

AWARD NUMBER: W81XWH-19-1-0735

TITLE: Loneliness and Its Relation to Health in People with Spinal Cord Injury

PRINCIPAL INVESTIGATOR: Susan Robinson-Whelen, Ph.D.

CONTRACTING ORGANIZATION: Baylor College of Medicine

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14. ABSTRACT The objective of this study is to enhance the understanding of loneliness in people with SCI and examine its relation to psychological and physical health through a longitudinal survey study. We propose four specific aims designed to enhance the understanding of 1) the experience of loneliness in people with SCI, 2) the contextual factors (e.g., demographics, disability characteristics) related to loneliness, 3) the relation between loneliness and psychological and physical health in people with SCI, and 4) the extent to which loneliness predicts health independent of contextual variables, including social isolation. We will conduct a national longitudinal survey study of 350 people with SCI. Participants will complete the survey at baseline and again 12 months later. Data collection has not yet begun, but findings have the potential to both advance SCI research by informing intervention development and improve clinical care by alerting health care providers of the importance of addressing loneliness in their patients.						
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1. Introduction

Research with the general population demonstrates the adverse effects of loneliness on health. Few studies, however, have addressed loneliness and its relation to health in people with SCI who often lack opportunities for social connection. The objective of this study is to enhance the understanding of loneliness in people with SCI and examine its relation to psychological and physical health through a longitudinal survey study. We propose four specific aims designed to enhance the understanding of 1) the experience of loneliness in people with SCI, 2) the contextual factors (e.g., demographics, disability characteristics) related to loneliness, 3) the relation between loneliness and psychological and physical health in people with SCI, and 4) the extent to which loneliness predicts health independent of contextual variables, including social isolation. With input from a community advisory board (CAB) of men and women with SCI, we will conduct a national longitudinal survey study of 350 people with SCI. Participants will complete the survey at baseline and again 12 months later. With a detailed plan to minimize attrition, we anticipate having longitudinal data on a sample of 300. Findings have the potential to both advance SCI research by informing intervention development and improve clinical care by alerting health care providers of the importance of addressing loneliness in their patients.

2. Keywords

Spinal cord injury, loneliness, social isolation, physical health, psychological health

3. Accomplishments

What were the major goals of the project?

Specific Aims 1-4	Timeline Yr/Qrtr	Progress
Major Task 1 – Study Initiation		
Secure approval from BCM's IRB	Y1Q1	Completed
Secure approval from UM's IRB	Y1Q1	Completed
Secure approval from TIRR-MH	Y1Q1	Completed
Secure USAMRMC Office of Research Protections (ORP) approval	Y1Q1-Y1Q2	Completed
Hire/train research assistant(s)	Y1Q1	Completed
Conduct regular meetings with research team	Y1Q1-Y3Q4	Completion ongoing
Convene/hold Community Advisory Board (CAB) meetings	Y1Q1-Y3Q4	Completion ongoing
Obtain IRB/HRPO approval for docs and protocols (ongoing, as needed)	Y1Q1- 3Q4	Initial approvals completed; IRB approval of amendments completed; HRPO approval of amendments is pending
<i>Milestone: IRB approvals, USAMRMC ORP approval, TIRR- MH approval</i>	Y1Q2	Initial approvals completed; Approval of amendments by HRPO is pending
Major Task 2 – Prepare for National Survey Study Data Collection		
Finalize list of measures	Y1Q1	Completed
Develop screening interview, consent script, consent form	Y1Q1-Y1Q2	Completed
Develop T1 and T2 surveys using Qualtrics	Y1Q1-Y1Q2	Completed
Establish procedures for study implementation	Y1Q1-Y1Q2	Completed
Develop/produce recruitment flyers, promotional items, news blurbs, posts, and recruitment letters	Y1Q2	Completed
Create/maintain databases for collecting participant data, tracking participant progress, and tracking recruitment activities	Y1Q2-Y3Q4	Completion of Database; maintenance ongoing

<i>Milestones Achieved: *Procedures finalized for Beta Test Screening interview; *Qualtrics survey developed for Beta Test *Databases created</i>	Y1Q2	Completed
Major Task 3 – Conduct Beta Test		
Conduct beta test with CAB	Y1Q2-Y1Q3	Completed
Revise procedures/docs based on beta	Y1Q2-Y1Q3	Completed
<i>Milestone(s) Achieved: All materials and procedures revised and ready for full survey study</i>	Y1Q3	Completed; Awaiting HRPO approval of amendments in order to begin enrollment.
Major Task 4 – Implement Full Study		To be completed Y1Q3 – Y3Q3
Distribute recruitment materials to organizations across the U.S.	Y1Q3-Y2Q3	Have begun contacting organizations. Not distributing flyers until final approval is obtained
Screen and enroll 350 participants in the national survey study	Y1Q3-Y2Q3	Awaiting HRPO approval of amendments in order to begin enrollment.
Collect T1 data	Y1Q3-Y2Q3	
Collect T2 data	Y2Q3-Y3Q3	
<i>Milestone Achieved: Data collection complete on 7% of sample Data collection complete on 39% of sample Data collection complete on 58% of sample Data collection complete on 84% of sample Data collection complete on 100% of sample</i>	Y2Q3 Y2Q4 Y3Q1 Y3Q2 Y3Q3	
Major Task 5 – Data Entry, Management, and Analysis		To be completed Y1Q3 – Y3Q3
Maintain data management systems and create/maintain comprehensive data codebook	Y1Q3-Y3Q4	Data management systems have been created and data codebook has been completed; maintenance will be ongoing
Conduct weekly data checks, test quality and integrity of the dataset	Y1Q3-Y3Q4	Awaiting HRPO approval of amendments in order to begin enrollment and data collection.
Complete data scoring and data consolidation of contextual variables	Y2Q3	
Analyze data and test hypotheses (cross-sectional analyses to begin Y2Q4; longitudinal analyses to begin Y3Q3)	Y2Q4-Y3Q4	
Present results to the advisory board for input on interpretation and ideas for dissemination to consumers	Y2Q4-Y3Q4	
<i>Milestone Achieved: Data analysis and interpretation complete</i>	Y3Q4	
Major Task 6 – Dissemination of Findings and Fact Sheets		
Complete deliverable reports to CDMRP	Y1Q1-3QY4	This is the first annual report provided.
Present findings at scientific meetings	Y2Q4-Y3Q4	Planned for Years 2-3
Prepare/submit manuscripts to peer-reviewed journals	Y2Q4-Y3Q4	Planned for Years 2-3
Develop Fact Sheets and materials with CAB for health care/disability service providers	Y2Q4-Y3Q4	Planned for Years 2-3
Prepare final report for CDMRP	Y3Q4	Planned for Year 3
<i>Milestone Achieved: Dissemination of study findings complete</i>	Y3Q4	Planned for Year 3

What was accomplished under these goals?

