

Seeking Sufficient and Appropriate Care after Spinal Cord Injury: The Complexities of Navigating Resources for Community Reintegration

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Overview

- Background and pathway to this work
- How people experience SCI
- The state of rehabilitation for people with SCI
- How can we “help the people until the revolution?”

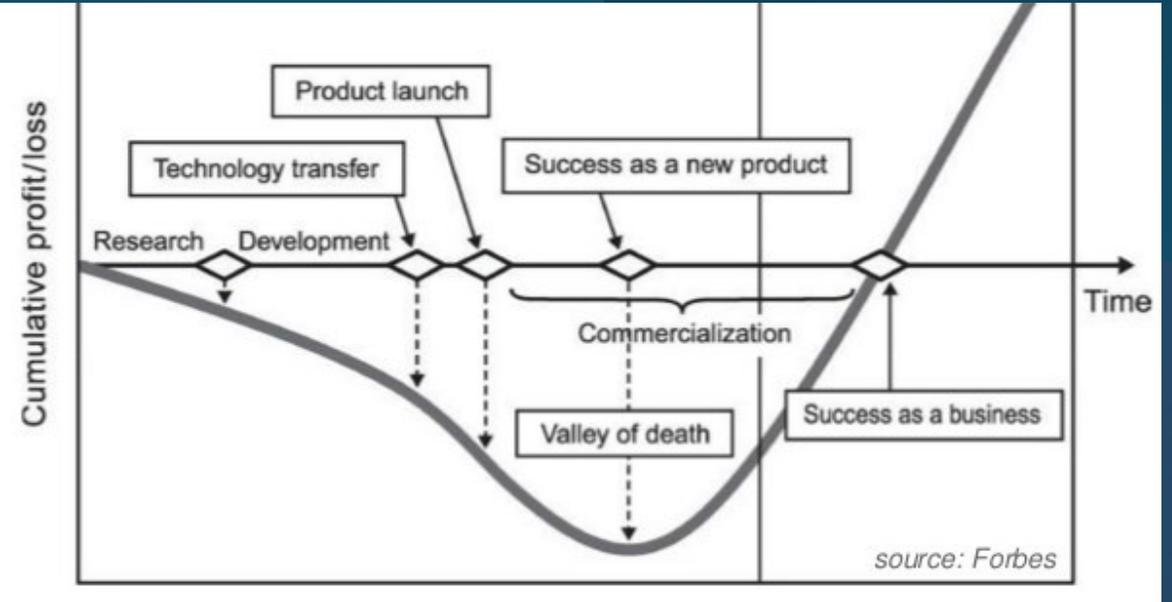
Background



2015



Science and Human Rights Coalition



Translational Valley of Death

Bryden, A. M., French, J., & Gran, B. (2023). Disability and human rights: The right to benefit from scientific progress. In S. Robinson & K. R. Fisher (Eds.), *Research handbook on disability policy* (pp. 582–598). Edward Elgar Publishing.

Questions

How do people with SCI experience the process of navigating health and social resources while managing physical and psychological recovery during their first year after injury?

What are the attitudes and perspectives of health professionals who specialize in SCI care regarding the utility of human rights within the context of disability, science and technology?

Spinal Cord Injury

- Catastrophic
- Sudden occurrence
- Young, healthy population
- Low Incidence and prevalence (18,000 / 305,000)
- Visible effects / invisible effects
- Secondary conditions
- High need, high cost (\$1,369,755 / \$237,862)
- Shorter life expectancy and health disparities

I wake up, someone's gotta take care of my bowels, someone has to help me urinate, someone has to ... They don't have to feed me thank God, but I'm only a few levels higher from having that be a problem. Everything that I do, any aspect of my life has to have some intervention by some other person to either find and give me a tool that I need, like the accommodations with the computer.

Max. Interview 2

What will improve life expectancy?

