes presented above.

Name: Erin H. Kelly, PhD
Project Role: Principal Investigator
Nearest person month worked: 2.4
Contribution to Project: No Change

Name: Titilope Akinlose, MPH
Project Role: Research Coordinator
Nearest person month worked: 11.25
Contribution to Project: No Change

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:
Organization Name:
Location of Organization: (if foreign location list country)
Partner's contribution to the project (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.*

Organization: Shriners Hospitals for Children – Chicago
Location: 2211 N. Oak Park Ave
Chicago, IL 60707
Contribution: Dr. Kelly and Ms. Akinlose use Shriners Hospital's facilities for project activities. In addition, Shriners serves as a site of participant recruitment for individuals with SCI and their caregivers.

Organization: Edward Hines, Jr. VA Hospital
Location: 5000 S. 5th Ave
Hines, IL 60141
Contribution: Hines is one of the project's collaborating partners and serves as the site of recruitment for veterans with SCI and their caregivers.

Organization: Rehabilitation Institute of Chicago
Location: 345 E. Superior St.
Chicago, IL 60611
Contribution: RIC serves as another site of participant recruitment for individuals with SCI and their caregivers.

Organization: Schwab Rehabilitation Hospital
Location: 1401 S. California Ave
Chicago, IL 60608
Contribution: Schwab serves as our final 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 provided valuable information on program and services that the organization offers to paralyzed veterans.

Organization: Spinal Cord Injury Association of Illinois
Location: 1032 South La Grange Road #5
La Grange, IL 60525
Contribution: Provided valuable information on program and services the organization offers to persons living with SCI and their families.

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.

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.