

Quadriplegia, virtue theory, and flourishing: a qualitative study drawing on self-narratives

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Quadriplegia, virtue theory, and flourishing

Abstract

Grounded in the logic of the virtue tradition, the qualitative study “the good life and quadriplegia” collected the self-narratives of people that have lived with the impairment over the medium to long term. This article draws on those narratives to describe how people understood the good life in the context of the losses and hardship of their spinal-cord injury, and the virtues and attitudes that helped them to achieve it. While highlighting the importance of virtue, participant stories resisted the ideology of the positivity myth, recognising that flourishing includes hardships, limitation, and failure, as well as meaning, virtue, and accomplishment.

Keywords: virtue, spinal cord injury, narrative, the good life, flourishing, eudaimonia.

Quadriplegia, virtue theory, and flourishing

Introduction

‘I’ve had a fabulous life, and I’ve got no regrets about anything.’ With this summative statement, spoken only months before she passed away aged 45, Sheree judged the quality of her life. Her assessment is noteworthy because, for 18 of those years, Sheree lived with quadriplegia, and in the public imagination it is generally assumed that people with high-level spinal cord injuries would suffer an extremely compromised quality of life, and may even be better off dead (Coleman and Drake 2002; Sauder 2016). Yet, like Sheree, many people with quadriplegia assert that life is good, notwithstanding its hardships and complications. This paper draws on the logic of the virtue tradition, and utilises qualitative method to collate and examine the stories of people living with quadriplegia, to see how they understand the good life, and describe the personal and social resources that have helped them to reach for it. It utilises participant’s own words to weave together a complex narrative showing how people find meaning and exercise virtue to make the most of their circumstances.

Background

The virtue tradition

This paper summarises the insights of a qualitative study, ‘living the good life with quadriplegia,’ which was grounded in the theoretical tradition of virtue ethics, and explored the ways in which people dealing with severe impairment understand their own flourishing. 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 (A. C. MacIntyre 2007; M. Nussbaum 1993). *Eudaimonia* has traditionally been translated as

Quadriplegia, virtue theory, and flourishing

‘happiness,’ but is better captured by the notion of flourishing, which elicits a longer term and more complex vision (Hursthouse 1999; A. C. MacIntyre 2007; Seligman 2012). Traditionally, *eudaimonia* was understood teleologically, and was linked to objective accounts of human nature. Thus for Aristotle, humanity was a reasoning animal, so happiness was best achieved in a life devoted to philosophical contemplation (Aristotle 2011; Collins and Bartlett 2011). While the post-Nietzschean critiques of objectivity have rightly identified the fluidity and subjectivity of happiness and human teleology (Nietzsche 1974), 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 (A. C. MacIntyre 2007; Hursthouse 1999; M. C. Nussbaum 2006). Thus, the good life entails the maximisation of physical and mental health, the pursuit of meaning, and the making and sustaining of deep relationships. Virtue theory goes on to argue that *eudaimonia* is 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 (Aristotle 2011, 1099b)), but is made possible by the exercise of virtues; courage, self-control, patience, wisdom, perseverance, honesty, and the like. Virtues are the habits of character that enable a person to succeed in particular activities and, over the long run, to live the good life (A. C. MacIntyre 2007). 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 (A. MacIntyre 1999; M. C. Nussbaum 2006; See also Merriam 2009; Clifton 2013; Yong 2012). In *Dependent Rational Animals*, MacIntyre critiques the individualist tendency of virtue theory, and asks what difference it would make to moral philosophy if

Quadriplegia, virtue theory, and flourishing

disability and dependency were treated as central to the human condition (A. MacIntyre 1999). He notes that we are born utterly dependent on our parents, that the goal of parenthood is to raise independent moral agents (people capable of exercising intelligent moral judgements), but that we are always vulnerable and at risk of illness and impairment, especially as we age. For MacIntyre, then, independence and dependency go together, so that conceptions of *eudaimonia* need to take our vulnerability and dependency into account, and incorporate virtues that facilitate our interdependency.