Reducing mortality rates from respiratory diseases and septicemia

Reversing current trends in diabetes and unintentional injury deaths

Continuing to reduce mortality from heart disease and other leading causes

But what else?

DeVivo, Michael J., Yuying Chen, and Huacong Wen. 2022. "Cause of Death Trends Among Persons With Spinal Cord Injury in the United States: 1960-2017." *Archives of Physical Medicine and Rehabilitation* 103(4):634–41. doi: 10.1016/j.apmr.2021.09.019.

Challenges of Spinal Cord Injury

- Lower quality of life
- Reduced social integration
- Financial and insurance challenges
- Employment barriers
- Lack of accessible housing

Methodology

Qualitative interviews of people with SCI (20)

- Longitudinal – up to six interviews over one year
- Newly-experienced SCI (6 months or less)

Qualitative interviews of health professional (15)

- One time
- Specialize in SCI management

Analyses

- Audio files transcribed verbatim
- Cyclical process of line by line coding and analytical memo writing facilitated by NVivo qualitative data analysis software

SCI Participant Demographics (n=20)

Race:

Black / White	20% / 80%
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Ethnicity

Hispanic / Non-Hispanic	10% / 90%
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Median Age (years)	43 (18 – 64)
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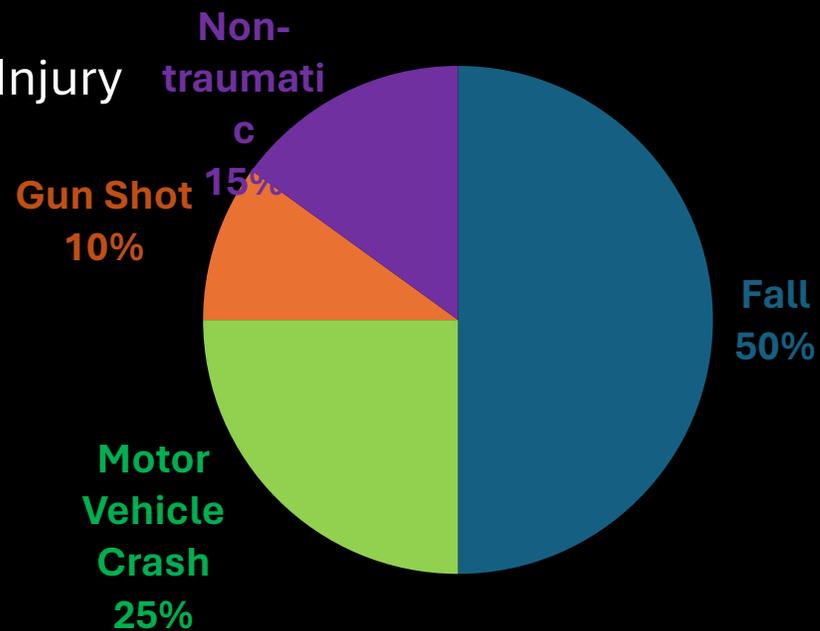


