



Clifton, Shane; Llewellyn, Gwynnyth; Shakespeare, Tom (2018) Faith, spirituality, and living the good life with quadriplegia. *Psychology of Religion and Spirituality*. ISSN 1941-1022 DOI: <https://doi.org/10.1037/rel0000215>

Downloaded from: <http://researchonline.lshtm.ac.uk/4650614/>

DOI: [10.1037/rel0000215](https://doi.org/10.1037/rel0000215)

#### Usage Guidelines

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact [researchonline@lshtm.ac.uk](mailto:researchonline@lshtm.ac.uk).

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

## Quadriplegia and the good life: a qualitative study of self-narratives

by Shane Clifton, Gwynnyth Llewellyn, and Tom Shakespeare

### Introduction

This paper summarises the insights of the qualitative study, “living the good life with quadriplegia,” which explores how the stories people tell about themselves reveal their understanding of what it means to flourish, and how they have all accomplished it.

As reflected in media and pop cultural advocacy promoting the legalisation of euthanasia for people who become a quadriplegic,<sup>1</sup> it is generally assumed that it is impossible to live the good life with a severe spinal cord injury (SCI). In fact, contrary to expectations, the majority of people adapt to life with the injury. The so-called disability paradox describes the difference between the seemingly inescapable conclusion that disability negatively impacts happiness, and the reality that many people with serious disabilities report to having a good life.<sup>2</sup> In part, this follows the theory of the hedonic treadmill, which asserts that although positive and negative events temporarily impact happiness, people quickly return to hedonic neutrality - to a set point level of subjective well-being that is substantially determined by personality traits.<sup>3</sup> In respect to hedonic theory and SCI, it has been found that even though people do adjust to the injury, achieving a relatively stable level of happiness, the losses and pains they suffer do substantially and permanently reduce life satisfaction.<sup>4</sup> The real problem with hedonic theory, however, is the implication that individual choices and circumstances make little difference to a person’s happiness.

---

<sup>1</sup> Consider the recent controversy around Jojo Moyes book and film *Me Before You*, see crip responses such as Crippledscholar, “Why Are You Complaining? Some People Actually Feel That Way: A Critique of Me Before You,” <https://crippledscholar.wordpress.com/2016/05/21/why-are-you-complaining-some-people-actually-feel-that-way-a-critique-of-me-before-you/>, accessed 22/07/2016.

<sup>2</sup> G L Albrecht and P J Devlieger, “The Disability Paradox: High Quality of Life Against All Odds,” *Social Science & Medicine* (1982) 48, no. 8 (April 1999): 977–88; Tom Shakespeare, “Nasty Brutish and Short? On the Predicament of Disability and Embodiment,” in *Disability and the Good Human Life (Cambridge Disability Law and Policy Series)*, ed. Jerome Bickenbach, Franziska Felder, and Barbara Schmitz (Cambridge: Cambridge University Press, 2013), 95–98.

<sup>3</sup> David Lykken and Auke Tellegen, “Happiness Is a Stochastic Phenomenon,” *Psychological Science* 7, no. 3 (May 1, 1996): 186–89, doi:10.1111/j.1467-9280.1996.tb00355.x; Ed Diener, Richard E. Lucas, and Christie Napa Scollon, “Beyond the Hedonic Treadmill: Revising the Adaptation Theory of Well-Being,” *American Psychologist* 61, no. 4 (June 2006): 305–14; Robert A. Cummins and Mark Wooden, “Personal Resilience in Times of Crisis: The Implications of SWB Homeostasis and Set-Points,” *Journal of Happiness Studies* 15, no. 1 (November 9, 2013): 223–35, doi:10.1007/s10902-013-9481-4.

<sup>4</sup> Diener, Lucas, and Scollon, “Beyond the Hedonic Treadmill,” 309; R. F. Murray et al., “Impact of Spinal Cord Injury on Self-Perceived Pre- and Postmorbidity Cognitive, Emotional and Physical Functioning,” *Spinal Cord* 45, no. 6 (June 2007): 429–36, doi:10.1038/sj.sc.3102022; Andrew J. Oswald and Nattavudh Powdthavee, “Does Happiness Adapt? A Longitudinal Study of Disability with Implications for Economists and Judges,” *Journal of Public Economics* 92, no. 5–6 (June 2008): 1061–77, doi:10.1016/j.jpubeco.2008.01.002; Jerome Bickenbach et al, “International Perspectives on Spinal Cord Injury” (Geneva: World Health Organisation and The International Spinal Cord Society, 2013), 132–34, [http://www.who.int/disabilities/policies/spinal\\_cord\\_injury/en/](http://www.who.int/disabilities/policies/spinal_cord_injury/en/).

The hedonic treadmill is limited by its focus on subjective measures of happiness. Influenced by the emergence of positive psychology, more recent studies of the resilience of people with an SCI have sought to take into account broader conceptions of happiness, recognising that a person's flourishing is both subjective and objective, and includes: having a greater balance of positive over negative emotions, engagement in gratifying activities, experiencing positive relationships, living for purpose and meaning, and achieving goals.<sup>5</sup> Positive psychology set out to ground conceptions of flourishing and psychological strength in the rigours of empirical science; "in statistical tests, validated questionnaires, thoroughly researched exercises, and large, representative samples."<sup>6</sup>

In the context of SCI, positive psychology gave impetus to studies that sought to identify the virtues and strengths that help a person flourish with the injury, in particular those that facilitate resilience, which is generally defined as positive adjustment to adversity.<sup>7</sup> There are a myriad of factors that, to greater and lesser degrees, might contribute to resilience; biological, demographic, environmental/social, and psychological. It is noteworthy that biological determinants, such as the level and severity of injury, have less impact than might be imagined,<sup>8</sup> although the evidence is mixed, with some studies finding that people with high-level quadriplegia, and those who suffer substantive pain, do report lower levels of well-being.<sup>9</sup> As might be expected given the broader literature on the social determinants of health,<sup>10</sup> there is evidence that demographics impact both resilience and longer term well-being. Post injury employment and income are of particular importance, with studies showing that people who have lower levels of income and employment experience greater health problems and lower levels of life satisfaction.<sup>11</sup> In terms of social environment, studies repeatedly found that the

---

<sup>5</sup> PERMA: positive emotion, engagement, positive relationships, meaning, achievement Martin E. P. Seligman, *Flourish: A Visionary New Understanding of Happiness and Well-Being*, Reprint (New York: Free Press, 2012).

<sup>6</sup> *Ibid.*, 1.

<sup>7</sup> S A Kilic, D S Dorstyn, and N G Guiver, "Examining Factors That Contribute to the Process of Resilience Following Spinal Cord Injury," *Spinal Cord* 51, no. 7 (July 2013): 553–57, doi:10.1038/sc.2013.25.

