



CASE REPORT

# Thriving after pediatric spinal cord injury: two life stories

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## Abstract

**Introduction** The primary objective of this qualitative study was to explore the lived experience of spinal cord injury (SCI) as described by life story interviews with two adults who sustained SCI as children.

**Case presentation** Data were collected by conducting 15 life story interviews with two individuals with SCI. Atkinson's Life Story Interview approach along with open-ended questions was utilized to capture the narrative data. Polkinghorne's narrative analysis of eventful data approach was used to configure the data elements into a story with the purpose of understanding the lived experience of SCI of these two individuals. Four themes relevant to the experience of living with a chronic condition emerged: adjustment to life with SCI, hardiness, interdependence, and post-traumatic growth.

**Discussion** This study illustrated how the two participants' personal development and life trajectories were deeply shaped by pediatric-onset SCI. The life story interview process proved to be an effective approach to understanding the lived experience of SCI as told by two adults with pediatric-onset SCI. While the two participants represented unique contexts, their stories conveyed several cohesive, transcendent themes relevant to the experience of living with a chronic condition. Future narrative inquiry research in individuals with pediatric-onset SCI is necessary to build a representation of this population's lived experiences.

## Introduction

Life story interviewing is a method of qualitative inquiry designed to capture the essence of an individual's life through the collection of narrative data [1]. Participation in the experience of telling one's story through a formal interview process has been associated with positive outcomes including validation of personal experiences, the release of burdens, and improved self-knowledge and self-esteem [2]. The interpretation of life story interview data may reveal transcendent themes related to a specific experience or significant life event such as the experience of living with a disease or disability. Narrative inquiry is an effective approach to studying the experience of living with a disability because it allows individuals with disabilities to explain how their conditions have influenced their everyday lives [3]. Existing studies have explored the lived

experience of SCI from diverse perspectives but this study may be the first account of the life stories of individuals with pediatric-onset SCI who have now been living with SCI for decades [4–7]. The purpose of this qualitative study was to understand the lived experience of SCI as described in life story interviews with two adults who sustained SCI as children.

This study was approved by the Thomas Jefferson University Institutional Review Board (#18D.513). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed throughout this research. Open-ended interview questions were adapted from Atkinson's "The Life Story Interview" and were chronologically organized to facilitate reflection on the participants' lives. (Table 1) [1]. Interviews were conducted and audio recorded with each interview not exceeding 2 hours. The individual interviews were held in person in private spaces at the participants' respective homes, workplaces, and virtually via Zoom.

The audio-recordings were transcribed verbatim and analyzed according to Polkinghorne's qualitative analysis approach called "narrative data analysis of eventful data" in which all of the participants' narrated experiences were organized into chronological data points then configured into a story that united and gave meaning to the data as

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**Table 1** Example questions used in life-history interviews.

|                            |  |
|----------------------------|--|
| Family origin              | What characteristics do you remember about your parents? Your grandparents? Your siblings?   |
| Culture and traditions     | What family celebrations, traditions, rituals were important in your life? What values were passed on to you, and by whom?   |
| Leisure and social factors | What were you like as a child?<br>What did you do for fun?<br>What were your favorite toys or games?<br>Did you feel nurtured as a child?<br>Who shaped and influenced your life the most?   |
| Education                  | What are your best memories of school?<br>What are your worst memories of school?  |
| Love and work              | Did you have dreams and ambitions as a child? What were they and where did they come from?<br>What is important to you in your work?   |
| Spinal cord injury         | What do you remember about the circumstances of your spinal cord injury?<br>Who are some of the friends/people who have been with you and support you since the very time of your injury, and still today? How have they influenced you and your recovery? |
| Projecting the future      | What are your greatest hopes for the future?<br>What will your greatest accomplishment be?   |

Adapted from “The Life Story Interview” [1].

contributors to the purpose of this study [8]. This method was utilized in a previous qualitative study examining the narrated experiences of a woman with SCI which similarly required the researchers to uncover a plot consisting of connections between narrative data points [5, 8]. Narrative smoothing [9] was conducted, during which some details from the interviews that were judged by the authors and participants as non-essential to understanding the lived experience were omitted while specific details that aligned with the purpose of the study were integrated in order to tell a coherent story. The narrative analysis compared the emerging plot made up of pertinent events and experiences with omitted details to discern whether their inclusion would improve the understanding of the participants’ experiences. This process involves recursive movement between the emerging story and the data in its entirety [8]. Member-checking or sharing results and interpretation with participants for reaction, discussion, and affirmation were used to ensure accuracy and rigor.