Major Task 1 (Study Initiation) –

- We secured IRB approval from Baylor College of Medicine (Protocol #H-45581), secured approval from the University of Montana IRB to rely on the BCM IRB as the IRB of record (UM IRB #166-19), and secured approval from TIRR Memorial Hermann (TIRR-MH) through the Memorial Hermann Healthcare Foundation, and secured USAMRMC Office of Research Protections (ORP) approval for our *initial* protocol and all initial study materials.
- We interviewed research assistant candidates, checked references, and hired Jessica Rodriguez, a woman with experience working as a Research Assistant on other disability studies, to serve as project RA. Upon joining our team, she received training on research center processes and procedures, including instruction on suicide risk protocols and procedures. She also participated in the research center's training specific to spinal cord injury, including the *Introduction to SCI* video course. She was also trained in the Qualtrics software program for survey development. This training was supplemented with re-instruction utilizing online video training. We elected to use the secure data collection tool RedCap for our tracking database (to track screening, enrollment, survey completion, and participant payment). RA Rodriguez had not previously used RedCap, so we utilized online trainings and consultation with more senior research assistants to help her develop proficiency in creating our tracking database for the project.
- We have conducted regular investigator meetings, meeting bi-weekly throughout most of the project period. In addition, PI Susan Robinson-Whelen has met weekly with RA Jessica Rodriguez. Dr. Robinson-Whelen has sought input from our Consultant, Dr. Sally Ann Holmes via phone and email consultation. Dr. Holmes has also been able to attend and provide input as part of our series of CAB meetings.
- We met with our Community Advisory Board (CAB) for three of our four scheduled quarterly meetings. The advisors have been highly engaged in our first-year activities. The focus of our fourth and final meeting in Year was on recruitment, particularly ideas, suggestions, and resources for obtaining diversity in our recruitment efforts. Our fourth meeting was delayed while we wait for HRPO approval of our study amendments. The amendments were submitted to HRPO on July 28, 2020, after receiving approval through our institutional IRB. We plan to hold this additional CAB meeting as soon as HRPO approval is received and recruitment can begin. The CAB members have been fully engaged in our first-year activities. After identifying one replacement CAB member for an advisor who no longer had the time to serve on the CAB, we have had full participation of all 7 advisors. Their involvement has included: providing input on constructs and measures they thought should be included that might have a bearing on or influence loneliness in the context of SCI; offering suggestions on the wording of study documents (consent, comprehension of consent, survey instructions; flyers and recruitment materials); beta-testing and providing input on the survey instrument; providing input on processes and procedures; developing an easy to remember and recognize study name and logo (see Appendix 9e); assisting in selecting promotional items that would be useful and meaningful for people with SCI; and helping develop COVID-19 related items to capture the influence of COVID-19 on study participants and how those impacts might affect key study outcomes.
- As proposed and anticipated in the original grant submission, we made a number of changes to the protocol and study documents initially approved by our IRBs and by HRPO as a result of our CAB's input. Additional changes were incorporated, with CAB input, due to the potential impact of the pandemic. These amendments were approved by our BCM IRB of record. We are currently awaiting approval of the amendments by HRPO. (Amendment documents submitted to HRPO on 07-28-2020).

Major Task 2 (Prepare for National Survey Study) –

- During Year 1, with the input of community advisors, study investigators, and Consultant Holmes, we finalized our constructs and measures to be included in the national survey.
- We developed our screening interview and consent script. These initial documents were reviewed and approved by IRBs and HRPO. Minor edits were made (e.g., simplifying and clarifying language, included new study name and logo, adding new email address and phone number) which have been approved by the IRB of record. We are awaiting approval of these and other edits/amendments by the HRPO.

- We have developed our Qualtrics surveys and have incorporated the modifications and additions suggested by the CAB and the study investigative team.
- We have established procedures for study implementation. As part of this process, we created a project specific email address that corresponds to the CAB-suggested project title and will be easier for participants to remember (Social Connections after Injury Study, SCIstudy@bcm.edu). In the process of finalizing study processes and procedures, it was determined, with input from our advisors, that the method of payment originally proposed (e.g., ClinCard) was problematic for our study participants (requiring participants to provide additional PHI, provide a signature documenting receipt, and retain the card for a full year to be re-loaded at Time 2). The only alternative (use of a pre-paid Visa card) was cost-prohibitive. We have now modified our payment plan moving participant payment to the TIRR-MH subcontract. This was communicated with our Science Officer and has been approved through both BCM and TIRR-MH. Payment plans are in place and ready for participant enrollment.
- With the input of the CAB and Consultant Holmes, we also modified our recruitment materials to include the new study name, logo, project phone number and project email address. The CAB also assisted us in selecting promotional items to be sent to study participants to keep them engaged with the project and make it easier for them to reach us if they were to move or if their contact information were to change. We have ordered magnets with the study name and logo with a place to record the person's anticipated date of their 12-month (Time 2) assessment. These will be sent with their initial payment (and consent form, if electing to receive a paper copy of the consent information). We have also ordered birthday cards and stylus pens with the study name and logo to be sent to participants on their birthdays. The CAB provided input on a promotional item (i.e., a stylus pen) thought to be useful to all participants regardless of their level of injury and provided input on the recommended size and weight of the stylus pen.
- We have created the study's tracking database which we will use to track screening, enrollment, survey completion, participant payments, and other contacts with participants. Although we ask participants to complete the survey immediately- study enrollment, the study RA Rodriguez, has programmed the tracking database to send automated email messages (to participants completing the survey online) to remind them to complete the survey. If the survey has not been completed within two weeks, the tracking database alerts the RA to initiate phone calls to the participant to encourage survey completion and assess if the participant is experiencing any barriers to completing the survey. RA Rodriguez has also programmed the tracking database to send herself alerts indicating which participants are due to receive birthday cards, the 11-month reminder email, and the 12-month (Time 2) assessment.

Major Task 3 (Conduct Beta Test) –

- We completed the beta test with our investigative team and CAB members. We used an iterative process, making revisions after each advisor completed the survey before sending the link to the next CAB member. We balanced those completing the survey via computer or other device (e.g., smart phone, tablet).
- Changes were incorporated and the survey was being finalized as the impact of COVID-19 in the US became apparent. The investigative team held ongoing discussions of the potential impact of the pandemic on the study, and most importantly, the potential impact on the SCI population that would need to be assessed in the study survey. In fact, at this same time some of our CAB members proactively reached out to us to share their concern that the pandemic might have an impact on several of our outcome variables.
- RA Rodriguez met individually with each CAB member to seek their input on the perceived, actual, or anticipated impacts of COVID-19 on people with SCI, and their recommendations for questions to include in the survey to address/capture those impacts. We drafted additional items to assess the potential impact of the pandemic on participants' lives, and these items were reviewed with CAB members and incorporated into our study survey. The items generated ask about specific COVID-related experiences as well as the self-perceived impact of COVID-19 on their community participation and psychosocial health (e.g., stress, depression, anxiety, sense of loneliness). As our CAB members emphasized, COVID-19 is likely to impact the disability community longer than the general healthy population; therefore, we currently plan to include these additional items throughout the survey period at both Time 1 and Time 2.
- The final version of our survey, including COVID-19 items, was submitted as part of our IRB amendment and has received BCM IRB approval. After receiving IRB approval, the survey and all other study documents were submitted to HRPO for approval. We are currently awaiting HRPO approval to begin recruitment for the national survey.