<sup>8</sup> Nan Zhang Hampton, "Subjective Well-Being Among People with Spinal Cord Injuries: The Role of Self-Efficacy, Perceived Social Support, and Perceived Health," *Rehabilitation Counseling Bulletin* 48, no. 1 (Fall 2004): 31–37; Kilic, Dorstyn, and Guiver, "Examining Factors That Contribute to the Process of Resilience Following Spinal Cord Injury," 556.

<sup>9</sup> Diana H. Rintala et al., "Chronic Pain in a Community-Based Sample of Men with Spinal Cord Injury: Prevalence, Severity, and Relationship with Impairment, Disability, Handicap, and Subjective Well-Being," *Archives of Physical Medicine and Rehabilitation* 79, no. 6 (June 1, 1998): 604–14, doi:10.1016/S0003-9993(98)90032-6; James Middleton, Yvonne Tran, and Ashley Craig, "Relationship Between Quality of Life and Self-Efficacy in Persons With Spinal Cord Injuries," *Archives of Physical Medicine and Rehabilitation* 88, no. 12 (December 2007): 1643–48, doi:10.1016/j.apmr.2007.09.001.

<sup>10</sup> Michael Marmot, "Social Determinants of Health Inequalities," *The Lancet* 365, no. 9464 (March 25, 2005): 1099–1104, doi:10.1016/S0140-6736(05)71146-6.

<sup>11</sup> David W. Hess et al., "Psychological Well-Being and Intensity of Employment in Individuals with a Spinal Cord Injury," *Topics in Spinal Cord Injury Rehabilitation* 9, no. 4 (Spring 2004): 1–10; Martha H. Chapin and Donald Holbert, "Employment at Closure Is Associated With Enhanced Quality of Life and Subjective Well-Being for Persons With Spinal Cord Injuries," *Rehabilitation Counseling Bulletin* 54, no. 1 (2010): 6–14, doi:10.1177/0034355210367685; Yue Cao et al., "Household Income and Subjective Well-Being After Spinal Cord Injury: A Longitudinal Study," *Topics in Spinal Cord Injury Rehabilitation*

support of family and friends made an important difference to resilience,<sup>12</sup> and, similarly, that spirituality and faith helped people make sense of their experience.<sup>13</sup> Finally, various psychological resources were found to be significant. Foremost among them is self-efficacy, which refers to beliefs about one's capacity to exercise control and achieve desired outcomes.<sup>14</sup> Persons with high levels of self-esteem, likewise, showed higher life satisfaction,<sup>15</sup> as did those with positive, hopeful, and optimistic attitudes.<sup>16</sup>

Although a detailed review and evaluation of all of the literature is beyond the scope of this paper,<sup>17</sup> there is obvious support for the insights of positive psychology; that psychological resources (which are labelled by Seligman and others as virtues and strengths<sup>18</sup>) make a vital difference to resilience following an SCI, that social relationships are important, and that spirituality and faith can contribute to adjustment. The contribution of the empirical approach is obvious, providing as it does evidence of psychological strengths that might be developed to support the rehabilitation of newly injured people, helping them to make the most of their longer-term well-being. There are also some limitations. One of the key methodological issues facing researchers studying the resilience of people with SCI is the need to determine how to measure adjustment, and to this end most draw on subjective measures of happiness, such as subjective well-being and life satisfaction, since it is harder to measure the flourishing that is the goal of positive psychology. There are important philosophical reasons as to why empirical

---

20, no. 1 (January 1, 2014): 40–47, doi:10.1310/sci2001-40; Bickenbach et al, "International Perspectives on Spinal Cord Injury," 177.

<sup>12</sup> Hampton, "Subjective Well-Being Among People with Spinal Cord Injuries"; Anette Johansen Quale and Anne-Kristine Schanke, "Resilience in the Face of Coping with a Severe Physical Injury: A Study of Trajectories of Adjustment in a Rehabilitation Setting," *Rehabilitation Psychology* 55, no. 1 (2010): 12–22, doi:10.1037/a0018415; K. R. Monden et al., "Resilience Following Spinal Cord Injury: A Phenomenological View," *Spinal Cord* 52, no. 3 (March 2014): 199, doi:http://dx.doi.org.ezproxy1.library.usyd.edu.au/10.1038/sc.2013.159.

<sup>13</sup> Elizabeth N. Matheis, David S. Tulsy, and Robert J. Matheis, "The Relation between Spirituality and Quality of Life among Individuals with Spinal Cord Injury," *Rehabilitation Psychology* 51, no. 3 (2006): 265–71, doi:10.1037/0090-5550.51.3.265; Brian White, Simon Driver, and Ann Marie Warren, "Resilience and Indicators of Adjustment During Rehabilitation From a Spinal Cord Injury," *Rehabilitation Psychology* 55, no. 1 (February 2010): 23–32; Monden et al., "Resilience Following Spinal Cord Injury," 199.

<sup>14</sup> Quale and Schanke, "Resilience in the Face of Coping with a Severe Physical Injury"; Eleanor Weitzner et al., "Getting on With Life Positive Experiences of Living With a Spinal Cord Injury," *Qualitative Health Research* 21, no. 11 (November 1, 2011): 1455–68, doi:10.1177/1049732311417726; Kilic, Dorstyn, and Guiver, "Examining Factors That Contribute to the Process of Resilience Following Spinal Cord Injury."

<sup>15</sup> Ioanna Tzonichaki and George Kleftras, "Paraplegia from Spinal Cord Injury: Self-Esteem, Loneliness, and Life Satisfaction," *OTJR* 22, no. 3 (Summer 2002): 96–103; C Peter et al., "Psychological Resources in Spinal Cord Injury: A Systematic Literature Review," *Spinal Cord* 50, no. 3 (March 2012): 192, doi:10.1038/sc.2011.125.

<sup>16</sup> Kathleen B. Kortte et al., "Positive Psychological Variables in the Prediction of Life Satisfaction after Spinal Cord Injury," *Rehabilitation Psychology* 55, no. 1 (February 2010): 40–47, doi:10.1037/a0018624; Pat Dorsett, "The Importance of Hope in Coping with Severe Acquired Disability," *Australian Social Work* 63, no. 1 (March 2010): 83–102.

<sup>17</sup> For that purpose, see Peter et al., "Psychological Resources in Spinal Cord Injury."