## Case presentations

Participants were one man and one woman who will hereafter be referred to by the pseudonyms Malcolm and Camila, respectively. Both individuals were known to the authors and expressed interest in research participation.

### Camila

Camila was born outside of the United States of American (USA) and was a passionate, talented, highly self-

disciplined child who began training as an elite athlete at the age of 6. Camila competed in numerous international gymnastic competitions throughout her childhood and became the first gymnast from her home country to be named the champion. When she was 13 years old, Camila attended a national gymnastics competition and during the vault event, the vault moved and Camila’s hands slipped; causing her to lose control of her body and land on her head. As a result of this accident, Camila sustained a complete, C5 SCI.

Camila received inadequate immediate medical intervention and experienced immense pain and subsequent health complications as a result. Camila’s mother was present by her side constantly from the time of the accident as they both struggled to understand what was happening. Several months later, a charitable organization sponsored her transfer to a regional pediatric SCI center in a large city in the US. Camila experienced depression as a result of the immense physical pain and emotional trauma related to the care she received in the months following her injury. Camila was especially distressed by the removal of privacy in interactions with medical teams consisting of nurses, physicians, and students which made her feel exposed and objectified. Camila also experienced culture shock in adapting to life in the U.S. and quickly taught herself English in order to communicate her needs.

As Camila heard the testimonies of other young adults with SCI within the first few years of her injury, she began to envision having a fulfilling life while living with SCI. The experience of having examples to look toward had a profound impact on Camila’s future aspirations, mental health, and emotional well-being. Camila and her mother

**Table 2** Four themes reflected in example quotes from participants' life story interviews.

| Theme                                | Camila's quotes   | Malcolm's quotes   |
|--------------------------------------|---|--|
| Theme 1: adjustment to life with SCI | "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.'"  |
| Theme 2: hardiness                   | "My health had to come first...but 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 my brother's friends, I was the only one that graduated from college."  |
| Theme 3: interdependence             | "I'm not afraid of asking for help...people normally 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 situation...they looked at me and saw 'Malcolm'."   |
| Theme 4: post-traumatic growth       | "I believe that maybe it could be an inspiration to other people even though I don't like to say that I'm an inspiration. I would rather have other people believe that I'm an example that things are possible despite the circumstances." | "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 around... nobody can predict the future but I don't know where I would be right now if I was on my feet." |

decided to stay in the U.S. in order to have access to ongoing medical treatment and educational opportunities for Camila. Camila's educational interests and passion for helping others led her to study psychology as an undergraduate to pursue a career in marriage and family therapy, earning a doctorate in psychology, and teach psychology to undergraduate students. She recalled the day she earned her doctoral degree as one of the proudest and happiest days of her life. Camila dreamed of learning to drive after she first learned about adaptive vehicles several years after her injury. Camila described her desire to drive as a part of her life-long pursuit to achieve a distinct form of independence characterized by receiving assistance from others while fulfilling valued roles, habits, and routines herself. As an adult, Camila went on to pursue driving lessons, earned her driver's license, and was fitted for her own adaptive vehicle. Camila reflected on her experience living with SCI, stating, "I believe that maybe it could be an inspiration to other people even though I don't like to say that I'm an inspiration. I would rather have other people believe that I'm an example that things are possible despite the circumstances." In the future, Camila hopes to work as a full-time professor and mentor to students while continuing to advocate for accessible environments in the workplace.