25%

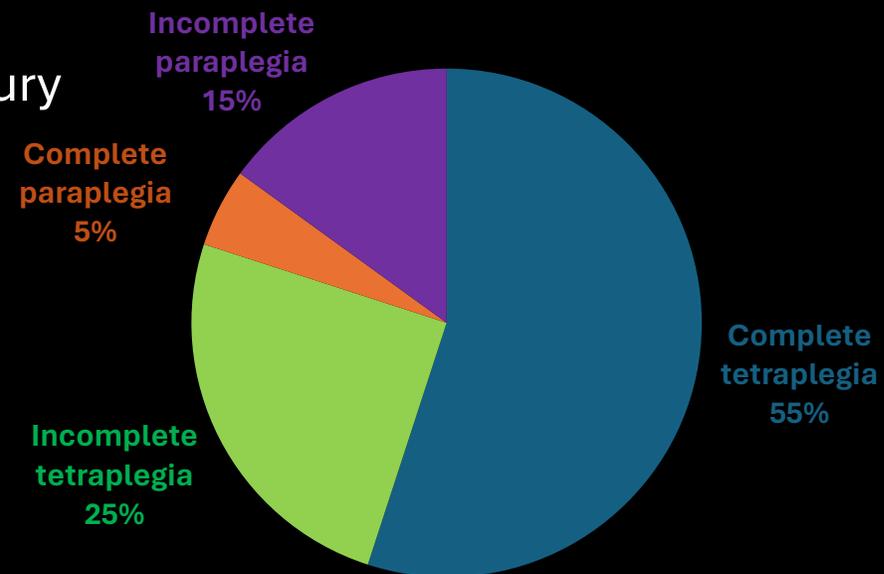


75%

Cause of Injury



Level of Injury



SCI Participant Social Demographics (n=20)

Employed at Time of Injury

Yes / No / Retired	80% / 10% / 10%
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Health Insurance Status at Injury

Private Insurance	70%
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Medicaid	20%
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Uninsured	10%
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Marital Status

Married	40%
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Committed Relationship	30%
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Single	30%
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Education

Advanced Degree	15%
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Bachelor Degree	20%
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Some College / Trade	35%
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High School	25%
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< High School	5%
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Resource Navigation by SCI Participants

Welfare State Rights and SCI

Rights to Sufficient and Appropriate Care after SCI

Navigating Rights to Community Reintegration after SCI

It's a circle, it's just like circles inside of circles inside of circles. Like you get one number to call and they can't help you, so they give you another number. I got a phone number. I called that phone number. The guy would not like, he would not give me any information. He just said I had to be transferred to this different person. So, then he transfers me to the different person. Of course, the different person doesn't pick up, so then I had to play phone tag with her for like a day. I had reached my level of call insanity... Zoe, Interview 6

Changes in Insurance

	Insurance Status at Injury	Insurance Status after Injury
Private Insurance	70%	40%
Medicaid	20%	60%
Uninsured	10%	0%
Social Security Disability Insurance	N/A	80%

Sufficient and Appropriate Care

Sufficient and appropriate care after SCI refers to addressing medical and rehabilitation needs in a comprehensive and timely manner to *maximize functional recovery and minimize complications* from secondary conditions.

Comprehensive, in this definition, refers not only to the broad range of services that may be required by a person with SCI, but also to the length of time that such services may be necessary, including acute inpatient rehabilitation and therapy interventions.

People with SCI are not receiving sufficient and appropriate care

Seeking Sufficient and Appropriate Care

Trajectories of medical and rehabilitation management

Transitions from acute inpatient rehabilitation

Transitions to and from skilled nursing facilities

Transition to outpatient services in the community

How, I mean, lifewise, how one day I could just be punching the clock and making twenty-one dollars an hour to a simple mistake putting me on my back, and then having to rely on the science side, and not being able to move anything. And just going through the protocols and the methods of being able to move my body parts, which (are) still having a few complications, you know what I'm saying? Life is pretty cruel. Like back to (the doctor), I just, I do trust him and I do believe in him, as well as (other doctor). I'm just hoping that as long as I keep fighting my fight... But I believe in them. Carter, Interview 1

Impacts of Insufficient and Inappropriate Care

Decreasing lengths of stay, inpatient rehabilitation

Two Saturdays ago, they made a phone call here to tell us that we had been denied since the 31st of (month), and it was already like the 4th of (month). So we were like, how can you deny us from days we've already been here. Logan, Interview 1

The practical issues are that I have found it impossible how the negotiations with the insurance company went on daily. It was a daily, it was a daily matter about being discharged or not. So I understood that it has become imminent and after five or ten such episodes, I said okay, I have enough of this, I'm just setting my own dismissal date and take day by day of what's going to happen... Yeah, if you cannot plan, I want to plan essentially. But then they let me know, no, no, no, I should play the game with them, and they were right, because within a week I could make the transition from being able to sit, to sit stably, not being able to walk, to walk, so a week timing (affected recovery) which it wasn't initially, so I wasn't at that point of my recovery yet.

