

Promoting longevity after spinal cord injury:
Some thoughts from a scholar with 50+ years of lived experience.

After spinal cord injury (SCI), we experience dramatic and immediate changes in our lives. Nothing known before will be quite the same. In the weeks and months after the onset of SCI, we seek answers to fundamental questions. “Will I recover? Will I be able to have a normal life?” As time goes by, everyone wants to know the answer to the inevitable question “How long will I live?” While nobody can answer these questions individually, as it is different for everybody, we have learned from the experiences of people with SCI and there are valuable lessons within those experiences.

My purpose is to share what we have learned about longevity and lifestyle with the hope that it will help others with SCI moving forward.

About the author: My name is Jim Krause and my SCI occurred while I was swimming in Minnesota in 1971. I was an average student in high school, at best. After I was injured, my family did everything imaginable to help me. My high school classmates in my small hometown of about 4,000 literally took to the streets to raise money. Vocational rehabilitation services put their full support behind me and helped me to obtain my PhD from the Department of Psychology at the University of Minnesota, which I obtained in 1990. I have been working on SCI research for nearly 35 years now, studying outcomes that include community participation, health, aging, and longevity.

Background: Back in 1973, researchers at the University of Minnesota Hospital, including my dear friend and mentor, Nancy Crewe, set out to learn answers to some of the most basic questions about health, quality of life, and longevity. At the time, practically nothing was known about people with SCI after they returned to the community. I personally

became involved with the research as a graduate student at the University of Minnesota in 1984. The study has gone on since that time with follow-up data collection every 4 – 5 years. As part of the research, we identify survival status to see what are the factors that differentiate those who survived to follow-up and those who do not survive to follow-up.

So, what have we (a dedicated team of people) learned about SCI that would help those more recently injured to better know what is in the road ahead, particularly as related to longevity?

At the outset, it is important to acknowledge that SCI affects longevity and that, on average, people with SCI will have a shortened life expectancy. Life expectancy is defined as the point at which half individuals with a particular set of characteristics will be expected to still be alive. The same principles apply with SCI as within the general population. The relative risk of loss of life compared with the general population is highest during the first year or two. People are still at medical risk during that time, particularly for things like blood clots. After the first 2 years, mortality rates will continue to be higher than for people without SCI, but longevity becomes more about doing the right things to stay healthy and avoid complications.

Our research and longevity: What does our research tell us about reaching longevity milestones? What are those things that hold those of us with SCI back and what are those things that help to push us forward and to have greater longevity?

The first thing to note is that experiences may vary depending on the age at SCI onset. For those who are injured very young, they will live a much greater portion of their life with SCI compared to those injured later in life. So, those medical conditions that take years or decades to develop are more likely to happen to those injured early in life. In contrast, those with

SCI occurring later in life may have more pre-existing conditions that can affect their longevity.

Risk factors for early mortality: From the very onset of SCI, we are at high risk for health problems like pressure ulcers, urinary tract infections, broken bones and other injuries, and even a higher risk of depressive symptoms. Avoiding these types of long-term secondary health conditions and containing their effects when they do occur is essential to promote longevity. Everyone with SCI will experience some types of health issues related to SCI. I myself have been blessed to not have experienced an overnight hospitalization in nearly 40 years (1985), but I have had multiple broken bones over the years, particularly as I have aged. It happens.

So how do we maintain our health? It is important to not allow one condition to spiral out of control and lead to other conditions which may compound the situation and lead to high risk of severe acute conditions, such as severe infections. We call this *containment*.

There are several things which may add to the risk of limited longevity (i.e., dying at a younger age). Prescription and nonprescription use of some medications, such as opioids to treat pain, raise the risk of mortality. They are necessary for some people to treat complications of SCI or other health conditions, but it is important to use them as directed and to be aware of the risk. Excessive alcohol use, particularly binge drinking (lots of drinks in a short period of time) is risky and it is riskier if alcohol is used at the same time as other substances. There are other well-known risk factors, like cigarette smoking, but it's beyond my purpose to provide a laundry list of what you already know you should not do.