**Malcolm**

Malcolm was born in the USA and was raised by his maternal grandparents and his mother. Malcolm's mother experienced drug addiction with frequent relapses and unpredictable behavior throughout his childhood. When he was 13 years old, Malcolm visited a local park where he often played in the woods and swam in the river with other children from the neighborhood. After joining a group of children who were diving into the river, Malcolm dove into shallow water and struck his head, leaving him unable to swim. As a result of this accident, Malcolm sustained a C5 complete SCI.

Malcolm was told that he would likely never walk again but he could not predict what his life would be like. Malcolm's grief first manifested as a denial of his condition and anger towards others. While it was comforting for Malcolm to have his mother visit the hospital consistently in the months that followed his injury, he also experienced stress when his mother would visit while under the influence of drugs. When Malcolm was entrusted to the care of his mother at home, she was unable to provide adequate care for him due to her behavioral health concerns. Fearing for his health and safety, Malcolm contacted trusted healthcare providers and asked for help to leave his unsafe home environment. Malcolm moved to a residential facility for children with physical and developmental disabilities where he received the care he needed in a supportive environment.

Becoming friends with other children with disabilities and observing them participate in academic and extracurricular activities encouraged Malcolm to participate as well.

Upon transitioning to a residential facility for adults with disabilities, Malcolm received support in pursuing a college education and employment. Malcolm found fulfilling work at a non-profit organization where he enjoyed an inclusive workplace environment. While working part-time, Malcolm pursued earning an associate's degree. Malcolm expressed immense pride when he reflected upon what earning a college degree meant to him in the context of his upbringing. With the encouragement of peers with chronic physical disabilities, Malcolm transitioned to independent, apartment-style living and takes pride in his home environment that has been customized to meet his needs. Malcolm reflected on his experience of living with SCI by stating, *"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 around...nobody can predict the future but I don't know where I would be right now if I was on my feet...I just want people to know who have injuries, not only spinal cord injuries, that there is life after. You can live being disabled. I am an example and I want to be an example for other people."* In the future, Malcolm hopes to find fulfilling employment, develop a long-term romantic relationship and eventually raise children.

## Discussion

A total of 15 interviews were conducted over 20 weeks, 7 with Camila and 8 with Malcom. Following the analysis, four common themes emerged: Adjustment to life with SCI; hardiness; interdependence; and post-traumatic growth (Table 2). The four themes that emerged from these life stories represent the ways in which the shared experiences of two individuals living with SCI convey a deeper understanding of the lived experience of SCI.

### Theme 1: adjustment to life with SCI

Malcolm and Camila described a grieving period that took place in the first few months after the injury. Camila recalled the emotional pain she felt as she was physically exposed to various medical teams consisting of providers who were strangers to her. She described discomfort with receiving stares from strangers or children in public and felt that others were prejudiced toward people with disabilities. Similarly, Malcolm recalled prohibiting his friends from visiting with him during the first year of living with his SCI because he did not want to be seen in a wheelchair. These experiences of shame are described in the literature as "the

body of the self as observed by the glance of the other", which illustrates how an individual's experience of his or her own body can be defined by how other people look at them [10].

Malcolm and Camila's stories revealed the importance of role models in the development of their respective perspectives on disability, personal acceptance of their injuries, and development of future aspirations. Camila reflected on the ways that building relationships with other children living with SCI who were having fun and socializing provided her with a new outlook on living with a chronic condition. As an adult, Malcolm was inspired by individuals with SCI who were able to navigate public transportation and decided to pursue independence with community mobility by taking the bus himself. Relationships with other individuals with chronic physical disabilities who were living fulfilling lives fundamentally changed Camila and Malcolm's respective narratives about what was possible for their own lives. These relationships amongst peers with SCI have been shown to have a positive impact on self-efficacy, health outcomes, and quality of life in individuals with SCI [11, 12].