Arthur, Interview 2

Impacts of Insufficient and Inappropriate Care

Half of the SCI participants were discharged to a skilled nursing facility, where knowledge of SCI care and therapy were deficient

I remember when the nurse was doing it, and watching her and thinking, I'm going to get a UTI, because I could tell like she wasn't doing it the right way, she wasn't staying sterile, she wasn't, you know, she was letting the tube touch the sheet and like, but you're in that position it's not like... you know (pause) I probably should have voiced it at that point and said stop, don't do anymore, because you're gonna give me a UTI, but I didn't, because you don't really feel like you can sometimes. Joseph, Interview 1

I said, "So, are you telling me right now that you're refusing to go get any other nurse?" Now, this is, depending on how you answer this, it's I win or you lose, except for I don't win. I can't get out of my bed, I can't walk out the door and go get another nurse. So, it's me trying to force the conversation based upon, you know, playing games at that point, you know... Yeah, she said, "If you're not gonna give me a chance to do it, I'll say you refused it." I kept on hitting the nurse button and then I had, finally one of the aides to go get one of the other nurses, to go get a nurse downstairs. Joshua, Interview 6

Policy Implications (The Revolution)

Enacting Greater Access to Rehabilitation for People with SCI

Neutral-Party Mediation of Medical Necessity

Immediate Qualification for Resources

Evening the Playing Field for People with SCI

That, if I had gotten onto it (waiver program) before, um, coming home, which we tried, it just took forever, but that would have helped with the bathroom remodel to get that done. Joseph, Interview

Resource Navigation
Guidance
(Help the People)

Psychosocial Impacts of Navigating Care Transitions on Caregivers of People with SCI

- Craig H. Neilsen Foundation
- Psychosocial Research Portfolio
- PI – Anne Bryden PhD, OTR/L
- Project Team
 - Brian Gran PhD
 - Susan Hinze PhD
 - Kim Anderson PhD
 - Daniel Lopez M.ED
- Approach – Mixed Methodology

Specific Aim #1

- **Specific Aim #1:** Investigate experiences encountered by caregivers of persons with SCI, as they negotiate transitions in care during the first year after injury.
- **Hypothesis #1:** Caregivers and people with SCI will encounter challenges negotiating healthcare and social service institutions throughout the first year after injury. Many experiences navigating resources are unrecognized by society. Challenges may pose significant psychosocial strains on caregivers as they face direct care demands in addition to time-consuming but largely hidden work necessary to coordinate resources for facilitating recovery and successful community reintegration. **Revealing this hidden work and understanding the needs of caregivers during the first year after injury is critical for identifying successful strategies for navigation that will improve community reintegration and quality of life.**

Methods – Aim #1

- In-depth, semi-structured interviews
- 15 SCI participant / caregivers
- Timeline of interviews:
 - Acute inpatient rehabilitation
 - 6 months post injury
 - 12 months post-injury
- Interview topics
- experiences during transitions across care, including negotiation of treatment and resources within healthcare and social systems, and how those experiences affect their emotional and physical wellbeing. The qualitative interviews at each stage will provide context and detailed information about how caregivers identified resources, including facilitators and barriers encountered to those resources.

Major Findings

- Caregivers undertake hidden work
- Beneficiary work
- Work changes over time
- Confusion over policies and institutional processes
- Support persons to people with SCI experience demands that transcend physical care. Revealing hidden work and understanding their broader landscape of demands during the first year after injury is critical for identifying successful strategies and resources that will improve quality of life for them and their loved ones with SCI.

