

Spring 2024

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Health Employment and Longevity Project



A Unique Perspective >>>

Please Welcome our Newest Team Member, Philip Edles

Philip is an author and published spinal cord injury researcher. He has spent *almost 30 years* as a professional caregiver, supporting disabled and injured vets, those diagnosed with ALS (Lou Gehrig's Disease, SCI, and anybody who needs physical and companionship assistance. He says the thousands of hours he's spent in the profession have given him a very special insight into what we do here at the project.

Read More about Philip on Page 5



Longevity News and Updates

Understanding and promoting longevity after spinal cord injury: A mixed methods study of participation, employment, and quality of life

Longitudinal changes in employment, health, participation, and quality-of-life and the relationships with long-term survival after spinal cord injury

Traumatic spinal cord injury (SCI) results in physical disability and impacts multiple aspects of the individual's life, including health, home and family life, employment, social and community participation, and quality-of-life (QOL). Individuals with SCI are also at an increased risk of death after SCI. However, not much is known about how non-health factors may affect survival. Our objective was to identify stability in rates of employment, health, participation, and quality-of-life outcomes (QOL) among participants with chronic spinal cord injury (SCI) and to compare the amount of change in these outcomes between those surviving and those not surviving at follow-up. We used 1157 participants from the SCI Longitudinal Aging Study, who have completed at least two self-report assessments separated by five-year intervals.

- Most of the participants were male (73%), non-Hispanic White (80%), non-cervical level injury (49%), and non-ambulatory (77%).

- Those who survived to follow-up had had higher likelihood of employment, better health, higher participation,

and better life quality compared to the deceased. Among survivors, longitudinal declines were limited to the percent employed and participation indicators, whereas those deceased had significant undesirable changes in employment, participation, health, and QOL.

- Study participants deceased by follow-up experienced a greater increase in hospitalizations, decrease in nights away from home, and declines in life satisfaction.

Although declines in employment opportunity and participation were observed as part of the natural course of SCI, those deceased experienced significantly more hospitalizations, less nights away from home, and lower global life satisfaction than the survivors. Health care professionals should be aware of those changes as early as possible and provide preventative measures.

This research brief is based on: Cao, Y., DiPiro, N.D. & Krause, J.S. (2023). Longitudinal changes in employment, health, participation, and quality-of-life and the relationships with long-term survival after spinal cord injury. *Spinal Cord*.

<https://doi.org/10.1038/s41393-023-00882-6>.
Support: 90IFRE0044, 90IF0112, 90IF0015, H133G060126, H133G020239

Health and Function:
Qualitative Longevity Study Update >>>

Fascinating Work in Progress

Kristian has completed 40 interviews for our longevity study after SCI, and life-quality

Most interviewees have been injured at least 20 years, and some 50 years or more. They are sharing some truly incredible experiences. We want to thank each and every one of you who have shared your stories of hope and perseverance. With your help, we will find better ways to understand how people live beyond what is expected after an SCI.

Kristian says one of the most common themes participants report is “just to keep trying and staying busy.” That might sound like a simple solution but experience suggests otherwise. We here at the project take lived-experience very seriously. We can run analysis and enter surveys over and over, but if our efforts doesn’t ultimately make a difference in the lives of those we seek to support, it didn’t work.



We will share some story themes over the next year: ways they were able to adapt to their environment, some subtle and also some tough learning experiences as well as hopeful anecdotes of survival and prosperity. Stay tuned.



James's Story

“Films (Before You, Million Dollar Baby) suggest suicide is preferable to quadriplegia, but I chose life.”

Shout out to James LaBelle and his new book, “Wheelchair Bound?” James challenges the assumption that a wheelchair is something that binds or confines, rather than frees those who need one...”absurd,” James says. [Check out his book at Barnes and Noble](#)

What's it Mean to be Disabled?

We will talk much more about it in our next newsletter, but March was Disability Awareness month. We are genuinely excited to celebrate it and here's why...

Let's talk truth: people with disabilities are 100% human in **exactly** the same way people without disabilities are. That should be self-evident. If it's not immediately apparent, don't worry. We know. And we'll share it with you. We're excited to celebrate Disability Awareness Month and the contributions people with disabilities have made to all our lives, every day. Don't forget to look out for whys and hows in our Spring Newsletter.

MARCH IS
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Health Employment and Longevity Project



Aging—50-Year News and Updates

Aging and Participation after Spinal Cord Injury: Promoting Utilization to Enhance Community Outcomes.”

Long-term survival isn't exclusive to, but it does have significantly different implications for, those with SCI.

Consistent with so much of what we do here every day at the project, this study seeks to promote longevity after spinal cord injury through exploration and discovery of how non-health related factors impact long-term survival. We will address the seeming contradiction that mortality rates over the last three or four decades have not improved in epidemiologic studies, while aging research indicates an increasing number of people reaching 40, 50, or more years post-injury. We propose a crosscutting, mixed methods approach combining traditional survival analysis with qualitative interviews of successful strategies to promote longevity. We will identify the survival status of 2210 participants who have completed 1-9 assessments between 1973-2018 using the National Death Index. Our objectives are to identify how different aspects of participation, employment, and quality of life relate to longevity after controlling for demographic, SCI, and health variables;

whether there are time points over the lifecycle where non-health factors are more highly predictive of longevity; and the extent to which a favorable history of participation, employment and quality of life may create a buffer leading to greater longevity. We will conduct in-depth qualitative interviews with 40 participants who have reached either their predicted SCI expectancy or 40 years post-injury. Our objective is to identify both the critical challenges and the successful strategies used to achieve longevity among long-term survivors. Anticipated outcomes include more effective practices for addressing non-health factors to promote longevity; enhanced self-management and self-advocacy for people with SCI; and overall enhanced longevity through promotion of participation, employment, and quality of life. The expected products include dissemination to professionals and stakeholders through publications, presentations, research briefs, fact sheets, and newsletters.