### Theme 2: hardiness

Malcolm and Camila both began to demonstrate elements of hardiness soon after their respective accidents. Hardiness has been defined in studies in the SCI population as consisting of control, commitment, and challenge [12]. Hardiness is 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) [13]. Malcolm demonstrated hardiness by taking control of the quality of care he received when he advocated for himself to be removed from his unsafe home environment. Camila demonstrated hardiness when she applied her strong sense of discipline to mastering English, her second language, in order to communicate her needs to health care providers. Camila's educational and professional journeys were often put on hold due to health concerns, yet she was committed to finishing her education no matter how long it took. The experience of having to prioritize the health of one's body and the effects that has on other priorities, one's sense of time, and one's sense of self is represented in the literature as unique to individuals with chronic illness and disability because the culture of those living without illness and disability is often forgetful of the body in daily life [10].

### Theme 3: interdependence

Camila and Malcolm's life stories revealed the shared value of coordinating support from the people around them such

as coworkers, caregivers, or even strangers in public places. Each life story demonstrated the importance of utilizing support in completing certain activities of daily living in order to pursue their respective goals and participate in desired roles. Camila's entire life story illustrated the impact of the constant support and devotion of her mother; whose roles she described broadly as her caregiver, nurse, friend, and closest confidant. Malcolm discussed his value for relationships with coworkers and friends who balanced acceptance of him for who he was with a willingness to assist him in a dignified manner. Similarly, when referring to her ability to find support in the workplace, Camila described her process of learning to ask for and accept help in order to ensure she could participate in her valued roles, habits, and routines. Malcolm and Camila's experiences reflect the motivational influence of receiving practical support from social networks on engagement in valued occupations after SCI as described in previous studies [14].

#### Theme 4: post-traumatic growth

Malcolm and Camila's stories demonstrate post-traumatic growth as Malcolm reflected on the long-term benefits he perceived from living with SCI and Camila reflected on the positive life changes she was able to accomplish in response to SCI. While SCI has been known to cause life-altering challenges, evidence suggests that many people with SCI demonstrate resilience and may perceive positive life changes resulting from SCI [15, 16]. This concept of post-traumatic growth has been defined in the literature as the capacity to perceive benefits emerging from a traumatic experience. Post-traumatic growth has been found to be higher in individuals with pediatric-onset SCI than in adult-onset SCI [15]. This is attributed to the idea that following pediatric-onset SCI, children's identities and overall development are more deeply shaped by the adjustment process when compared to individuals who were injured as adults [15].

#### Discussion

The life story interview process proved to be an effective approach to understanding the lived experience of SCI as told by two adults with pediatric-onset SCI. While the two participants represented unique personal, social and cultural contexts, their stories conveyed cohesive transcendent themes relevant to their shared experiences of living with SCI. The themes that emerged from this study support results from previous studies examining the positive impacts of peer relationships and supportive social networks on quality of life in individuals with SCI along with hardiness and post-traumatic growth in the SCI population

[11–15]. These life stories illustrate how the personal development and life trajectories of two people were deeply shaped by pediatric-onset SCI in ways that individuals with adult-onset SCI may not have experienced. Understanding the lived experience of pediatric-onset SCI can promote client-centered care by helping medical and rehabilitation teams develop empathy for past traumatic events and challenges that adults with childhood-onset SCI have endured across the majority of the lifespan. Providers of adults with pediatric-onset SCI enter the life story after many chapters have been written, and it is prudent to recognize that past experiences may be one of the greatest resources for adults with pediatric-onset SCI.

As with most qualitative inquiry, findings from this study cannot be generalized to the larger population of adults with pediatric SCI. The two participants were known to the investigators, and this relationship may have introduced bias. The narrative smoothing analysis method [9] also relied upon the authors' interpretation of which details were most aligned with the purpose of the study which may have also introduced bias. Future research with individuals with pediatric-onset SCI using qualitative methods including phenomenological and grounded theory approaches or quantitative methods such as survey and longitudinal approaches would further expand the understanding of the lived experience.

While the two participants represented unique contexts, their stories conveyed several cohesive, transcendent themes relevant to the experience of living with a chronic condition. Future narrative inquiry research in individuals with pediatric-onset SCI is necessary to build the representation of this population's lived experiences.

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#### Compliance with ethical standards

**Conflict of interest** The authors declare no competing interests.

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