Major Task 4 (Full Study Implementation) –

Screening/enrollment, and data collection have not yet begun as we are awaiting HRPO approval of our amendments. We have, however, begun to reach out to a few key organizations to request/remind them of their offer to assist with recruitment. Without sending recruitment flyers, we have contacted ILRU regarding CILs that serve predominantly minority consumers; we have discussed our rural recruitment strategy with Co-Investigator Hughes, and we have reached out to two leaders of PVA to discuss methods for reaching veterans without internet access and those in more rural areas of the country. We plan to begin our recruitment efforts targeting these hard-to-reach populations who are often underrepresented in research.

Major Task 5 (Data Management and Analysis) -

- The tracking database, data management systems, and data dictionary/codebook have been created and are ready for study implementation.
- Remaining Major Task 5 activities are scheduled to begin when data are available.

Major Task 6 (Dissemination) –

- These tasks are scheduled to be completed in later quarters with the exception of “complete deliverable reports to CDMRP (quarterly, annually).” This report is the first annual report outlining our progress.

What opportunities for training and professional development has the project provided?

RA Rodriguez has had the opportunity to acquire survey development and tracking database development skills as part of her work on this project as well as education regarding spinal cord injury. Some of this training was provided by more experienced research staff at TIRR-MH; much was obtained via online tutorials; some was obtained through consultation with software helplines/resources; and some was provided through consultation with senior research staff at collaborating institutions. RA Rodriguez has developed skills that will benefit our research center beyond this specific project. Members of the investigative team have recently submitted two grant applications to DoD as part of the Spinal Cord Injury Research Program, and it is anticipated that RA Rodriguez' expertise will be helpful on these DoD projects, if funded.

How were the results disseminated to communities of interest?

No data are available at this time; thus no results from the study were disseminated. However, information on constructs and literature relevant to the study were shared with people with SCI through a webinar hosted by the Christopher and Dana Reeve Foundation. PI Robinson-Whelen, Co-I Hughes and Community Advisor Norah-Davis co-presented a webinar entitled *Women's Mental Health after Paralysis*. In the webinar, we discussed the value of maintaining positive social connections and the importance to psychological health outcomes such as those examined in the current study. The information reviewed was from the broader literature. The current study will provide additional information specific to people living with SCI.

What do you plan to do during the next reporting period to accomplish the goals and objectives?

We do not anticipate any difficulties accomplishing the goals and objectives outlined in the Major Tasks outlined above. In the next reporting period, we plan to focus on recruitment, enrollment, data collection, and T1 data management activities.

4. Impact

What was the impact on the development of the principal discipline(s) of the project?

Nothing to report

What was the impact on the other disciplines? - Nothing to report

What was the impact on technology transfer? - Nothing to report

What was the impact on society beyond science and technology? - Nothing to report

5. Changes/Problems

Changes in approach and reasons for change

We have had only three unexpected changes. First, we have incorporated questions about the impact of COVID-19 on study participants. The addition of these questions were noted in previous quarterly reports and were described in our outlined amendments submitted to our IRB and to HRPO. These additional items are not intended to expand the scope of the study but rather to offer us the opportunity to consider the contribution of COVID-19 on outcome variables in our analyses. These items will be explored both as risk factors for loneliness (Aim 2) and as contextual covariates in the examination of study outcomes (Aim 4). Second, we changed participant payment to take place through TIRR-MH in order to make the payment process more user-friendly for study participants. We were able to do so with the approval of our Science Officer, BCM, and TIRR-MH. Third, our study statistician passed away in Year 1 after battling cancer. We disclosed the loss of our statistician (consultant) in our previous quarterly report and noted that we were engaged in a search for alternate statistical support services. We explored other resources for statistical support, and the project PI met with members of Baylor College of Medicine's Institute for Clinical and Translational Research. The PI met with two biostatisticians, Dr. Charles Minard and Dr. Kristen Andrews Staggers, and reviewed the study design and the planned analyses and shared the grant application and the survey instruments. In consultation with their business operations manager, Drs. Minard and Staggers agreed to conduct the analyses utilizing the funds that had been budgeted for Dr. Swank in Years 2 and 3, which translated to 1% FTE of Dr. Minard and 2.75% FTE of Dr. Staggers. In the upcoming quarter, we plan to submit an amendment to the IRB to reflect their addition to the project.

Actual or anticipated problems or delays and actions or plans to resolve them

We were delayed in finalizing our study measures as a result of COVID-19. As noted above, the investigators as well as the advisors recognized the potential impact of the pandemic on study outcomes. This caused us to delay moving forward while we paused to consider the impacts and generate questions to allow us to examine those potential impacts. We were then able to move forward submitting these as well as other amendments that resulted from the input and feedback of our advisors. We submitted these amendments to BCM's IRB for approval and subsequently forwarded the documents and IRB approval letter to HRPO for approval on 07/28/20. We are currently waiting for HRPO approval to begin recruitment and enrollment. If HRPO approval is received soon, we anticipate being able to increase our pace of recruitment and achieve our study enrollment near our originally proposed data collection milestones. While the Statement of Work reflects completing T1 data collection by Year 2 Quarter 3 (and T2 data collection by Year 2 Quarter 4), we should be able to stay near to this schedule with anticipated T1 data collection concluding in Year 2 Quarter 4.

Changes that had a significant impact on expenditures

As noted above, the investigators as well as the advisors recognized the potential impact of the pandemic on study outcomes. This caused us to delay moving forward while we paused to consider the impacts and generate questions to allow us to examine those potential impacts. We submitted these new items as well as other amendments to BCM's IRB for approval and subsequently forwarded the documents (and the IRB approval letter) to HRPO for approval. If HRPO approval is received soon, we anticipate being able to increase our pace of recruitment and achieve our study enrollment near our originally proposed data collection milestones. While the Statement of Work reflects completing T1 data collection by Year 2 Quarter 3, we should be able to stay near to this schedule with anticipated T1 data collection concluding in Year 2 Quarter 4. These changes have delayed the start of enrollment and thus they have postponed some expenditures; however, at this time we do not expect these changes to have a significant impact on expenditures over time.

Significant changes in use of care of human subjects, vertebrate animals, biohazards, and/or select agents - Nothing to report.

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

Publications, conference papers, and presentations

Journal publications

Nothing to report. No data yet collected.