Sen and Nussbaum build on Aristotle's application of virtue ethics to politics so as to develop a philosophical conception of justice labelled the capabilities approach (M. Nussbaum and Sen 1993). 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 supports and empowers disabled people and their families and carers (M. C. Nussbaum 2006). The capabilities provide a broad outline of the various dimensions of *eudaimonia*, including bodily health, the capacity to utilise the senses in imagination and thought, a richer emotional life, deep relationships, the capacity to play, and the opportunity to exercise a level of control over one's environment in the direction of life. It is obvious that spinal-cord injury can compromise many of these capabilities, and thus requires a person to rethink and reshape their vision of flourishing, and learn new virtues to bring that about.

Both MacIntyre and Nussbaum argue that narrative is central to our understanding of what it is to flourish. *Eudaimonia* is a long-term (even whole of life) concept, and it embraces the opportunities and challenges, successes and failures, joys and hardships, and meanings and values that make up the journey of life. As MacIntyre observes, 'Man [sic] is in his actions and practice, as well as in his fictions, essentially a story-telling animal' (A. C.

Quadriplegia, virtue theory, and flourishing

MacIntyre 2007, 216), 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. 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 (Morf and Mischel 2012). This will be important for people with an SCI, who have had to respond to the crisis of an injury that may change the course of their life. As Neimeyer says, ‘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’ (Neimeyer 2001, 263–64). When this rewriting fails to occur, a person is in danger of being trapped by lost dreams, and so unable to move forward. Thus, adjustment to spinal-cord injury isn’t simply a matter of picking up new skills, but involves the capacity to reimagine the story of one’s life – and to continue to do so in the long haul of learning to live with a severe impairment.

Happiness and the psychological sciences

The insight of the virtue tradition has been taken up in the psychological sciences, especially in the emergence of positive psychology. Martin Seligman is credited with setting in place the founding principles of positive psychology, which originally recognised three levels of happiness in ascending order of importance; positive emotion, gratification, and meaning, are achieved by exercising virtues and strength (Seligman 2002). In his more recent writings, Seligman has moved away from the label happiness to that of flourishing, which he now identifies as having five elements; having a greater balance of positive over negative emotions, engagement in gratifying activities, experiencing positive relationships, living for purpose and meaning, and achieving goals

Quadriplegia, virtue theory, and flourishing

(PERMA Seligman 2012). In emphasising longer term conceptions of happiness framed by purposeful living and the exercise of virtue, positive psychology mirrors and draws on the virtue tradition. It compliments and adds to that tradition by setting 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’ (Seligman 2012, 1).

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 refers to ‘important psychological skills and to the individual’s ability to use family, social, and external support to cope better with stressful events positive adjustment to adversity’ (Quale and Schanke 2010, 13). There are a myriad of factors that contribute to resilience; biological (the nature and extent of a person’s injury), demographic, and environmental/social, but psychological strengths are considered particularly important (Elliott, Kurylo, and Rivera 2002; Hampton 2004; Quale and Schanke 2010; White, Driver, and Warren 2010; Weitzner et al. 2011; Kilic, Dorstyn, and Guiver 2013; Cummins and Wooden 2013). These strengths (which are what Aristotle would label virtues) include self-efficacy and control, positive self-esteem, optimism, and hopefulness (Tzonichaki and Kleftaras 2002; Kortte et al. 2010; Dorsett 2010; Peter et al. 2012). Likewise, resilience is enhanced by the belief that life is manageable, meaningful, and purposeful (Lustig 2005; deRoon-Cassini et al. 2009; Kennedy et al. 2010).