<sup>18</sup> Martin E. P. Seligman, *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment* (New York: Simon and Schuster, 2002), chap. 8.

studies utilise subjective assessments,<sup>19</sup> not least of which is the elevation of individual agency; the recognition that the individual should be the arbiter of her or his own good. This is especially important in the context of disability, where paternalism has too often silenced the disabled voice.<sup>20</sup> Even so, subjective assessments of well-being have their limitations, in part because they are influenced by an individual's hedonic set-point, but also because human flourishing is not easily reduced to a point in time measurement. And when it is, that which is most important may be lost, since flourishing is a lived reality. It occurs over the course of a life, in its ups and downs, challenges, successes, and failures, and it is precisely the journey of flourishing that is not readily captured by simple quantitative measures. The second difficulty of many of the studies is that they generally focused on the period of rehabilitation, extending for some studies a few years post injury. Very few studies take a longer term focus.

### **The virtue tradition**

The science of positive psychology draws from a much older virtue tradition. With its origins in Aristotle, its development by Aquinas, and its re-appropriation by contemporary moral philosophers such as Alasdair MacIntyre, Amartya Sen and Martha Nussbaum, the virtue tradition is concerned with the goal of happiness (*eudaimonia*), understood not as short-term pleasure, but as lifelong flourishing – the good life.<sup>21</sup> Indeed, *eudaimonia* has traditionally been translated as “happiness,” but is better expressed by the notion of flourishing, which elicits a longer term and more complex vision.<sup>22</sup>

Traditionally, the good life was linked to conceptions of human nature and understood objectively. For Aristotle, it related to the human capacity to reason, and thus found its high point in philosophical contemplation.<sup>23</sup> While the post-Nietzschean critiques of objectivity have rightly

---

<sup>19</sup> Jukka Varelius, “Objective Explanations of Individual Well-Being,” in *The Exploration of Happiness*, ed. Antonella Delle Fave, Happiness Studies Book Series (Springer Netherlands, 2013), 15–30, doi:10.1007/978-94-007-5702-8\_2.

<sup>20</sup> Ron Amundson, “Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics,” in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. David T. Wasserman, Robert Samuel Wachbroit, and Jerome Edmund Bickenbach (Cambridge, UK; New York: Cambridge University Press, 2005).

<sup>21</sup> Alasdair C. MacIntyre, *After Virtue: A Study in Moral Theory*, 3rd ed. (Notre Dame, Ind.: University of Notre Dame Press, 2007); Martha Nussbaum, “Non-Relative Virtues: An Aristotelian Approach,” in *The Quality of Life*, ed. Amartya Sen and Martha Nussbaum (Oxford: Oxford University Press, 1993).

<sup>22</sup> Rosalind Hursthouse, *On Virtue Ethics* (Oxford: New York: Oxford University Press, 1999), 9; MacIntyre, *After Virtue*, 162; Seligman, *Flourish*.

<sup>23</sup> Aristotle, *Nicomachean Ethics*, trans. Susan D. Collins and Robert C. Bartlett (University Of Chicago Press, 2011), 1177b; Susan D. Collins and Robert C. Bartlett, “Interpretive Essay,” in *Nicomachean Ethics*, by Aristotle (Chicago, IL: University Of Chicago Press, 2011), 224; C. D. C. Reeve, *Action, Contemplation, and Happiness: An Essay on Aristotle* (Cambridge, MA: Harvard University Press, 2012), chap. 8, <http://www.jstor.org.ezproxy1.library.usyd.edu.au/stable/j.ctt2jbqsb>.

identified the fluidity and subjectivity of happiness and human teleology,<sup>24</sup> virtue theorists note that, in all its varieties, the good life nevertheless retains certain objective elements related to our common human nature as physical, psychological, intellectual/moral, and social beings.<sup>25</sup> That is to say, the good life entails the maximisation of physical and mental health, the pursuit of meaning, and the making and sustaining of deep relationships. Virtue theorists go on to argue that these things are not merely a product of circumstances (although Aristotle recognises that happiness is partially dependent upon the luck of one's social context, social determinants are not everything<sup>26</sup>), but are made possible by the exercise of virtues; the habits of character that enable one to succeed in particular activities and, over the long run, to live the good life.<sup>27</sup> It is virtue that enables a person to maximise their physical and psychological health, to make wise choices, to direct their life toward meaning, and to develop deep friendships and rich communities.

Both MacIntyre and Nussbaum have developed the logic of virtue theory in the context of disability.<sup>28</sup> In *Dependent Rational Animals*, MacIntyre critiques the individualist tendency of virtue theory, and asks what difference it would make to moral philosophy if disability and dependency were treated as central to the human condition.<sup>29</sup> He goes on to explore the implications of interdependency for our understanding of virtue. Sen and Nussbaum builds on Aristotle's application of virtue ethics to politics so as to develop a philosophical conception of justice labelled the "capabilities approach."<sup>30</sup> It describes a set of core capabilities that they take to be the minimum basis for the good life. In *Frontiers of Justice*, Nussbaum explores the implications of the capabilities approach for social policy that reports and empowers people with disabilities and their families and carers.<sup>31</sup> While the detail of their contribution is beyond the scope of this present work, it is noteworthy that both emphasise the importance of narrative for

---

<sup>24</sup> Friedrich Nietzsche, *The Gay Science: With a Prelude in Rhymes and an Appendix of Songs*, trans. Walter Kaufmann (New York: Vintage, 1974), s.335.

<sup>25</sup> MacIntyre, *After Virtue*, chap. 15; Hursthouse, *On Virtue Ethics*, ch.9; Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership*, The Tanner Lectures on Human Values (Cambridge, Mass.: Harvard University Press, 2006), 69–81.

<sup>26</sup> Aristotle, *Ethics*, 1099b.

<sup>27</sup> *Ibid.*, 1106a; Hursthouse, *On Virtue Ethics*, 21.

<sup>28</sup> Alasdair MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues* (Chicago, Ill.: Open Court, 1999); Nussbaum, *Frontiers of Justice*; Others exploring the intersection between virtue ethics and disability include Garret Merriam, "Rehabilitating Aristotle: A Virtue Ethics Approach to Disability and Human Flourishing," in *Philosophical Reflections on Disability*, ed. D. Christopher Ralston and Justin Hubert Ho, Philosophy and Medicine 104 (Dordrecht, Netherlands: Springer, 2009), 133–51, doi:10.1007/978-90-481-2477-0\_8; Shane Clifton, "Happiness and Spinal-Cord Injury: A Journey through Traditions of Virtue to Positive Psychology," *Journal of Religion, Disability & Health* 17, no. 4 (2013): 347–68; Amos Yong, "The Virtues and Intellectual Disability: Explorations in the (Cognitive) Sciences of Moral Formation," in *Theology and the Science of Moral Action: Virtue Ethics, Exemplarity, and Cognitive Neuroscience*, ed. James A. Van Slyke et al. (New York: Routledge, 2012), 191–208.