Books or other non-periodical, one-time publications

Nothing to report. No data yet collected.

Other publications, conference papers, and presentations

No data have yet been collected; thus, there have been no publications or conference presentations specifically about this study. However, qualitative feedback from a current intervention study seems to reflect perceptions of loneliness among women with SCI. These findings are noted and the current DoD project is mentioned as part of an upcoming conference presentation at ACRM (see reference and PPT slides in the Appendix 9d). In addition, as noted above, PI Robinson-Whelen, Co-I Hughes, and Advisor Norah-Davis presented a webinar entitled *Women's Mental Health after Paralysis* through the Christopher and Dana Reeve Foundation. This webinar is relevant to the subject matter of the current study.

Website(s) or other Internet site(s) - Nothing to report

Technologies or techniques - Nothing to report

Inventions, patent applications, and/or license - Nothing to report

Other Products - Nothing to report

7. Participants and Other Collaborating Organizations

What individuals have worked on the project?

Name:	Susan Robinson-Whelen, PhD
Project Role:	PI
Researcher Identifier (e.g., ORCID ID)	https://orcid.org/0000-0002-8942-9721
Nearest person month worked:	3
Contribution to Project:	Dr. Robinson-Whelen is responsible for supervising the activities of the project team and coordinating the work of the consultants and advisors. She oversees all project activities, implements quality control measures, monitors fiscal management, and assures adherence with commitments described in the proposal. She meets regularly with all study contributors to ensure that implementation of the study is smooth. Dr. Robinson-Whelen will work closely with the research assistant and the statisticians on the maintenance of the databases and the scoring and consolidation of data in preparation for analysis. She will work with the statistician and the investigative team to analyze and interpret the data and disseminate findings to consumer and professional audiences.
Funding Support:	-----

Name:	Heather Taylor, PhD
Project Role:	Co-I
Researcher Identifier (e.g., ORCID ID)	https://orcid.org/0000-0003-3578-2113
Nearest person month worked:	1.2
Contribution to Project:	Dr. Taylor serves as Co-I and PI of the TIRR-MH subaward. She monitors fiscal management of the subcontract. She participates in regular meetings with the investigative team and the community advisory board (CAB) and advises on study measures, procedures, and protocols. As the Director of the Texas Model Spinal Cord Injury System, she will use her connections with fellow SCI Model Systems Directors to promote distribution of study recruitment materials across the U.S. Dr. Taylor will also assist with the interpretation and dissemination of study results, collaborating on conference presentations, peer-reviewed journal articles, and consumer fact sheets.
Funding Support:	-----
Name:	Rosemary Hughes, PhD
Project Role:	Co-I
Researcher Identifier (e.g., ORCID ID)	https://orcid.org/0000-0001-5327-4740
Nearest person month worked:	1.2
Contribution to Project:	Dr. Hughes is Co-I and PI of the University of Montana subaward. Dr. Hughes oversees all subcontract activities and maintains IRB approval from the University of Montana. She participates in regular teleconferences with the project team and coordinates the activities of the community advisory board. She contributes to all aspects of the measurement development as well as the planning and implementation of the study. Dr. Hughes will access multiple networks in rural settings to ensure the participation of people with SCI living in remote and rural America. In Year 3, Dr. Hughes will collaborate on the submission of abstracts for conference presentations and manuscripts.
Funding Support:	-----
Name:	Jessica Rodriguez, BS
Project Role:	Research Assistant (RA)
Researcher Identifier (e.g., ORCID ID)	-----
Nearest person month worked:	9
Contribution to Project:	RA Rodriguez schedules, attends, take notes, and records proceedings of regularly scheduled CAB meetings. She manages payment of CAB members. She assists in maintaining IRB approvals and assists with quarterly and annual reports to the funding agency. RA Rodriguez has created the participant tracking database as well as the data collection surveys. She worked with the investigative team and the CAB to revise and refine these documents. She will be responsible for screening, enrolling and consenting study participants; sending participants links to the surveys; and monitoring survey completion. The RA also will be responsible for making and tracking participant payments. Under the PI's direction, the RA will maintain the databases, check the data for inaccuracies and outliers, and develop the data dictionary. In year 3, the RA will also assist with the preparation of the fact sheets, presentations, and manuscripts.
Funding Support:	-----

Has there been a change in the active other support of the PD/PI or senior/key personnel since the last reporting period?

No

What other organizations were involved as partners?

Organization Name: TIRR Memorial Hermann

Location of Organization: Houston, TX

Partner's contribution to the project:

Financial support:

In-kind support: Makes computers, software, equipment available to TIRR-MH Co-I/RA

Facilities: TIRR-MH Co-I/RA use TIRR-MH facilities/office space for project activities

Collaboration: TIRR-MH Co-I/RA collaborate with PI and UM Co-I on project activities

Personnel exchanges

Organization Name: University of Montana, Rural Institute for Inclusive Communities

Location of Organization: Missoula, MT

Partner's contribution to the project:

Financial support:

In-kind support: Makes computers, software, equipment available to UM Co-I

Facilities: UM Co-I uses UM facilities/office space for project activities

Collaboration: UM Co-I collaborates with PI and other project personnel on project activities

Personnel exchanges

8. Special Reporting Requirements

Collaborative Awards – Not applicable

Quad Chart

Loneliness and Its Relation to Health in People with Spinal Cord Injury

PI: Susan Robinson-Whelen, Ph.D. Org: Baylor College of Medicine Award Amount: \$607,008.00



Study/Product Aim(s)

We aim to enhance understanding of:

- the experience of loneliness in people with SCI, including veterans;
- the contextual factors (demographics, disability characteristics) related to loneliness;
- the relation between loneliness and psychological and physical health in people with SCI; and
- the extent to which loneliness predicts psychological and physical health independent of the influence of contextual variables, including social isolation.

Approach

With input from a community advisory board of people with SCI, we plan to conduct a longitudinal national survey study of 350 civilians and veterans with SCI. Surveys will include contextual variables as well as measures of loneliness, social isolation, and physical and psychological health administered at baseline and 12 months later, allowing us to examine cross-sectional as well as longitudinal associations.

One of the major issues [for people with SCI] is loneliness, which of course is very present in the early days of injury but continues throughout our lives.

~ Veteran with SCI serving on the project's Community Advisory Board

You can feel just as lonely in a crowd.