Thus, there is support for the insights of positive psychology – and by extension the virtue tradition – that psychological resources make an important contribution to flourishing with a spinal-cord injury (for a comprehensive view of the literature, see Peter et al. 2012). The value of the empirical analysis is that it provides evidence of psychological strengths that

Quadriplegia, virtue theory, and flourishing

might be developed to support the rehabilitation of newly injured people, helping them to make the most of their longer-term well-being. Even so, empirical measures have their limitations, primarily because human flourishing is not easily reduced to a statistical measure. 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. It is precisely the journey of flourishing that is not readily captured by quantitative science. In focusing on positivity and personal strengths, there is also the danger of individualising a person's achievements and blaming them for perceived failures, and so not recognising that disability is both an embodied and sociocultural reality, and that social and political responses are central to a person's flourishing (Shakespeare 2013).

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 collect the stories of people that have lived with SCI over the medium to long term, and examine what they might reveal about a person's understanding of the good life in the context of a severe impairment. Through analysis of their stories, it sought to examine: 1. How individuals negotiate the losses and permanent impairment 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.

The study recognises that loss is inherent to the experience of a SCI. While disability theorists have rightly rejected the medical model of disability, this study follows Shakespeare (2014) in understanding disability as a complex interaction between

Quadriplegia, virtue theory, and flourishing

individual and structural factors (also Crowe 1996; Williams 1999). Indeed, unlike some other disabilities, quadriplegia entails severe functional loss irrespective of the nature of the social environment. Even so, the study leaves open the question as to whether functional loss impacts quality of life over the medium to long term, exploring the issue from the opposite perspective; whether it is possible for people with an SCI to flourish.

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 (Plummer 2001). 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' (Plummer 2001, 39–40). To avoid this danger, interviews were relatively 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 participants were 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, recommendations from the Spinal Cord Injury Association, and snowball sampling from one participant to another. While it is beyond the scope of this paper to detail their stories, a brief description of each will help set the scene. Mark incurred his SCI playing rugby at age 35, and has since lived for eight years with quadriplegia. It has been a difficult journey, which included a split with his long-term partner, but he has

Quadriplegia, virtue theory, and flourishing

become a disability advocate, and is grateful to God for the things he has learned through hardship and suffering. Sheree was a 27-year-old schoolteacher when she broke her neck in a serious car accident. She lived with the injury for 18 years, and for much of that time was employed as a peer support worker. She passed away unexpectedly in 2016 from kidney damage and the complications of SCI. Sara was studying architecture when she incurred her injury while playing in the surf. Living with quadriplegia for 19 years, in addition to her love of art, dance, and meditation, she and her partner parent a primary school aged boy. 19 at the time of his injury, Glenn has lived with SCI for three decades, and in addition to his involvement in Christian ministry, he is married with three children. Philip was also 19 when he incurred his SCI, and has since lived 37 years independently; an accountant by trade and an adventurer and traveler by passion. Bruce was also just out of school when he broke his neck diving into shallow water, and has since negotiated more than four decades with quadriplegia, working in disability support, and volunteering with his local Council to make his suburb wheelchair friendly. Finally, John was also 19 when he broke his neck in a car accident, and against all expectations, he lived 54 years with quadriplegia, during which time he worked at ParaQuad, married, and raised two adopted children. He also died following our interview, having lived a full and rich life.

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.

Quadriplegia, virtue theory, and flourishing

Of importance is the publication of the life stories as a key element of the research output. As Ellis and Bochner (2006, 436) observe, stories are evocative, and can themselves ‘do the work of analysis and the theorizing.’ 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 with quadriplegia. It is hoped that what emerges is itself a multifaceted web of narratives that gives some insight into ways in which people with an SCI conceive of their flourishing and the virtues that have helped them to achieve it.

Narrative Results and Discussion

Unsurprisingly, participants described their injury as redirecting the expectations and plans that they had for their future. 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 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, this was not the focus of attention. As Sheree says, ‘the truth is that it’s been so long since my accident – 16

Quadriplegia, virtue theory, and flourishing

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.' It is also true that Sheree benefited from various social supports. Sheree's independence is not just her own doing and is never absolute, but is made possible by the social support of her family and the Australian welfare system that provided her with the requisite funded care – but more on this later.