<sup>29</sup> MacIntyre, *Dependent Rational Animals*, 8.

<sup>30</sup> Martha Nussbaum and Amartya Sen, eds., *The Quality of Life* (Oxford: Oxford University Press, 1993).

<sup>31</sup> Nussbaum, *Frontiers of Justice*.

understanding conceptions of the good life. As MacIntyre observes, “Man [sic] is in his actions and practice, as well as in his fictions, essentially a story-telling animal,”<sup>32</sup> so that the contours of the good life emerge in story, both in cultural narratives, and in the stories we tell about our own lives.<sup>33</sup> Indeed, the way in which people tell their story is an exercise in self-understanding that emerges as we interpret our own experiences, achievements, crises, and failures, in interaction with significant others and with and social and cultural attitudes and symbols.<sup>34</sup> This is particularly important for people with an SCI, who have had to respond to the crisis of an injury that changed the course of their life. As Neimeyer observes, “Like a novel that loses a central character in the middle chapters, the life story disrupted by loss must be reorganised, rewritten, to find a new strand of continuity that bridges the past with the future in an intelligible fashion.”<sup>35</sup> And since adjustment takes months and years and involves various stages (intensive care, in-hospital rehab, return to home and to vocation et cetera), a person’s storied self-understanding may well undergo continual rewriting.

## Goals and Method

In the light of virtue theory’s emphasis on understanding flourishing by way of narrative, the project on which this paper is based set out to investigate whether the stories of people that have lived with SCI over time might complement and extend what has been learned by empirical studies on the various factors that contribute to subjective well-being, *eudaimonia*, and resilience. In particular, the study aimed to examine whether and how the self-narratives of individuals living with quadriplegia over the medium to long term revealed a person’s understanding of the good life in the context of their severe disability, and gave insight into how they had gone about achieving it. Through analysis of their stories, it sought to examine: 1. How individuals negotiate the losses and subsequent disability following SCI, 2. How individuals construct and reconstruct their lives, and 3. Whether particular virtues, skills, and attitudes contribute to (or undermine) a person’s capacity to live the good life flourish with the injury over the medium to long term.

---

<sup>32</sup> MacIntyre, *After Virtue*, 216.

<sup>33</sup> While it is beyond constraints of this paper, it is important to note that the relationship between individual stories and cultural narratives is complex, especially in the context of disability. See also Nussbaum’s discussion of narrative imagination. Martha Craven Nussbaum, *Cultivating Humanity: A Classical Defense of Reform in Liberal Education* (Cambridge, Mass.: Harvard University Press, 1997).

<sup>34</sup> Carolyn C. Morf and Mischel, “The Self as a Psycho-Social Dynamic Processing System: Toward a Converging Science of Selfhood,” in *Handbook of Self and Identity*, ed. Mark R Leary and June Price Tangney (New York; London: Guilford Press, 2012).

<sup>35</sup> Robert A Neimeyer, *Meaning Reconstruction & the Experience of Loss* (Washington, DC: American Psychological Association, 2001), 263–64.

Adopting a qualitative method, this study used life stories for the purpose of investigating peoples' understandings of themselves and the social worlds in which they live.<sup>36</sup> The study involved conducting open and in-depth interviews of participants, who were asked to share the story of their life. As Plummer notes, "most social science, in its quest for generalizability, imposes order and rationality upon experiences and worlds that are more ambiguous, more problematic and more chaotic in reality."<sup>37</sup> To avoid this danger, interviews were deliberately unstructured, and participants encouraged to tell their story in their own way. The interviewer facilitated conversation, and invited participants to describe key events, difficulties faced, and accomplishments, regrets and so on. No fixed structure or extensively predetermined questions constrained the interviews, except that every participant was asked to give their conception of the good life, and comment on whether and how they have gone about achieving it.

Seven participants were involved in the project, each of whom had lived with the injury over the medium to long term (for at least five years). They were recruited from informal networks, and snowball sampling from one participant to another. There was an inevitable selection bias in this approach to recruitment, since people were likely to have been recommended to the study because others judged they lived well with their injury. While there is much to be learned from positive narratives – as we shall see – it is certainly true that a fuller understanding of the challenge of living with an SCI would emerge with access to darker stories (a goal for a future study). The following participants were involved in the study:

Name	Sex	Age	Injury	Years with SCI	Spouse/ Partner
Sheree	F	45	C5/6 complete quadriplegic	18	No
Sara	F	43	C6/7 complete quadriplegic	19	Yes
Glenn	M	47	C5/6 complete quadriplegic	28	Yes
Philip	M	55	C4/5 incomplete quadriplegic	37	No

<sup>36</sup> Ken Plummer, *Documents of Life 2: An Invitation to A Critical Humanism* (London: SAGE, 2001).

<sup>37</sup> *Ibid.*, 39–40.



Mark	M	43	C3/4 complete quadriplegic	7	Potential
Bruce	M	64	C6 incomplete quadriplegic	43	No
John	M	72	C5 complete quadriplegic	54	Yes

Participants were involved not only in the telling of their story to the first author, but in overseeing and authorising its construction and final form. To that end, each participant was involved in a lengthy recorded interview (usually 1.5 to 2 hours), which was then transcribed. Thereafter the first author wrote up a summary of the story, which was returned to the participant for their comment. A second interview discussed any suggested additions and/or changes that participant would like to make to the summary, and a final copy of the narrative was forwarded to and approved by the participant.

Of particular importance for this project is the publication of the life stories as a key element of the research output. As Ellis and Bochner (2006) observe, stories are evocative, and can themselves “do the work of analysis and the theorizing.”<sup>38</sup> Unfortunately, it is not possible in a journal article to publish the detail and depth of insight of all the participant’s stories. What we can do, however, is weave together their narratives, to provide an overview of the rich and complex experiences of seven people who have lived over the medium to long term as quadriplegics. It is hoped that what emerges is itself a multifaceted narrative of a group of Australian quadriplegics that helps us to understand the contours and ambiguities of living with SCI.

### **Narrative Results and Discussion**

Participants began telling their story by describing their life pre-injury. As would be expected, their backgrounds were varied, and while it is beyond the scope of this paper to describe the detail, it is noteworthy that for most, the accident did represent a significant turn in direction of life. Sheree was a schoolteacher prior to the injury, and afterwards worked in SCI rehabilitation and support. While in hospital, Mark and Glenn made religious commitments that influenced their subsequent journey. Mark also changed careers and Glenn went back to school and then to University. Sara was studying architecture, and after the accident transferred to the study of fine

---

<sup>38</sup> Carolyn S. Ellis and Arthur P. Bochner, “Analyzing Analytic Autoethnography: An Autopsy,” *Journal of Contemporary Ethnography* 35, no. 4 (August 1, 2006): 436, doi:10.1177/0891241606286979.

art. Bruce and John eventually took jobs in the disability sector. And Philip, who before his accident had completed his HSC but had no ambition to go to University, says of the injury:

It has taken me in a totally different direction, and I'm pretty sure that if I hadn't broken my neck I wouldn't be living here [owning a house in Sydney's northern beaches], because I may not have gone to University, and so my income would have been less.