~Anonymous



Social Connections after Injury Study

Timeline and Cost

Activities	FY1	FY2	FY3
Obtain approvals/maintain regulatory compliance; Prepare documents/materials for survey study			
Beta test materials, procedures, databases; Revise based on beta test input			
Recruit, screen, enroll, and collect data at baseline and at 12 months		Anticipated	
Analyze data, disseminate study results to academic and consumer audiences			
Estimated Budget (\$607K)	\$212K	\$199K	\$196K

Updated: 14 SEPTEMBER 2020 (Annual Report 2020)

Goals/Milestones by Funding Year (FY)

FY1 Goals – Study Start-up and Survey Preparation

- Secure approvals; hire/assign staff; convene advisory board
- Prepare all documents, surveys, recruitment materials and databases for study implementation
- Conduct beta test and revise based on input
- Connect with community organizations
- Begin recruitment
- Begin national survey study

FY2 Goal – Survey Implementation

- Complete recruitment, enrollment and baseline survey
- Retain participants through attrition reduction efforts
- Begin 12 month surveys
- Score and analyze baseline data

FY3 Goals – Survey Completion, Data Analysis, and Dissemination

- Complete 12 month surveys
- Analyze and interpret data with input from advisory board
- Disseminate findings through local and national conferences, academic journals, consumer-oriented materials; Prepare final report

9. Appendices

9a. Study Logo Developed by Community Advisory Board

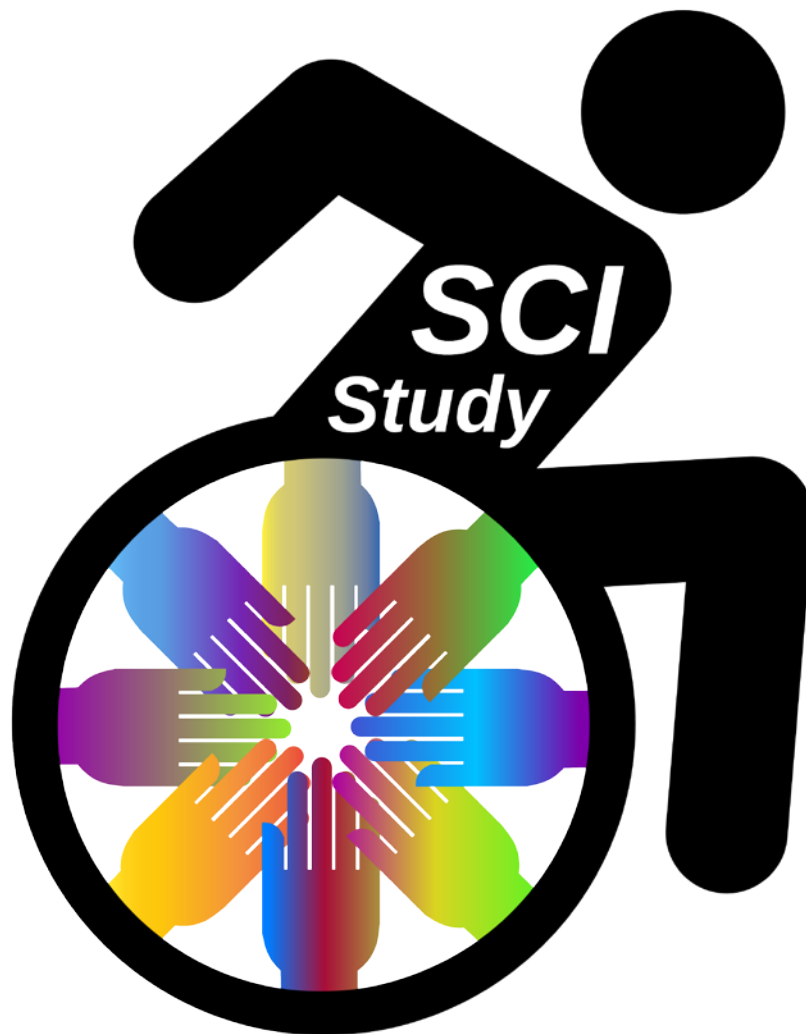
9b. Study Recruitment Flyer

9c. Study Survey

9d. ACRM 2020 Reference and Final PPT Slides

9e. Images of Promotional Items

9.a. Study Logo Developed by our Community Advisory Board



Social **C**onnections after **I**njury **S**tudy

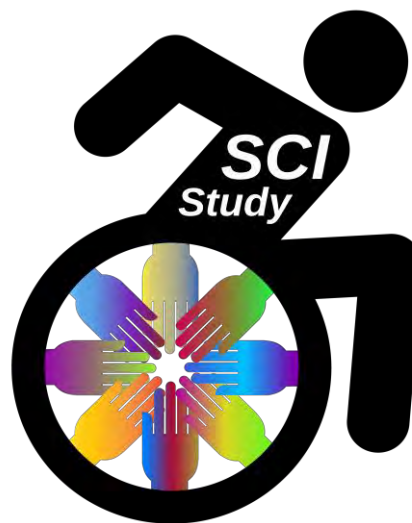
The SCI Study

The Social Connections after Injury Study

A Research Study on the Social and Psychological Health of People with SCI

You may qualify if you:

- Are at least 18 years of age
- Have a spinal cord injury (SCI)
- Have had your injury for at least 1 year
- Are able to answer questions in English



Study participants answer questions (by phone, online survey, or paper-and-pencil questionnaire) twice, one year apart.

A small payment is offered for completing the questionnaires.

CONTACT US today and ask about the SCI Study!

Phone: **713-797-7107**

Email: **SCIstudy@bcm.edu**

Please leave your name and phone number, and we will contact you right away.

We are committed to including, men and women, people of ethnic/racial and sexual minority groups, veterans, and people from rural communities.



This research study is being funded by the Department of Defense. It is conducted by Baylor College of Medicine, the Spinal Cord Injury and Disability Research Center at TIRR Memorial Hermann, the University of Texas Health Science Center at Houston, and the University of Montana.



Social Connections after Injury Study - PreTest Survey

These first questions ask some basic information about you.

What is your sex?

- Male
- Female
- Other _____

Do you have a Latino or Hispanic background? (please check one)

- Yes - Latino or Hispanic
- No - Not Latino or Hispanic

What is your race?

- American Indian/ Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White
- More than one race _____
- Other _____
- Do not wish to say

What is the highest grade/year of school that you completed?

- Never attended school or only kindergarten
- Grades 1 through 8 (elementary)
- Grades 9 through 12 (some high school)
- Grade 12 or GED (high school graduate)
- High school graduate plus 1 to 3 years of college or technical school
- College (Bachelor's degree)
- Graduate degree (Master's) or Doctorate (PhD, MD, JD, etc.)

Are you currently working for pay?

- Yes, full-time
- Yes, part-time
- No

Which group best describes your total family income or household income in the last year? This includes your income from all sources (like work, social security, pension, disability, etc.) and the income of family or a partner living with you who helps pay your expenses. Is your total family income:

- Less than \$15,000
- \$15,000 - \$24,999
- \$25,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000 or more
- I don't know
- I don't wish to say

Including you, how many people are supported by the family income or household income?

What is your current relationship status now?

- Single
- Married
- Member of an unmarried couple
- Divorced
- Separated
- Widowed
- Do not wish to say

In general, how satisfied are you with your relationship?