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. Optimism is a virtue, offset on the one hand against the vice of pessimism, that encourages perseverance. 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:

Quadriplegia, virtue theory, and flourishing

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. 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 perspectives. The way in which the different participants tell of their hospitalisation and early rehabilitation varies from one to another, but several highlight negative attitudes and low expectations of rehabilitation professionals. John, whose injury was incurred in 1959 – at a time when many people with quadriplegia 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.

Quadriplegia, virtue theory, and flourishing

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.

Others had a very different experience of rehabilitation. 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.’ 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 transition from rehabilitation to living at home was 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 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

Quadriplegia, virtue theory, and flourishing

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 few 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. More to the point, their stories of how they have flourished embrace life's difficulties and dark times. The good life emerges, not from the absence of hardship, but in in the journey through it.

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:

Quadriplegia, virtue theory, and flourishing

I'm still fighting the same battles today, and it 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.

As is now well documented, disability is a social phenomenon. But whatever the challenges faced, participants generally identified positive thinking and determination as contributing to their eventual coming to terms with the injury, and so enabling them to live a good life. 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 lives 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.

Quadriplegia, virtue theory, and flourishing

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

Hope, optimism, determination, encouragement and the like are all virtues; habits of character that facilitate success and make the good life possible. 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. This reflects the social expectation that a positive attitude trumps all. But is it necessary to set aside the reality of failure, doubt, and negative emotions to defeat suffering, or do such denials diminish the colour and ambiguity that is inherent to stories of flourishing with a SCI?

In fact, 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 (Clifton 2014). 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

Quadriplegia, virtue theory, and flourishing

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

Quadriplegia, virtue theory, and flourishing

Again, this is a reminder that flourishing cannot be conceived of as relentless positivity, self-efficacy, self-control, and success (as empirical studies tend to imply). Rather, to live the good life with quadriplegia requires one to face up to one's embodied vulnerabilities and limitations. In doing so we recognise that a person cannot get by on their own, but are dependent upon a social environment that makes their flourishing possible. It is noteworthy that independence does not mean that a person functions without help but, on the contrary, it is best achieved when properly directed social supports are in place (Morris 2004); which brings us to the significance of friendship and (inter)dependency.

Love, friendship, and care

Sara spent six months in severe physical and psychological pain, and her gradual healing, she says, 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 being a mother with quadriplegia 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 partner and mother, Sara must be a skilful negotiator of relationships in which the lines between friend/lover/carer are blurred, employing virtues of wisdom, patience, gratitude, and the intuition to know when and how to intervene and take a stand. These are what Macintyre labels the virtues of interdependency.

Quadriplegia, virtue theory, and flourishing

For Glenn, the love and support of his wife has been central to his flourishing. He met and married Theresa while still at university, and says their relationship has been strong and joyous. Together they are raising twin teenage boys and a daughter. 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 SCI 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.

Glenn believes that his impairment 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 brought 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

Quadriplegia, virtue theory, and flourishing

relentless support was fundamental to his fifty-year thriving with quadriplegia. 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 insists, 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 SCI 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.

In the years since the breakup, as Mark learned to negotiate his dependency and friendships, he has concluded 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

Quadriplegia, virtue theory, and flourishing

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. ... 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 credits the need of his injury for him to learn relational virtues; to avoid grumpiness and be friendly, grateful, and cooperative. He needs fortitude, wisdom, and patience to ask for help and wait for things to get done.

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, 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

Quadriplegia, virtue theory, and flourishing

out into the surf on an inflatable rubber 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 takes many different forms, are vital to the good life. It is noteworthy that some of these friendships are a result of a social welfare system in Australia that ensures that people are provided with funding for care workers that help them to live independently. But it is still

Quadriplegia, virtue theory, and flourishing

up to the individual to make the most of this support; individual responsibility and the social model of disability are not polar opposites but go hand-in-hand. 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’. Thus, the injury required that they develop virtues related to friendship and dependency, and they derived great satisfaction in doing so.