While participants identified the preinjury capacities they had lost –and every story is essentially about how people negotiate loss – this was not the focus of attention. As Sheree says, “the truth is that it's been so long since my accident – 16 years now – so that I don't miss anything. If you had asked me 4 to 5 years after my accident, I'm sure I would have responded quite differently.” More important to participants was describing the opportunities they grasped after the injury, and exploring their challenges and achievements.

It is also noteworthy that while SCI effected change, participants generally felt that their preinjury character was important to post injury resilience; that although the injury changed them, it did not define them. As Sheree observed, “I think it's the person you were before that determines whether you will be able to live independently.”

All participants gave substantive descriptions of their accident and the experience of ICU and rehabilitation. It is noteworthy that most recall having a certain level of optimism very early on. Reflecting on the days and weeks immediately after her injury, Sara says that:

I always felt like I would be okay. I had bad days, but I knew I would pull through. It was when I thought about other people worrying about me that I got most upset. I remember my dad saying to me on the phone one day, “every time you speak to me Sara, you make me feel better.”

Sheree, similarly, recalls that:

I wasn't enormously upset about the injury – at least I don't remember being so. I was quite resigned to the fact that this was my life, and that I had a rehab experience to get through. So I was quite fine with it. I never thought I was going to walk – not ever. I knew what the damage was, and the doctors told me it was permanent. I was very realistic. So, at no point did I think I was going to return to my previous life. But I had lots of hope.

This pragmatic but realistic attitude is characteristic of most participant recollections, but as Sheree's “at least I don't remember being so” reminds us, events that occurred many years

earlier are inevitably interpreted through the lens? of present-day attitudes. The way in which the different participants tell of their hospitalisation and early rehabilitation varies from one to another, but a number of them highlight negative attitudes and low expectations. John, whose injury was incurred in 1959 – at a time when many newly injured quadriplegics did not live for long – received very little in the way of rehabilitation and was discharged from hospital to Weemala nursing home, which displayed a sign on entrance with the tag, “Home for the incurables.” He remembers asking the matron,

“How long am I going to be in here?” She replied, “When you come in here son, you don't come to get better. You slowly get worse and die.”

By 1970s, when Bruce and Philip had their injuries, specialised spinal units and rehabilitation services were in place. Even so, Philip recalls that the expectations for his future were low,

they expected me to leave the hospital and go to a sheltered workshop. ... I told them I intended to go to university, which they didn't really think was possible. So I told them where they could put their sheltered workshop, and just went ahead and enrolled in the course that I had intended to do before the accident.

Even Mark, whose injury was the most recent of all the participants (2008), provides a largely negative account of rehabilitation. He felt that rehab and medical staff left him fearful and ill-equipped to deal with life outside the hospital.

If you had a catheter blockage, you could die, or have a heart attack or stroke. I thought, dude, give me some positive language. I was scared to go home, but I did because I had no choice.

In highlighting some of these negative experiences, the point is not to argue that Australian spinal units and rehabilitation centres have offered poor care, especially since adjustment to a spinal cord injury is inevitably traumatic. Indeed, Bruce and Sheree praise the support they received, and Glenn is extremely thankful that the staff who coached him “focused on what was possible rather than what was lost and impossible” – he thinks present-day rehab is “too soft.” Rather, what is noteworthy is that participants drew on negative experiences to highlight the challenges that they have overcome along the way. From every angle, each of the participants tell stories of persevering and beating expectations. Glenn, for example, was told by a driving instructor that he would never learn to drive, but he persevered in his lessons and, one year later, earned his

license. He says that being able to drive “changed my life completely,” giving him a freedom he hadn’t had prior to the injury.

For many of the participants, the early years of living at home with quadriplegia were extremely challenging. Mark’s observation is typical:

This time of my life really tested me. There is no book on these things. You just play it as it comes, as the landscape unfolds in front of you. You make decisions, and you don’t know if it’s right or wrong. It was a really steep learning curve. 2008 – 2011 was a really dark period. I was just absorbing the injury and its consequences. I had struggles breathing, and eating was a chore. I had bad health, I got pneumonia every winter. I had pressure sores, one keeping me in bed for nine months. Everything was coming at me from all corners, and there were too many variables.

Sheree, who prior to her injury was a teacher in Brisbane, spent five years in relative isolation on her parents’ farm in outback New South Wales, before being ready to move back to the city (this time to Sydney). Bruce, similarly, spent a number of years living in his parents’ home, but he hated having to depend on them, and felt like a burden (he was relieved, eventually, to be provided accommodation in a specialised SCI facility). A few years after her discharge from hospital, Sara collapsed completely, and was bedridden for six months. Participants lay some of the blame the difficulty of adjusting to the injury on inadequate support services, especially after leaving rehabilitation and returning to the community. As Mark notes:

There was a lot of gaps in the system – gaps in helping families. The health system has kept us alive, but in hospital they push you to the door, and then waive you off, and say good luck.

At the same time, participants recognise that adjusting to life with the injury is difficult, and takes time.

### **Positive attitude but not super quads**

The challenge of SCI extends beyond rehabilitation, and participants described various ongoing hardships that attend to their SCI, including nerve pain, sexual loss and so on. Glenn, for example, described repeated instances of discrimination that hampered his career development:

I’m still fighting the same battles today, and it really depresses me that nothing has really changed. ... There is a glass ceiling with a disability. ... All the people who studied with

me have great positions and climbed the corporate ladder, but I've never been able to. I face prejudice and ignorance, because there's not many people with disabilities in the workforce, so the prejudice persists. And men don't want to be seen to be bettered by someone with a disability.

Whatever the particularities of the challenges faced, participants generally identified positive thinking, optimism, and hopefulness as contributing to their eventual coming to terms with the injury, and so enabling them to live a good life – character traits that empirical studies have emphasised as being central to resilience.<sup>39</sup> For one participant, so important was a positive attitude that he deleted most of the seemingly negative references that had been discussed in the initial interview and written into the first draft of his life narrative. Bruce, speaks for many when he observes:

If I wanted to do something, I'd think of a way to do it, rather than let people say "you can't do that or you can't go there" I'd find a way – and say to people well, there's probably a way to do things that you don't know. So I thought positively about things. I don't think negative about stuff. I have good reason to be negative, with my waterworks, they're terrible. But overall, I've been able to overcome everything – in a chair you can do it one way or another. I feel lucky that I've had a positive attitude, right from the beginning, and that I try to encourage others.