Specific Aim #3

- **Specific Aim # 3:** Develop and disseminate an online guide to assist caregivers and people with SCI with navigating transitions across stages of care.
- **Hypothesis #3:** Accurate, easily-accessible, evidence-based guidance about resources and processes for managing transitions across care institutions will foster psychosocial wellbeing of caregivers and their persons with SCI.

Methods

Specific Aim

#3

- Based on information provided by caregivers, the guide will consist of resources and suggestions for navigating each potential transition that may be encountered by a person with SCI.
- Examples of such transitions include: acute care setting to acute inpatient rehabilitation facility; acute inpatient rehabilitation to home and home health or outpatient services; acute inpatient rehabilitation to sub-acute skilled nursing facility; and potential transitions in and out of health institutions due to medical complications.
- Each transition will have specific information including: definitions and terminology, time critical activities, important questions to ask, useful resources and search guidelines for local availability, and anticipating future steps. This online resource guide will be hosted on the Northeast Ohio Regional SCI System website, and will also include access to a printable PDF.

An Evidence- Based Resource

North Star

Home About Immediately After Injury Rehabilitation Rehabilitation 2 Community Education FAQs  Contact Us 

~ North Star ~

Navigating Life After Spinal Cord Injury

Empowering Individuals with SCI and the People who Support Them

About Us

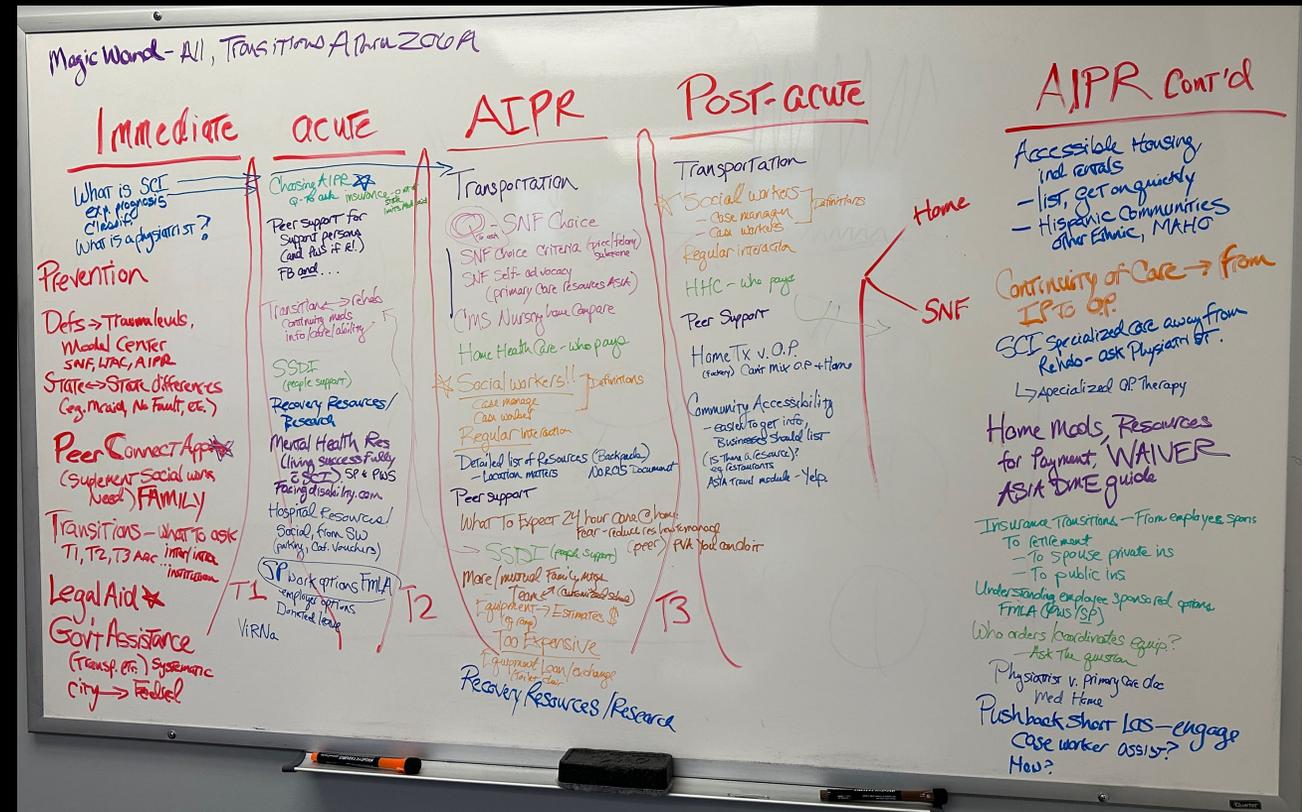
"Empowering caregivers to support and advocate for people with spinal cord injuries"