The good life

Finally, in terms of the overall evaluation and understanding of flourishing with quadriplegia, 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.

Quadriplegia, virtue theory, and flourishing

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, 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.'

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 SCI 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.

The virtue tradition and religious faith have gone hand-in-hand since Thomas Aquinas' embrace of Aristotle (Keys 2006; Hoffmann, Müller, and Perkams 2013; Stenberg 2016), and virtue ethics remains central to Catholic morality. From this perspective, religious faith provides the person with purpose and meaning that facilitates flourishing and promotes the virtues that establish bonds of family and friendship (for empirical support the contribution of religion see Marini and Glover-Graf 2011; Jackson and Bergeman 2011).

Quadriplegia, virtue theory, and flourishing

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.’ Sara reminds us that much of life is a journey that can’t be controlled, or rather, that regaining control 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 (see also Brillhart 2005; Franklin et al. 2008; Chlan, Zebracki, and Vogel 2011).

Religion and/or spirituality were not important to any of the other participants. Bruce and Philip both proud of achieving things and going places that others thought impossible, and emphasise positive thinking, a can-do attitude, and the importance of relationships with friends and carers. For them, there is power in the idea of life with quadriplegia as an adventure negotiated with friends.

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 (45), 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 nondisabled people. She spent the bulk of her time after her injury supporting newly injured people as a peer support worker in

Quadriplegia, virtue theory, and flourishing

Sydney's spinal. She made deep friendships. 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.

Conclusion

Drawing on the logic of the virtue tradition, including its emphasis on whole of life and storied conceptions of flourishing, 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 impairment. More to the point, the hardships and challenges they have faced are central to the story of their flourishing; they live well, not despite quadriplegia, but with it.

The virtue tradition is not meant to be a narrow and dogmatic vision of the good and ethical life, but a heuristic structure that helps to make sense of our diverse human experiences. It is teleological, emphasising the value of living with purpose and meaning, and holds that habits of character (virtues) help to make this possible. The elevation of virtue should not lead one to conclude that social injustice can be 'overcome' by morally strong individuals, nor to blame victims of injustice for their 'failure' to flourish; *eudaimonia* is framed by the luck of one's social context. Rather, it is to claim that social determinism is not everything; that individuals do have opportunity to shape the direction of their life, even in the face of extreme hardship. Participants in our study found meaning and purpose from a variety of sources; religion, spirituality, advocacy, helping others with SCI, and

Quadriplegia, virtue theory, and flourishing

adventure. Friendships were especially important, and although relationships were sometimes complicated by the injury, the process of rehabilitation 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 – which the tradition incorporates as virtues – are central to resilient flourishing with quadriplegia. To this end, participants drew on experiences and capacities developed prior to the injury. But to manage increased dependency, they were also required to develop existing virtues and learn new ones, such as the virtues of friendship and interdependency; gratefulness, friendliness, patience, forgiveness, interpersonal wisdom and so on. The participants understood that life is a journey replete with joys and sorrows, and that lifelong hardships can be navigated by exercising positive virtues such as optimism, hopefulnes, determination, and by focusing on what is possible rather than impossible.

The danger of misconstrued emphases on virtue and positive attitudes is capitulating to the ideology of the positivity myth. Participants in this study had to face up to the limits, constraints, and vulnerability of their bodies; and in this some were helped by faith, others by quieting the spirit (or inner life), and all by the support of family and friends. They were not afraid to admit to anger, disappointment, frustration, and weakness. Their stories are not what Stella Young would label ‘inspiration porn,’ (Young 2012) and we misunderstand the narratives if we think of these people as super-quads (to use Sheree’s label). But neither are they tragic (Shakespeare 2014, 104). Rather, they show the up-and-down messiness of living with quadriplegia, and reveal some of the virtues needed to live a more up than down life, and so over the longer term to flourish.

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