There are also many positive activities like nutrition and following common sense guidelines. What is particularly important is that people with SCI need to be more vigilant in maintaining healthy skin, preventing

urinary tract infections, and avoiding unintentional injuries such as falls. We simply are at greater risk for these things and even a single time of staying in the wheelchair for too long can lead to serious problems. As we get older, it is more difficult to recover.

Promoting longevity:

As people live with SCI, we have found many factors that are associated with greater longevity. We have learned this from surveying the life experiences of large numbers of people with SCI over the years, even decades, and interviewing people who have been successful in achieving longevity. We identify trends over time and attempt to better understand those things that are normal aging versus those things that may indicate decline.

No matter how many different ways we look at longevity, it is clear that people who are active, work, and maintain overall health are more likely to live longer. My own very first publication in 1987 reflected these findings.¹ So, what more have we learned?

At one time, researchers only looked at longevity related to basic characteristics such as age or SCI characteristics, including the severity of the SCI, which relates to whether the injury is neurologically complete (i.e., whether there is movement or sensation below the level of injury) and where the injury is within the spinal column. On average, people with less severe SCI will live longer, yet many people with severe SCI who were injured in their teens survive 50+ years. It is interesting to note how many people reach these milestones, when other researchers have not found longevity to improve for people with SCI at the same rate as it has in the general population.² Regardless of whether rates are improving or remaining the same, it is important to understand the factors that help people to promote their longevity.

Our research – survey:

We sought to better understand why some people live well beyond their predicted life expectancy. We first found that economics were highly related to longevity.³ In a nutshell, we found those who had higher family incomes had greater longevity. We confirmed this in multiple studies.⁴⁻⁶

When we first looked at employment, we were surprised by the number of differences in longevity based on employment. We found that for those with high cervical injuries who were injured very young, those who worked 30 or more hours per week, had a college degree, and had family income above \$75,000 per year, had twice the life expectancy of those with less than 12 years of education, who were unemployed, and were in the lowest economic group.⁷ We believe that this was likely due to having better access to resources and this no doubt is part, but not all, of the reason.

In our current project, we analyzed the relationships between socioeconomic factors based on work and earnings and social participation, defined as getting and staying out of bed and into the community. Those who had better socioeconomic conditions were much more active terms of the time they spent out of bed and got out of their homes.⁸ It appears that having good socioeconomic factors, including employment, education, and income, are highly related to social participation and this promotes longevity, perhaps as much or more than the tangible resources that come with good economics.

We also sought to discover whether people who had lived extensive periods of time with favorable participation, employment, and health would continue to have greater longevity after some of the positive factors in their lives had changed. In other words, would there be a long-term benefit of having lived a good portion of one's life with favorable circumstances after those circumstances change? We found that the benefits for longevity largely disappeared after lifestyle changes and

reduced participation. We were surprised by this, but it does emphasize the importance of maintaining social participation and strong economics.⁸

Using another approach, we just looked at people who had been in the study a long time, comparing those who have reached the 95% of their predicted life expectancy after SCI with those who died prior to reaching that milestone. We again found that the same set of life conditions was related to longevity. The findings were of great magnitude and across most every outcome that we had including related to social participation, employment, health, and healthcare utilization (i.e., treatments and hospitalizations). This confirmed what we believe and, most importantly, confirmed it for people working in rehabilitation and healthcare.

Lastly, we looked at outcomes over time to see whether there were different changes over time between people who did and did not survive to follow-up. This helped us to pinpoint changes that were related to normal aging and those that were indicators of risk for mortality. We knew that some areas of life would likely decline, even among those who were doing very well, simply because of aging and changing circumstance. We indeed found that some changes in reduction in employment and participation were found even among those who continue to survive to reach longevity milestones.