Bruce has lived for forty-three years with permanent neurological pain (like many with an incomplete injury), and says he has coped because:

I always maintain a positive attitude. I keep busy and occupy my mind. Being active enables you to overcome. If you're sitting around all day at home, not doing anything, you dwell on the pain. But If your mind is occupied, busy with something, a hobby or interest, listening to a radio or reading a book, then you can teach yourself to accept it.

Philip, similarly, notes that "I've met some guys in wheelchairs who really irritate me, but I have a positive and carefree attitude." Sheree says that she owes much to the fact that she had "lots of hope about moving on and continuing to live a meaningful life." She ended up becoming a peer support worker with the Spinal Cord Injury Association, and says that she understood her

---

<sup>39</sup> Timothy R. Elliott, Monica Kurylo, and Patricia Rivera, "Positive Growth Following Acquired Physical Disability," in *Handbook of Positive Psychology*, ed. C.R. Snyder and Shane J. Lopez (Oxford University Press, 2002), 687 – 689; Kortte et al., "Positive Psychological Variables in the Prediction of Life Satisfaction after Spinal Cord Injury."

role as providing “hope and encouragement.” Mark, likewise, observes that “it might seem like a cliché, but making sure I’m positive really works.”

Even so, most of the participants recognised the danger of what might be labelled the positivity myth; the prevailing cultural ideology that insists that a positive attitude overcomes all barriers and is the certain pathway to achievement.<sup>40</sup> This was apparent in Glenn’s frustration about the impact of discrimination on his career. Sheree, for example, insists that there is nothing unique or special about her accomplishments, highlighting the support she has received from others. Asked about how she has managed to live in a house on her own in Sydney she responds:

I guess I just haven't had any choice. If I was going to move to Sydney and get on with next stage of my life, then that was my option. It's not as if I'm playing super-quad and getting myself in and out of bed, or showering myself or anything. My care incorporates house work; washing, sweeping the floor or whatever. So all of those things are done, and there's nothing else remarkable about how I live.

Sara’s narrative is particularly insightful. She describes how, after discharge from rehab, she returned to university, lived as independently as she could, and to all outside appearances was positive and successful. But she soon discovered that life with quadriplegia had its limits:

I call it super cripple complex. I was being a super cripple. I was achieving everything but not really for myself.... It was a pattern within our family. We were always very busy – busy and achieving. That was the way I’d grown up - happiness in our family was to be busy and successful. And I was happy. I got a lot of joy from my art, and interacting with people, but I was also in complete denial of the impact it was having on my body. My body was weak, and it was crazy what I was doing. I was teaching classes of 80 students with no experience in teaching, no support, in a manual wheelchair, a quadriplegic, talking for hours, and then coming home and doing my degree and cooking and on and on. I’m a high achiever. If I’m going to do something, I do it fully. And I try to do it really, really well. I’m pretty competitive.

It took some time, but ultimately she discovered that her body could not keep up. The result:

I completely collapsed. I could no longer push my manual chair, so I couldn’t get out of the house. I was just too weak to push the chair or do anything. ... This occurred because

---

<sup>40</sup> Shane Clifton, “Disability and the Dark Side of the Positivity Myth,” *ABC Religion and Ethics*, September 18, 2014, <http://www.abc.net.au/religion/articles/2014/09/18/4090190.htm>.

I was trying to live in denial of my situation. I was finding happiness through doing – through being busy.

### **Love, friendship, and care**

Sara spent six months in severe physical and psychological pain, and her gradual healing owes much to the love and care of her partner, Ben. Sometime later, Sara was surprised to discover that she was pregnant, eventually giving birth to a son. Of motherhood as a quadriplegic she says:

I've absolutely loved it and it's something that comes to me naturally. You know my mother always called me 'Mother Sara' when I was little because I just loved little kids ... And Ben is the same. He's one of those kid-magnets. ... The challenge has been negotiating with other people to help me – having to have an intermediary (the carers and Ben) to do all of the stuff. The key has been maintaining a strong relationship with Jake through that, and keeping people out of his face who were people who'd help me to care for him.

To succeed as a quadriplegic partner and mother, Sara has to be a skilful negotiator of relationships in which the lines between friend/lover/carers are blurred, employing virtues of wisdom, patience, gratitude, and the intuition to know when and how to intervene and take a stand.

The love and support of his wife has been central to Glenn's flourishing. He remembers being fearful, as a young quadriplegic, about whether the injury would rob him of a loving relationship,

You had the big gnarly question, will I meet a girl, will I get married, what am I going to do with my life. ... But the good thing is that girls aren't as physically wired as blokes. There is quite a lot of girls out there that, if you're nice and kind, that is appealing to them.

He met and married Theresa while still University, and says their relationship has been strong and joyous. Together they are raising twin teenage boys and a daughter (conceived through IVF). He admits that marriage and parenting is not easy. It wasn't too long ago that Theresa asked "why did I marry a guy in a wheelchair?" But Glenn believes that, in some surprising ways, his disability has helped his marriage, making him less self-centred, more patient, and more forgiving. He says that his dependence on his wife means that when conflict arises he has to make things right, and so be quick "to say sorry and I love you." He notes also:

I haven't got the distractions that others have. I've got a friend who wants to go out and "play" but because of his family, he feels that he can't go and do all the things that he wants to do. But I'm more focused on my wife. My first job is to keep Theresa and the kids happy. So in a way, my disability has been a good thing, because I'm not so self-focused. I see a lot of breakups in marriage that had to do with self-centredness. Men or women feel that they're missing out on something that they're not getting in their marriage, and that breaks them up. Teresa is not that way, and I'm not that way. [Reflecting on the few times they have fought he continues] I tried to pack my bags a couple of times, but I can't do it. I have to suck it up, no matter how wrong she's been, and go in and say sorry, and I love you, and it's amazing how that turns things around.

Similarly, Glenn thinks that his disability has helped him be a better parent, not only because he spends time with his children that others might dedicate to their own pursuits, but because they learn unique attitudes and skills:

The disability is a positive. They are good kids. They come and help; they put my shoes and socks on, they help me out a lot. So it's caused them to be really caring. And we're closer. They have grown up with me, so if I need help they'll come and give it. They are very compassionate. In a way the challenge of my disability has bought us together. We hug, and I'm really close to the kids. Other fathers probably have to try a bit harder to get that closeness.