- Not at all
- A little
- Somewhat
- Mostly
- Almost Completely
- Completely

Do you consider yourself to be...

- Straight/Heterosexual
- Gay/Lesbian
- Bisexual
- Other _____
- Do not wish to say

- Where do you live?**
- A city or large town
- A suburb or just outside a city or large town
- A small town
- In the country or a long way from town
- On a reservation

Have you served in the U.S. Armed Forces (Army, Air Force, Navy, Marine Corps, Coast Guard) OR been in the U.S. Military Reserves or National Guard?

- Yes
- No

Please select the statements below that apply to you. (Select all that apply.)

- I have served on active duty (full-time military service) in the U.S. Armed Forces (Army, Air Force, Navy, Marine Corps, and Coast Guard)
- I have been in the U.S. Military Reserves or National Guard

While serving, did you experience any of the following?

(Please select all that apply)

- Assigned to a hostile or combative area
- Experienced enemy fire, saw combat, or witnessed casualties
- Were wounded, injured, or hospitalized
- Were exposed to chemicals, gases, or hazardous substances

This section will ask questions about your injury, your disability, and your personal assistance needs.

How old were you when you had your spinal cord injury?

How do you typically get around?

- Power wheelchair
- Manual wheelchair
- Ambulatory (e.g., I walk with a brace, cane, crutches, walker)
- I walk without assistive devices or mobility aids

I walk with..

(Please select all that apply)

- a brace
- a cane
- crutches
- a walker
- Other _____

Do you use a ventilator?

- Yes
- No

If yes, how many hours a day do you typically use it?

Are you deaf, or do you have serious difficulty hearing?

- Yes
- No

Are you blind, or do you have serious difficulty seeing, even when wearing glasses or contact lenses?

- Yes
- No

Using the 0-10 scale with a 0 being no pain and a 10 being pain so severe you couldn't stand it, what has been your usual level of pain over the past 4 weeks?

	0	1	2	3	4	5	6	7	8	9	10
Bodily Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- I had pain, but it did not interfere at all
- A little bit
- Moderately
- Quite a bit
- Extremely
- I don't know
- I decline to answer
- I had no pain in the last 4 weeks

This next section asks about your personal care and assistive devices.

Do you need help with any of the following activities? Bathing, grooming, getting dressed; eating; transferring to bed, chair, wheelchair, tub or shower, or toilet; bladder or bowel management, toileting?

- No
- Yes

In the past year, how often did you have the help you needed?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often
- Always

Do you need help with any of the following activities? Housecleaning, yard work, home maintenance or repairs, managing personal finances, planning social arrangements, meal preparation?

- No
- Yes

In the past year, how often did you have the help you needed?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often
- Always

Do you need help getting out of your home to do any of the following activities? Running errands, grocery shopping, going to the doctor, attending events in the community, going to church?

- No
- Yes

In the past year, how often did you have the help you needed?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often
- Always

Do you need assistive equipment or devices (e.g., wheelchair, walker, scooter) to get out in the community?

- No
- Yes

In the past year, how often did you have the equipment or devices (in good working order) that you needed?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often
- Always

Please indicate the degree of assistance needed with each of the following personal care activities.

Grooming

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Dressing

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Bathing

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Meal preparation

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Please indicate the degree of assistance needed with each of the following personal care activities

Eating

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Bladder care

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Bowel care

- I need **no** help
- I need **some** help from someone else
- I need **assistive equipment** to perform this activity independently
- I need **a lot** of help from someone else

Now, here are some questions about your typical activities and how you spend your time.

On a typical day, how many hours are you out of bed?

In a typical week, how many days do you get out of your house and go somewhere?

In the last year, how many nights have you spent away from your home (excluding hospitalizations?)

- None
- 1 to 2
- 3 to 4
- 5 or more

How many hours a week do you spend working in a job for which you get paid?

How many hours a week do you spend in school working toward a degree or in a technical training program (including hours in class and studying)?

How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation?

How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement?

How many hours a week do you spend in recreational activities such as sports, exercise, playing cards, or going to the movies? Please do not include time spent watching TV or listening to the radio.

Do you live alone?

- Yes
- No

How many people do you live with?

Is one of them your spouse or significant other?

- Yes
- No
- Not applicable--I live alone

Of the people you live with, how many are relatives?

How many businesses or organizational associates do you visit, phone, email, or write to at least once a month?

How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, email, or write to at least once a month?

With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?

- None
- 1-2
- 3-5
- 6 or more

Next we have some questions about your use of the internet and social media.

Do you get on the internet at home, outside the home, or both?

- No
- Yes, I get on the internet at home only.
- Yes, I get on the internet outside the home only
- Yes, I get on the internet both at home and outside the home

How often do you use email to communicate with family and friends?

- Several times a day
- About once a day
- 3-6 times a week
- 1-2 times a week
- Every few weeks
- Less than every few weeks
- Never

How often do you text or use Facebook Messenger to communicate with family and friends?

- Several times a day
- About once a day
- 3-6 times a week
- 1-2 times a week
- Every few weeks
- Less than every few weeks
- Never

How often do you use video streaming (Facetime, Skype, Zoom, etc.) to communicate with family and friends?

- Several times a day
- About once a day
- 3-6 times a week
- 1-2 times a week
- Every few weeks
- Less than every few weeks
- Never

How often do you use online support groups or special interest groups (e.g., Facebook support group)?

- Several times a day
- About once a day
- 3-6 times a week
- 1-2 times a week
- Every few weeks
- Less than every few weeks
- Never

Which social media do you use regularly (check all that apply)

- Facebook
- Snapchat
- Instagram
- Twitter
- YouTube
- Tumblr
- Pinterest
- LinkedIn
- What'sApp
- Reddit
- Other _____
- I do not use social media

How often do you post (e.g., share ideas, photos, opinions, events, etc.) or comment/reply to what others have posted?

- Several times a day
- About once a day
- 3-6 times a week
- 1-2 times a week
- Every few weeks
- Less than every few weeks
- Never

How often does social media help you feel connected or close to others?

- Always
- Very often
- Fairly often
- Sometimes
- Almost never
- Never

How often does social media make you feel disconnected or cut off from others?

- Always
- Very often
- Fairly often
- Sometimes
- Almost never
- Never

These next questions ask about your satisfaction with social roles and activities.

Please respond to each question or statement by selecting one answer per row **In the past 7 days...**

	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am satisfied with my current level of social activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my ability to do leisure activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my current level of activities with my friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my ability to do things for fun at home (like reading, listening to music; etc.).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my ability to perform my daily routines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the past 7 days....					
	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
I am disappointed in my ability to meet the needs of my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am bothered by my limitations in regular family activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am disappointed in my ability to to socialize with friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am disappointed in my ability to take care of personal and household responsibilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am bothered by my limitations in performing my work (including work at home).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For this next measure, indicate how often each of the statements below is descriptive of you.