On the other hand, substantial declines in quality-of-life were found among those who did not survive to follow-up. Quality-of-life is defined by several things including how satisfied people were with their lives. We also found that health-related quality-of-life, including increases in poor health days and poor mental health days, were related to greater risk of mortality. Depression also related to decreased longevity and increased over time from those who did not reach longevity milestones. Increases in hospitalizations and physician visits were also found among those who did not survive to follow-up. Lastly, there was a greater reduction in the

number of nights spent away from home among those who did not survive. Therefore, even though participation overall declines, changes in nights away from home is more of concern regarding longevity.

In summary, achieving longevity after SCI will depend on many factors that include: (1) your characteristics - things you cannot change (e.g., age, SCI severity); (2) medical complications during the first year or two after SCI onset; (3) regularly doing healthy activities and avoiding high risk activities to the greatest extent possible (e.g., excess opioids, smoking, drinking a lot over short period of time); (4) living an active lifestyle that includes time out of bed and time away from home, (5) working if possible and, if not, maintaining financial resources, and (6) maintaining the highest possible quality of life and avoiding depression.

Overall, the findings are consistent with rehabilitation approaches that help people to live active, healthy lives, with employment or good economics. Staying active seems to be essential. Having good social support and a strong social network is important.

We did not touch upon the many environmental factors that may be associated with longevity, like access to attendant care. We know that people who require attendant care sometimes stay in bed all day and even all night in the wheelchair because of not having someone there to help.⁹ We do not claim to have all the answers, but just wish to encourage everyone to be mindful of what they do, so they can help them to reach longevity milestones.

Detailed interview with participants:

We also interviewed 40 people with long-standing SCI, starting with people who had outlived their SCI life expectancy. We first defined SCI life expectancy by the average (essentially) for those who were in our study based on their biographic characteristics, such as age, gender, and race

ethnicity; as well as their SCI characteristics including their injury level and whether they can walk. We also interviewed people who had lived 40 or more years as part of the 40 interviews. It is not as straightforward to identify themes from interviews that are open-ended – just asking people what they want us to know. That said, we identified some preliminary themes. Not surprising, they matched and actually provided more detail into what we had seen with their larger scale survey.

Our participants emphasized the importance having strong support. Those who were married or in a committed relationship identified their spouse. Family members other than spouse were also strongly noted. More general support, friends, and social support networks were identified as prominent. Fitting with the same basic scheme, people really talked about staying busy. The specific activities may have been different, but people mentioned hobbies, education, and employment as ways of staying busy. They also emphasized the importance of maintaining a positive attitude.

Given that these are the long-term survivors, their experiences are invaluable to us in understanding reaching longevity after SCI. People may find purpose in different ways, but those who do well and who survived the longest consistently showed positive attitudes and were engaged in life. That is not to say that life has been easy for them. They face many barriers, setbacks, and challenges. However, they were resilient and survived.

My personal experience:

Personally, it is encouraging, to say the least, to have been able to be a part of this research and meet and get to know so many long-term survivors. I have a friend who was injured the same day as I, and we once talked about being part of the 40/60 club (40 years post injury; 60 years of age). We now are part of the 50/70 club. As my grandfather always

said, “growing old is a privilege, denied to many”. That certainly is true for people with SCI.

I was injured at a time when reaching 40 years post-injury was seen as impossible. I remember an old Army nurse who worked at the Children’s Hospital where I was at when I was 17 telling me I better take care of myself, because I could live 20 years. Now it is commonplace, or at least much more common than has ever been possible. Our longest survivor lived 67 years after SCI after being injured during the teen years.

Ironically, if I had to point to things in my own life that have made a difference, certainly gaining as much education as I could and going to work have driven my life. I met my wife through work and when I look at new friends that I have made over all the years, most have been either through needing attendant care or through work. It has been a great ride, and I know that the work we have done ultimately has helped people with SCI, so I truly am personally grateful to each and every one who has participated in our research over the years.

Could we make a bigger difference? Yes! And, that’s what drives me and our team to continue this work.

I hope this provides hope for a long life after SCI and some ideas on how to get there.

Jim Krause

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