The participants who are in long-term relationships emphasise the importance of their loving partners for their flourishing. John, for example, married a nurse, Pam, and her relentless support was fundamental to his fifty year thriving as a quadriplegic. In the days before state-sponsored support, she performed his personal care, a role she retained for the rest of their shared life (even after changes to government funding, she refused to allow care workers into the privacy of their home). She helped him get to and from work, and together they built a home, and raised two adopted children before John passed away in 2013. Pam would insist, though, that their relationship was always one of mutual giving and receiving.

Relationships with quadriplegia are, nevertheless, complicated. Mark was in a long-term relationship prior to his accident, but the stresses of learning to live with a disability meant that he didn't pay enough attention to his partner, or realise the burdens she faced:

She was working in a pressured job full-time, spending late hours in the hospital, getting home at 11 o'clock at night. She got really depressed, and something had to give. Before,



she had someone who is looking after the house, mowing the lawn et cetera, and all of a sudden her life was turned upside down. I couldn't contribute anything, so the pressure came on her. When I got home, she stayed with me, and filled the gap where my family weren't supporting me. [After the relationship breakdown] I tried to win her back. But it's just so hard to do that with your mouth only. To win someone back, you need action, and I couldn't do it – all I could do was talk. It was hard for her. It was hard for both of us. Half of me felt that I couldn't put the pressure back on her, but the other half of me wanted her back. I didn't want to be alone, and I was scared.

In the years since the breakup, as Mark learned to negotiate his dependency and friendships, he has come to the conclusion that his injury has made him friendlier. Why?

Because I need help. I can't do anything for myself, so the only skill that I have is to form relationships with people. It was hard, at first, to ask people to do things for me, but I've come to realise that everyone has got something to contribute – to help – and generally they're willing to do so. It might sound like I'm devious, like I'm manipulating people, but I'm not. Sometimes I get carers who get grumpy. Once, when I asked the nurse for something, she said, "say please." That really hit home. On the one hand, I think it's pathetic that a person needs to get a please out of a quad. But even so I learned early on that it makes a difference if I say please. The old Mark would fight it. But the new Mark that I'm developing now is about cooperation, collegiality, and team effort.

Mark this credits the need of his injury for him to learn relational skills; to avoid grumpiness and be friendly, grateful, and cooperative. He has to have the fortitude, wisdom, and patients to ask for help. In terms of another intimate relationship, Mark now has a close friend who'd like to take things deeper, but he remains uncertain – "You're taking on another person in your life, and maybe I'm selfish, maybe I'm scared. I'm just surprised that she is interested in me."

Sheree was in a long-term relationship at the time she incurred her injury, but it broke down soon after. She says:

I've got a disability that makes relationships complicated, and I don't think people really understand it, so I just haven't wanted anything to do with relationships. ... I have no interest whatsoever. More than no interest; there's a bit of a fear there, to be honest

Even so, she insists that she is not lonely:

Definitely not. How can you be lonely when you're working so much, and have care morning and night. I get on with my carers very, very well. So much so, that one of them is a great friend, and we ring each other in the day time, and say "guess just what happened". So there's always those social opportunities – and communication is so much a big part of my life, that when I'm at home, mostly I'm just happy to be alone.

Philip, similarly, has never married or had a committed relationship, noting that:

I don't really know why – it was probably my expectation. But I've got a few mates who haven't gotten married either, and I know others who've been married and then divorced. So I don't feel like I've missed out too much.

Yet Friendship has been central to his happiness. Philip's injury was incurred in the surf, and he relied on his mates to help him get back into the water. "I was scared stiff" he observes, but before he knew it they'd carried him out into the surf on inflatable lilo mattress, and he never looked back. Thereafter, he notes, "we did a lot of stupid things." Indeed, Philip's friend took him on holiday to Hawaii, and insisted he go scuba diving. Ignoring his reply (a very Aussie "bullshit") they goaded him into the water, and he has since dived the Barrier Reef, and throughout the world. One friend "encouraged" him to take on paragliding, again exceeding the expectations of the experts – "my doctor thought I was a lunatic." It's not simply the generosity of family and friends, though, that matters, but that he cleverly negotiates the fine line between friendship and dependency. Philip notes that

[it's important] to know when not to ask for help – although for most of my life I've been very happy to ask anybody to do anything, on the assumption that they know I won't be upset if I say no. They all know that if they say no, I'm not going to cry or hold it against them. I'm also cautious, I don't ask people too often.

Bruce, who has never married but has travelled the world with friends, likewise highlights the important skills of negotiating friendship and care:

It's not easy finding someone who is going to look after you 24/7, do your personal care, help you out, and at the same time maintain a good friendly working relationship. You might think you know a guy, but when you get together with someone that intensively, it can become difficult. I managed it because I have a generally friendly and easy-going nature, and I said to them, "if I do anything that you don't like, tell me rather than mope about it, and I'll do the same."

Taken altogether, a prominent theme in all the narratives was that friendships, which take many different forms, are vital to the good life. Because of the challenges of day-to-day life – the need for help, and the fact that functional loss impacts on relational capacities – people were forced to work hard on their personal relationships with spouses, carers, neighbours, and ‘mates’. In some ways, the injury required people to be friendlier, and they derived great satisfaction in doing so.

### **The good life**

Finally, in terms of the overall evaluation and understanding of flourishing as a quadriplegic, every participant concluded that their life had been good, and they believed it would continue to be so. Mark was the most ebullient, asserting:

I’ve not said this to many people, because it’s embarrassing to say it, but this is the best thing that could have happened to me. You might say, “Oh what, you’d rather be in the chair?” Don’t get me wrong, I’ve got difficulties. Like last night I couldn’t sleep, my blood pressure was up, my bowels were going off. Who’d want that? But for me, what I’ve gone through now, what I’ve achieved, where I’m going, and my goals. I never had that before – I wasn’t that focused. A lot of good things have happened to me, really good things. And it’s all happened because I’m in the chair. It’s the best thing that’s happened to me. It’s brought me closer to God, it’s given me purpose, it’s given me focus, it’s brought lots of people around me. To say that to someone who is able-bodied, it’s hard to comprehend. Does that make me sound crazy? Who wants to sit on the toilet for an hour every day, and have a PR every day? Who wants to sit there and their nose is itchy all day and they can’t scratch it. Me! I do. It’s the bigger picture.

Mark’s contentment draws on his religious faith, and the joy he experiences advocating for disabled rights. Mark is a director of two disability associations, serves on his local council’s access committee, is an ambassador for two charities, and has recently been appointed as the chair of the Disability Council of New South Wales. Mark alone sees his quadriplegia as a gift, believing that it has given more than it has taken, because it forced him to re-evaluate his life, and be more deliberate and focused in his goals for the future - “I’m getting a bigger buzz now. I’m giving up a lot to get this gold. But I’m willing to do so – it’s worth it.” It is sometimes argued that people like Mark are in denial about their situation; that his positivity is a psychological coping mechanism that prevents him from being weighed down by his losses and so able to get on with life. But as Ron Amundson argues, whose testimony should be believed? The

philosophical outsider, or the person who lives with a disability; do we “really want to claim that nondisabled people know better than disabled people what the different lives are like?”<sup>41</sup> Indeed, unlike others looking in, Mark has lived both with and without disability, so his judgement should be treated seriously.