	Never	Rarely	Sometimes	Often
How often do you feel that you are "in tune" with people around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that you lack companionship?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that there is no one you can turn to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel alone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel part of a group of friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Indicate how often each of the statements below is descriptive of you.

	Never	Rarely	Sometimes	Often
How often do you feel that you have a lot in common with the people around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that you are no longer close to anyone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that your interest and ideas are not shared by those around you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel outgoing and friendly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel close to people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Indicate how often each of the statements below is descriptive of you.

	Never	Rarely	Sometimes	Often
How often do you feel left out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that your relationships with others are not meaningful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that no one really knows you well?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel isolated from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel you can find companionship when you want it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Indicate how often each of the statements below is descriptive of you.

	Never	Rarely	Sometimes	Often
How often do you feel that there are people who really understand you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel shy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that people are around you but not with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that there are people you can talk to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you feel that there are people you can turn to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next questions ask how you have been feeling over the last 2 weeks.

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling down, depressed, or hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling or staying asleep, or sleeping too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling tired or having little energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Poor appetite or overeating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling bad about yourself or that you are a failure or have let yourself or your family down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble concentrating on things, such as reading the newspaper or watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moving or speaking so slowly that other people could have noticed? Or the opposite being so fidgety or restless that you have been moving around a lot more than usual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you checked off ANY problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not at all difficult
- Somewhat difficult
- Very difficult
- Extremely difficult

You are halfway!

Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half of the days	Nearly every day
1. Feeling nervous, anxious, or on edge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Not being able to stop or control worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Worrying too much about different things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Trouble relaxing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Being so restless that it is hard to sit still	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Becoming easily annoyed or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Feeling afraid as if something awful might happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not at all
- Somewhat difficult
- Very difficult
- Extremely difficult

The next questions ask how you feel your life is going.

Below are 5 statements with which you agree or disagree. Using the 1 - 7 scale below, indicate your agreement with each item. Please be open and honest in your responding.

In most ways my life is close to my ideal.

- Strongly Disagree
- Disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Agree
- Strongly agree

The conditions of my life are excellent.

- Strongly Disagree
- Disagree
- Slightly Disagree
- Neither Agree nor Disagree
- Slightly Agree
- Agree
- Strongly Agree

I am satisfied with my life.

- Strongly Disagree
- Disagree
- Slightly Disagree
- Neither Agree nor Disagree
- Slightly Agree
- Agree
- Strongly Agree

So far I have gotten the important things I want in life.

- Strongly Disagree
- Disagree
- Slightly Disagree
- Neither Agree nor Disagree
- Slightly Agree
- Agree
- Strongly Agree

The next questions ask about your health, health conditions, and hospitalizations.

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate if you have had each condition in the past 12 months and rate the severity of the condition, if applicable.

In the past 12 months, have you had the following?

	No, I have never had this condition	No, I have not had this condition in the past year	Yes, Mild	Yes, Moderate	Yes, Severe
High blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dysreflexia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart disease (including heart failure, A-Fib, Angina)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peripheral artery disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carotid artery disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stroke (stroke occurred within the past year)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TIA/ Transient Ischemic Attack (TIA occurred in the past year)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart attack (heart attack occurred in the past year)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Date of stroke

Date of Transient Ischemic Attack (TIA)

Date of heart attack

These next questions ask about secondary health conditions common among people with SCI.

For the following health problems, please indicate how often these problems occurred in the last 3 months and how severe they were.

Pressure sores, decubitus

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Injury caused by loss of sensation. These are e.g., burns from carrying hot liquids in the lap or sitting too close to a heater or fire.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Muscle spasms, spasticity

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Contractures. This is a limitation in range of motion of a joint.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Heterotopic bone ossification. This is an overgrowth of bone, often occurring after a fracture. This condition must be diagnosed by a physician.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Diabetes

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Bladder dysfunction. This includes incontinence, bladder or kidney stones, kidney problems, urine leakage and urine back up.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Bowel dysfunction. This includes diarrhea and constipation

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Urinary tract infection. This includes kidney or bladder infection.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Sexual dysfunction. This includes dysfunction in sexual arousal, erection, and reaching orgasm.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Autonomic dysreflexia. Symptoms are sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation, and headache.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Postural hypotension. This involves strong sensation of lightheadedness following change in position. It is caused by a sudden drop in blood pressure.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Circulatory problems. This involves swelling of veins, feet, or the occurrence of blood clots.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Respiratory problems. Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Pain

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

Sleep problems

- Not experienced, insignificant problem
- Mild or infrequent problem
- Moderate or occasional problem
- Significant or chronic problem

In the past 12 months, have you stayed overnight in a hospital?

- Yes
- No

In the past 12 months how many different times have you stayed in the hospital overnight?

Please list the reason and the number of days you stayed in the hospital for each hospitalization

Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____
Reason for hospitalization _____	Number of days hospitalized _____

These next questions ask about abuse you may have experienced in the past.

Have you ever been hit, slapped, kicked, pushed, shoved, or otherwise physically hurt by someone?

- Yes
- No

Has anyone ever forced you to have sexual activities?

- Yes
- No

Has anyone ever prevented you from using a wheelchair, cane, respirator, or other assistive devices?

- Yes
- No

Has anyone you depend on ever refused to help you with an important personal need, such as taking your medicine, getting to the bathroom, getting out of bed, bathing, getting dressed, or getting food or drink?

- Yes
- No

These questions are about problems and complaints that people sometimes have in response to stressful life experiences. Please indicate how much you have been bothered by this problem in the past month:

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Repeated, disturbing memories, thoughts, or images of a stressful experience from the past	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling very upset when something reminded you of a stressful experience from the past	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate how much you have been bothered by this problem in the past month:

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Avoided activities or situations because they reminded you of a stressful experience from the past	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling irritable or having angry outbursts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling jumpy or easily startled	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next questions ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

	Never	Almost never	Sometimes	Fairly often	Very often
In the last month, how often have you felt that you were unable to control the important things in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the last month, how often have you felt confident about your ability to handle your personal problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the last month, how often have you felt that things were going your way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next set of questions ask about the coronavirus pandemic (COVID-19). Please take a moment to think about the way that you and/or your life has changed as a result of COVID-19.

Please rate how much each of the following has changed due to COVID-19.

Your face-to-face social interactions with people you feel close to

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now

Your remote or virtual social interactions (email, phone, text, Facebook, Skype, etc.) with people you feel close to

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now

Your employment

- Working much more now
- Working somewhat more now
- No change
- Working somewhat less now
- Working much less now

Your participation in other activities or life roles (school, volunteer, advocacy, leisure, volunteer activities, religious activities, etc.)

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now

These next questions ask about your mood and your feelings. Please rate how much each of the following has changed due to COVID-19.