   |  



The Process – Finding the Evidence

- Questions
- Transitions
- Decision-making
- Help you the most
- Eligibility for gov't benefits
- Insurance / financial
- Information for the next steps
- Advice to new caregivers
- Info from the research team



Welcome!

This website is intended to help families and individuals navigate the difficult terrain after spinal cord injury (SCI). The first few years after SCI can be challenging for both the person with SCI and their support person. There may be many transitions in medical and rehabilitative care that involve navigating different kinds of institutions and resources. As a support person, you play a central role by taking on the tasks of finding resources to help your loved one recover and get back to their roles in the community. While your loved one is focusing on physical rehabilitation and emotional recovery, you may be left wondering how you can help. You may be spending long hours on the phone or searching the internet (or both!) to find information about recovery and care. At times, you may be overwhelmed with information, yet still seek answers to questions that you don't even know you have. This website is designed to navigate you through the questions to ask during the stages of recovery after SCI as well as to the resources that will answer those questions.



The Need for Guidance

I'm glad we had this conversation because actually I do feel a tad more focused because we've been brainstorming. ... this has been huge. You've really gotten me talking about things that I haven't talked about with anybody else.

Um, the biggest thing that I would like to see is just the resources. It's very difficult if you don't have a, a team of, of individuals that have been around situations like this. Like, it's easy to say, "Well, you know, you've got the world wide web. Go, go search something." But- You know, just searching something isn't enough sometimes.

Knowing the Questions to Ask

God, I wouldn't know what was missing. I mean, it's all uncharted territory for us. I mean, I don't know enough to know that something's missing.

(regarding SSDI) Yeah, I suppose I just have to ask them and I'm sure, I mean, I'm not sure, but I would assume that if I asked her she would probably help, but someone in my situation is not necessarily thinking about that.

But I guess notifying them of the organizations that can help. And as soon as the dust settles, I should have been applying for the SSI and SSI disability before we left (other state).

The content in this site is developed not only for support persons and people with SCI - it's developed BY these interested parties. Our team spent three years and numerous conversations with support persons to identify their questions, their struggles, and their wins! Everything included in this resource is a direct reflection of a need, a question, or an information resource expressed by a support person or individual with spinal cord injury.

There are a lot of great existing resources available. Our intention is not to reinvent the wheel, but to help you better navigate the resources that are already out there! Our research shows that people with SCI and their support persons desire a clearinghouse of sorts to identify what questions to ask in anticipation of next steps. We will not link to every single resource, but will link to a few good resources across a wide variety of topics to point you in the right direction!



Content - What to Know During Rehabilitation

Equipment and Home Modifications

Accessible Housing Options

Certified Independent Living Centers

Social Security and other Government Resources

Choosing a Skilled Nursing Facility

Length of Stay – How is it Determined?

Home Health

What to Expect When You Get Home

Conclusion

- Overwhelming need for resources
- Institutional practices:
 - Dominant
 - Unclear
 - Inconsistent
- Still grieving
- Systemic barriers to recovery and community reintegration
- Disregard for inherent dignity and autonomy