Glenn, like Mark, finds meaning and purpose in his religious faith; “it was God who got me through.” For him, the good life is about focusing on God and his family. And while he would rather have lived without a spinal-cord injury, he recognises that disability has contributed to his happiness:

Our culture is so self-centred. ... When you’ve got a disability, and others have careers – that starts to look like the good life. But really it’s not. I’ve met people who look like they have it all, and they’re not happy. But when you eliminate the superficial, and look at my life and I say: I’ve got a great wife, and kids who love me. And that’s the most important thing in my life at the moment. So that’s where I spend my energy.

Sara, while not religious, identifies various streams of spirituality that have been central to her emerging happiness, especially after her collapse. She has drawn on meditation to “keep my heart open; a melting together of meditation techniques and body centring dance has been profound.” She also practices the Japanese martial art Aikido, “to work with my “chi – my body’s energies – to stay present and centred.” As noted earlier, the literature on positive psychology and resilience focuses on the need for a person to be positive, exercise self-efficacy, and regain control of their life.<sup>42</sup> Sara reminds us that much of life is a journey that can’t be controlled, or rather, that regaining control actually requires a person to let go and find ways to flow with the ups and downs of life. For her, spiritual practices have provided rest and peace, helped her to deal with the ongoing physical and psychological pain that often accompanies SCI, and enabled her to devote her love and attention to her partner and son.

Religion and/or spirituality were not important to any of the other participants. Bruce and Philip both lived daringly (achieving things and going places that others might think impossible), and emphasise positive thinking, a can-do attitude, and the importance of relationships with friends and carers. There is power in the idea of life with quadriplegia as being an adventure negotiated with friends. Bruce has also been involved in advocacy, working closely with his local council to

---

<sup>41</sup> Amundson, “Disability, Ideology, and Quality of Life,” 112.

<sup>42</sup> Kilic, Dorstyn, and Guiver, “Examining Factors That Contribute to the Process of Resilience Following Spinal Cord Injury.”

make his suburb accessible to people with disabilities (and mothers in prams, older residents et cetera).

Both John and Sheree passed away after our interviews. John died after a full and rich life with Pam, and not before meeting his grandchildren. Against all expectations at the time of his injury (1959), when he found himself trapped in a home for incurables, he and his wife could look back on a life they judge to have been full of joy and love. Sheree died too young (forty-five), of a kidney issue that arose as a secondary complication attending to her SCI. Even so, her friends would insist that she lived a richer life than many able-bodied people. She spent the bulk of her time after her injury supporting newly injured people as a peer support worker in Sydney's spinal units at Prince of Wales Hospital in Randwick and at the Royal North Shore Hospital. She made deep friendships, including with her beloved service dog Jade. Speaking about her own happiness, she said:

I feel like I'm making a contribution to people's life, and that's quite a profound thing to have, really. I get so much joy by watching people get on. It really gives me a spark, having opportunities to brighten up people's lives.

She concluded her interview by asserting that "I've had a fabulous life, and I've got no regrets on anything." What more could anyone hope for?

## **Conclusion**

Drawing on the logic of the virtue tradition, this paper set out to explore what the stories of people living with quadriplegia over the medium to long term might reveal about the good life, and how to go about accomplishing it. Notwithstanding that participants dealt with permanent pain and loss (physical, psychological, and social), their stories show that it is possible to flourish with a severe disability. Participants found meaning and purpose from a variety of sources; religion, spirituality, advocacy, helping others with SCI, and adventure. Friendships were especially important, and although relationships were sometimes complicated by the injury, adjustment to the disability provided opportunities to strengthen and deepen friendships between spouses and other family members, and with neighbours, mates, peers, care workers and other professionals.

The narratives show that positive attitudes and virtues seem to be central to resilient flourishing with quadriplegia. To this end, participants drew on experiences and capacities developed prior to the injury, but were also required to develop new and existing skills and virtues, such as the

relational virtues of gratefulness, friendliness, patience, forgiveness, interpersonal wisdom and so on. The participants understood that life is a journey replete with joys and sorrows, and that shockingly negative experiences and lifelong hardships can be navigated by exercising positive virtues such as optimism, hopefulness, determination, and by focusing on what is possible rather than impossible.

Most refused, however, to capitulate to the positivity myth (the ideology that assumes positive thinking inevitably facilitates success and achievement), having learned by hard experience that life has its limits, constraints, ups and downs. Indeed, participants were not afraid to admit to anger, disappointment, frustration, and weakness. Their stories are not what Stella Young would label “inspiration porn,”<sup>43</sup> and we misunderstand the narratives if we think of these people as inspirational, heroic, super-quads (to use Sheree’s label). But neither are they tragic.<sup>44</sup> Rather, they show the up-and-down predicament of quadriplegia, and reveal some of the attitudes and virtues needed to live a “more up than down life” – i.e. to flourish with a disability.

#### **Future research:**

While there are a number of studies utilising qualitative research methods to explore the resilience and well-being of people with a spinal cord injury, there are few that utilise life stories in a systematic way. Indeed, there are no longitudinal studies that consider resilience and the good life over the medium to long term, with most studies concentrating on the months and early years of rehabilitation following the injury.<sup>45</sup> Even so, this present study is limited by its scope, and a fuller account of the good life and quadriplegia would broaden the mix of gender and sexuality, and take a more systematic approach to investigating stories at particular points in the recovery process. Ideally, participants would be interviewed periodically, at different stages of recovery and life, in which case it would be possible to reflect upon the ways in which a person’s storied identity and conception of the good life changes over time. Also, increasing the number of participants would improve the generalisability of insights.

As noted earlier, this study was likely subject to selection bias, and a more complete understanding of life would emerge with access to the stories of people who have a more negative outlook.

---

<sup>43</sup> Stella Young, “We’re Not Here for Your Inspiration,” *The Drum, ABC News*, July 3, 2012, <http://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006>.

<sup>44</sup> Tom Shakespeare, *Disability Rights and Wrongs Revisited*, 2nd ed. (New York: Routledge, 2014), 104.

<sup>45</sup> Shane J. Lopez and C. R. Snyder, eds., *The Oxford Handbook of Positive Psychology*, 2nd ed. (New York: Oxford University Press, USA, 2011), 658.