Your stress

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your mood (depression or feeling down)

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your mood (feeling anxious or worried)

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your sense of loneliness

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your sense of safety and security

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

These next questions ask about your health and health behaviors. Please rate how much each of the following has changed due to COVID-19.

Your eating habits

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your exercise habits

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your sleep or sleeping habits

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

Your overall health

- Much worse now
- Somewhat worse now
- No change
- Somewhat better now
- Much better now

These next questions ask about additional health behaviors. Please rate how much each of the following has changed due to COVID-19.

Your alcohol use

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now
- N/A

Your tobacco use

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now
- N/A

Your use of other drugs

- Much more now
- Somewhat more now
- No change
- Somewhat less now
- Much less now
- N/A

Only one more set of questions to go!

Next are some questions about support that is available to you.

About how many close friends and close relatives do you have (people you feel at ease with and can talk to and about what is on your mind)? Write in number of relatives and friends

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to help if you were confined to a bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone who shows you love and affection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to have a good time with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to confide in or talk about yourself or your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to help with your daily chores if you were sick	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to share your most private worries and fears with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to do something enjoyable with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to love and make you feel wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

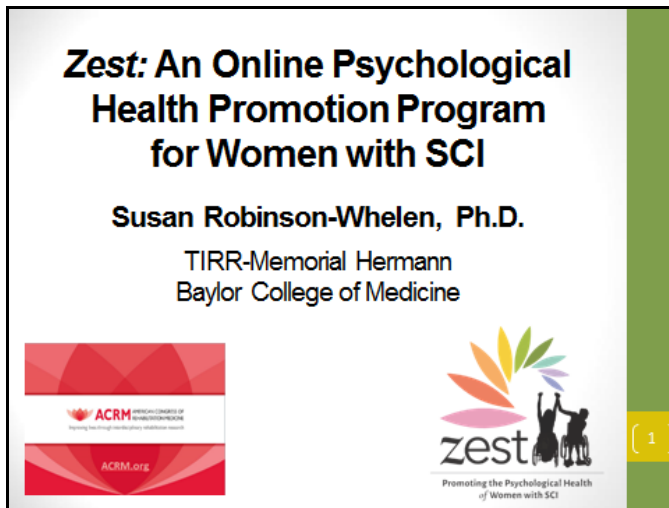
Overall, how satisfied are you with your friends and relationships with others?

- Very much satisfied
- Somewhat satisfied
- Not at all satisfied

Please share any comments or feedback you have for us.

9.d. ACRM 2020 Reference and Final Slides with Mention of Loneliness Grant

Robinson-Whelen, S., Hughes, R. B., Taylor, H. B., Norah-Davis, L., Gonzales, B. A., Nosek, M. A., and the Zest Consortium. (2020, October). *Zest: An Online Psychological Health Promotion Program for Women with SCI*. Accepted for presentation at the American Congress of Rehabilitation Medicine Annual Meeting, Atlanta, GA.



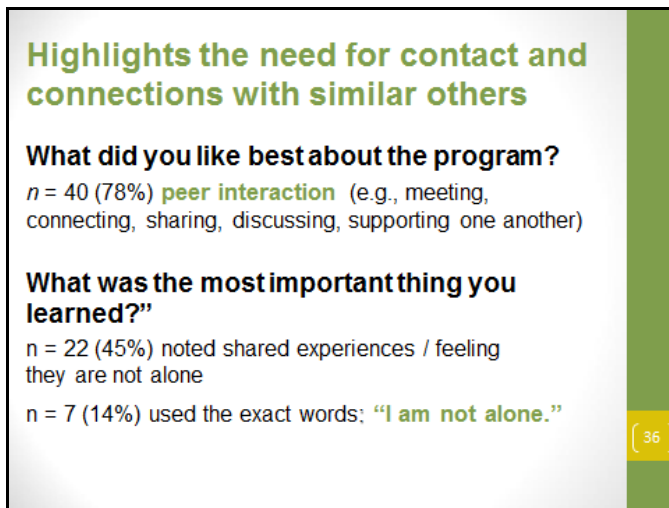
Zest: An Online Psychological Health Promotion Program for Women with SCI

Susan Robinson-Whelen, Ph.D.
TIRR-Memorial Hermann
Baylor College of Medicine

ACRM logo: ACRM PROMOTING THE PSYCHOLOGICAL HEALTH OF WOMEN WITH SCI
ACRM.org

zest logo: Promoting the Psychological Health of Women with SCI

[1]

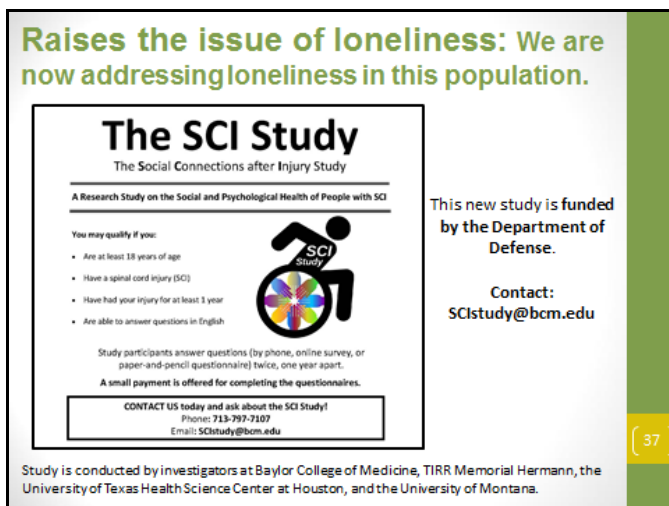


Highlights the need for contact and connections with similar others

What did you like best about the program?
n = 40 (78%) **peer interaction** (e.g., meeting, connecting, sharing, discussing, supporting one another)

What was the most important thing you learned?"
n = 22 (45%) noted shared experiences / feeling they are not alone
n = 7 (14%) used the exact words: **"I am not alone."**

[36]



Raises the issue of loneliness: We are now addressing loneliness in this population.

The SCI Study
The Social Connections after Injury Study

A Research Study on the Social and Psychological Health of People with SCI

You may qualify if you:

- Are at least 18 years of age
- Have a spinal cord injury (SCI)
- Have had your injury for at least 1 year
- Are able to answer questions in English

Study participants answer questions (by phone, online survey, or paper-and-pencil questionnaire) twice, one year apart.
A small payment is offered for completing the questionnaires.

CONTACT US today and ask about the SCI Study!
Phone: 713-797-2107
Email: SCistudy@bcm.edu

This new study is funded by the Department of Defense.

Contact:
SCistudy@bcm.edu

[37]

Study is conducted by investigators at Baylor College of Medicine, TIRR Memorial Hermann, the University of Texas Health Science Center at Houston, and the University of Montana.

9.e. Promotional Items – Ready for Distribution

Birthday Card



Stylus Pen



Magnet with Reminder Date