C.A.P. Update >>>

C.A.P. stands for Community Advisory Panel. It is one of our most valued resources, allowing us to more closely connect to our community and keep us connected to each other. C.A.P. meets at least quarterly or when we need to connect without community. This month our C.A.P. leader, Richard, identified several topics our community brought up:

-How Covid affected your lifestyle including isolation, feeling stuck inside and caregiving assistance, as many who need daily assistance did not have the option of going without it.

- Combining and using online surveys when possible to reduce repetition: Fewer paper surveys means less paper sitting around your house, ensuring the Redcap “save feature” works well and ensuring we don’t double up surveys.

- **Interested in participating on a CAP? Please see our contact information Call or email**

Need us? 843-792-2605

<https://chp.musc.edu/research/centers/crrnc/help/tools>

We're Moving on Up!

The Health, Employment and Longevity Project is part of the College of Health Professions at MUSC here in Charleston, SC. The college is growing so big we need a new building.



A local couple, Tina and Ricky Doscher, donated 10 million dollars to help build a new facility, scheduled to be completed in 2025.

In 2010, Tina had life-saving spinal cord surgery that left her temporarily paralyzed. She credits physical therapy at MUSC with helping her walk again. She also participated in research studies.

at the college that have improved her mobility. “There are many worthy nonprofits, but a gift to help provide lifesaving technology and treatments that continue to save lives many years down the road is the best gift of all,” said Tina.

In addition to housing our project, the new 6-story building will also be the home of education and research facilities to train a new generations of health professionals including occupational/physical therapists, Physicians assistants and researchers. It will also include an exercise and training facility, and, critically, an accessible place for those with neurological conditions to participate in regular exercise and focus on their mental and emotional wellbeing with others who share their experiences.

We know it can feel like slow - going, but we don't stop..won't



Research Highlights

The following manuscript has been submitted and is under review with *Archives*.

Krause, J.S., Cao, Y., Forcier, N. (under review). Longitudinal comparisons in health, participation, life satisfaction, and depressive symptoms among people with spinal cord injuries: How much change was observed pre-to post COVID-19 pandemic?

Support: 90DPEM0006 and 90RT5035

We are working on the following manuscript:

Krause, J.S., Dismuke-Greer, C.E., & Reed, K., Foulger, I., Rumrill, P. (under review). A Survival Model of Work Life Expectancy after Multiple Sclerosis: Relationships with Race/Ethnicity, Education, Disease, and Aging Factors.

Thanks, JK, Libby, Karla, Isabell, and Dr. Rumrill!! We will keep all of you posted.

support: 90DP0050 (emp SCI) and 90DPCP0009 (new emp)

Looking Ahead...

- In bed or in wheelchair all day/night?
- Latest Study Updates
- In-depth on CAP pain management and holistic treatments.
- March: Disability Awareness Month

A Conversation with our Newest Team Member, Philip, Continued

We have a new team member here at the **project** and we think he's very special. Philip has spent the past 30 years as a caregiver for disabled, injured and elderly members of his community. Oh, and he also has a master's degree in counseling. We think he is a great fit. Dr. Krause asked him a few questions.

J.K. Thank you for joining us, Philip. We're excited to have you on the team. Please tell our readers a little bit more about yourself and your connection to people with disabilities.

Philip Absolutely. I'm the stereotypic middle child. I always loved caring for my family and friends. I fell in love with psychology in college and began working in a group home to pay my way through graduate school. I had absolutely no idea that would lead to an incredible career. I specialize in working with disabled and injured veterans, those with spinal cord injury and ALS (Lou Gehrig's Disease). I've supported clients from every war since WWII to the present, been published in the field a number of times and have worked with clients from every walk of life: generals and congress members, pilots, professors and everyday people like me. Caregiving is the second greatest privilege of my life next to being a dad.

J.K. That's great. Do you have any other particular connection to people with disabilities? A family member or friend?

Philip Great question. No. Somehow, and I'm not sure why, I always understood that people with disabilities were 100% human in the EXACT same way able-bodied people are. They just might need some extra assistance. I figured if there was something I could do to elevate a person's quality of life by supporting them in whatever they needed, that's exactly what I wanted to do. I had no idea my work could touch people in ways I never imagined. But it has.

You don't want to get me blathering on about how much I love my clients, and vice versa. Suffice it to say that the worst part of being a caregiver is losing my clients to this world.

J.K. That makes sense. What does bringing all of your experience to The Health, Employment and Longevity Project mean to you...and us?

Philip I have worked with clients from diagnosis to death, with every kind of need and many you may have never thought of--with diagnosis from SCI, early Parkinsons or Alzheimer's, to elderly clients and those who could only communicate with eye blinks. That type of experience is invaluable to the work we do here at the project. First of all, *this will never be just a job to me*. I see the possibility of elevating life quality for everyone who can benefit from what we do...in everything we do. I also know many people just want to know we are here working every day to find ways to make their lives better: finding good jobs, direct care and access, providing information for what is happening to real-world people and influencing public policy. Also, let's not forget that for virtually everybody with a disability, there are many others who love them. I know that first-hand as a caregiver. Finding ways to increase life quality for everyone with a disability and those that support them is also a goal at the project and one of the things that inspired me to be here.

J.K. Well, we are very happy to have you here and thank you for taking the time to speak with us. We hear that you are going to be the new editor of the quarterly newsletter and we look forward to hearing more from you and about the project's work. You are an inspiration. We wish you the very best.