

# Thriving After Pediatric SCI: Two Life Stories

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# **Purpose and Introduction**

- To understand the lived experiences of spinal cord injury (SCI) as described by two people with SCI through life story interviewing.
- Narrative inquiry is a useful method to study the experience of living with a disability because story-telling allows individuals to explain how their conditions have influenced their everyday lives.<sup>1,3,7,12,13,14</sup>
- Existing narrative studies have explored lived experiences of SCI and the distinct perspectives of men and women, athletes with SCI, and caregivers of persons with SCI. 3,9,12,13,15
- This study may be among the first accounts of life stories of adults with pediatric onset SCI. \*The two participant's names have been changed to protect their identities.



Erica\* (left)

Malcolm\* (right)



Methods

# Approach

Qualitative method using narrative inquiry

# Life Story Interviews

- Conducted by two trained OT doctoral students (first and second authors)
- Questions adapted from Atkinson's The Life Story Interview<sup>2</sup>
- Interviews (n=15) over 16 weeks, two hours each, audio-recorded (Fig. 1)
- Transcribed verbatim

# Analysis

## Narrative analysis of eventful data

Constant recursive movement between emerging plot made up of details most relevant to the study's purpose and the data as a whole<sup>12</sup> (Fig. 2)

### **Narrative Smoothing**

Some details from the interviews were omitted while specific details that aligned with the purpose of the study were integrated in order to tell a coherent story<sup>1,12</sup>

# Acknowledgement

### **Figure 1: Interview Process**

15 Life Story Interviews
Co-facilitated by two
doctoral students

Erica: Interviews conducted in her workplace

in his home

N=8

interviewer:

Malcolm:

iterviews conducted

# Figure 2: Analysis

Organization of events and experiences

Narrative smoothing<sup>1</sup>

Comparison of emerging plot with bank of omitted details

Recursive movement between plot and entirety of data

# \_

Four themes emerged (Table 1)

Results

Two distinct life stores (Fig. 3)

# **Figure 3: Narrative Life Stories**

 Born in Columbia in 1977 to a young, single mother and devoted extended family.

Erica

- Talented and highly selfdisciplined athlete.
- Competitive gymnastics career, starting age of 6.
- Competed internationally, many prestigious titles.
- August of 1990 accident during vault routine in a competition.
- Sustained cervical level SCI, 13 years old.
- Transferred to United States pediatric SCI center
- Grieved loss of the body she knew
- Learned meaning of SCI while learning English and adjusting to a new culture.
- Used her experiences with overcoming adversity to help others
- Pursued degrees in psychology, counseling, and education and earned her PhD.
- Hopes for the future to help others to pursue dreams regardless of adversities

# Raised by grandparents

Born in the USA in 1977.

Malcolm

- Parents both experienced drug addiction throughout his childhood.
- Active, mischievous, loved playing with other children.
- June of 1991 dove into shallow water
- Sustained cervical level SCI, 13 years old.
- Malcolm's mother unable to provide adequate care.
- Malcolm transitioned to an assisted living community, age 15
- Achieved goals college degree and living independently.
- Coordinates own care, navigates community in power wheelchair and socializes with friends.
- Believes SCI protected him from an alternate future in which outcomes not as positive.
- Hopes for the future to stay healthy and to live life to the fullest.

# Table 1

| Table 1                        |  |  |  |  |
|--------------------------------|--|--|--|--|
| <u>Themes</u>                  | <u>Context</u>   | Erica's Quotes   | Malcolm's Quotes   |  |
| Adjustment to Life with SCI    | positive impact on self-efficacy, health   | "When I started seeing other patients laughing, making jokes and riding their chairs, that started giving me a different outlook on life."   | "My buddy had less movement than I have and I'd watch him get on the bus. I just watched him do it and I'm like 'Wow. I can't believe this.' So I said, 'I'm gonna try to get on the bus."   |  |
| Hardiness                      | Hardiness defined as taking responsibility for one's decisions (control), committing to the choices one has made (commitment) and reframing obstacles as stepping stones in order to generate alternative solutions to problems (challenge). <sup>10</sup> | "My health had to come firstbut something within me said 'Okay, I've gone through way too much; through all these loans, my mom's sacrifice my sacrifice, my time, everything. I just can't give up right now."        | "Out of all my friends and<br>my brother's friends, I was<br>the only one that<br>graduated from college."   |  |
| Interdependence                | valued occupations   | "I'm not afraid of asking for helppeople normally want to want to do everything by themselves, but the reality is sometimes you do need help and you do need to ask for it"  | "I was a little nervous at first cause I didn't know like what to expect. But they helped me with open arms. they understood my situationthey looked at me and saw Malcolm."   |  |
| Post-Traumatic<br>Growth (PTG) | capacity to perceive<br>benefits from and<br>making positive<br>changes in response<br>to tragic experiences.<br>7,8,9   | "Everything in my life since my injury has revolved around my health. That's why when I finally graduated it was like the biggest accomplishment ever because it almost felt like I was swimming against the current." | "I think God put me in this wheelchair for a reason 'cause the things that I was doing before my accident and the culture and environment that I was aroundnobody can predict the future but I don't know where I would be right now if I was on my feet." |  |
|                                |  | James 2. 12 3.1.1 3.1.1  |  |  |

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