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Ageing with spinal cord injury: a longitudinal study

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Abstract

Limited studies have evaluated the impact of recreation on successful ageing (SA) for individuals with spinal cord injury (SCI) in a longitudinal manner. Most existing SA models emphasise biomedical-based dimensions of physical functioning, which has been criticised as unrealistic and limited, especially for people with disabilities. Various researchers and organisations have proposed that SA needs to be reassessed using more self-perceived, self-reported measurements. Understanding long-term life satisfaction predictors for individuals ageing with SCI is still limited, particularly when including longitudinal recreation participation data. This study, based on Rowe and Kahn's SA model and utilising self-reported measurements, observes the long-term changes in self-reported health status, recreation participation time and social integration levels, and evaluates the long-term impacts of these predictors on life satisfaction among individuals with SCI. The sample comprises individuals with SCI (N = 11,450) who are at least 45 years old at the time of injury or have lived with their injury for over 15 years. Results indicate that when ageing with SCI, life satisfaction increases over time, but their recreation time, social interactions and self-perceived health status decline. Moreover, regular participation in recreational activities, engagement in and maintenance of certain levels of social relationships, and high self-evaluation of health can positively impact life satisfaction during ageing. The study explores the feasibility of using self-perceived measurements to replace biomedical-based variables in Rowe and Kahn's SA model and examines their impacts on life satisfaction among people ageing with disabilities. In the future development of SA models, researchers can incorporate more self-reported, self-evaluated assessment variables to better capture the ageing experience, especially for people with disabilities.

Keywords: ageing with disabilities; life satisfaction; recreation; self-perceived health status; social engagement; spinal cord injury

Introduction

Over the past few decades, a major demographic shift has occurred among people living with long-term medical disabilities, such as cerebral palsy, spinal cord injury (SCI) and multiple sclerosis (Strauss *et al.*, 2007; DeVivo and Chen, 2011; Molton and Yorkston, 2017). This is largely due to the improved medical care, survivorship and disease control that have helped increase the average life expectancy of individuals with long-term disabilities (Strawbridge *et al.*, 2002; DeVivo and Chen, 2011). Among the SCI population, ageing-related issues have been widely discussed and studied, yet most attention has been given to the negative impacts of ageing on health conditions (Whiteneck *et al.*, 1992; Ballinger *et al.*, 2000; Furlan *et al.*, 2009; Jensen *et al.*, 2013; Chiaravalloti *et al.*, 2020; Peterson *et al.*, 2020). With people experiencing increased longevity, the concept of successful ageing has become an emerging theme for academic fields related to gerontology, health care, recreation and leisure, *etc.* Yet there are limited studies on long-term successful ageing for people with SCI, a population who have unique health-care needs.

Conducting research on successful ageing is challenging, largely due to complexities and lack of consensus on its conceptualisation. Early study on successful ageing in the 1960s focused on defining the criteria. However, these studies showed inconsistent interpretations of ageing and ageing-related behaviours, such as the well-known disengagement theory (Cumming and Henry, 1961), continuity theory (Havighurst and Albrecht, 1953) and activity theory (Havighurst, 1961, 1963). As can be expected, all three theories have their supporters and detractors. Amongst those three most established theories on ageing, activity theory posits that the more active people are, the better the quality of their ageing experience. Introduced by Havighurst (1961), activity theory posits that successful ageing results from older adults staying socially active and engaged with society, encompassing the maintenance of life roles, personal relationships and other activities. In contrast, the disengagement theory posits that, while middle-aged and older people might attempt to maintain existing structures, ageing inevitably leads to reduced social activity. According to this theory, an older adult's withdrawal from society is natural, voluntary and acceptable (Cumming and Henry, 1961). Another widely discussed ageing theory is continuity theory. Developed by Havighurst and Albrecht (1953) and popularised by Atchley (1989), this theory proposes that in response to the reduction of opportunities for social interaction for ageing populations, well-adjusted, determined or resilient individuals have attempted to maintain their lifestyle into middle age as long as possible. A central premise of continuity theory is that, in making adaptive choices while ageing, middle-aged and older adults will attempt to preserve and maintain existing internal and external life structures that are already in place, characterised as continuity (Atchley, 1989).

In gerontology research of the 1970s, recreation and leisure scholars found activity theory and continuity theory more compelling, since such studies have found recreation activity in later life yields life satisfaction (Lemon *et al.*, 1972), and have been proposed in a bio-psycho-social model of successful ageing (Kanning and Schlicht, 2008). Later on, scholars have shown that individuals with physical disabilities use leisure and recreation as a means to optimise their health perception and life satisfaction, developing social skills and improving the perception of their

own health (Van Leeuwen *et al.*, 2012; Tomasone *et al.*, 2013; Kim *et al.*, 2018). Recreation has been proven to have positive impacts on people's ageing and life satisfaction (Rantanen *et al.*, 2019; Reich *et al.*, 2020; Yoon *et al.*, 2020, 2021). But recreation and leisure has been rarely included in the longitudinal studies on successful ageing among people with SCI.

In recent decades, while formulating the criteria of successful ageing, both theoretical considerations and empirical applications have been addressed (Ouweland *et al.*, 2007). Among these theories, the famous model of Rowe and Kahn (1987, 1997) emphasises three biomedical-based dimensions of successful ageing, including disease and disability avoidance, high cognitive and physical functioning, and active engagement with life. It has led to a remarkable boost in empirical studies examining factors responsible for successful ageing (Ouweland *et al.*, 2007).

Rowe and Kahn's (1987, 1997) conceptualisation, however, has been criticised by many researchers as unrealistic, static and limited, as disease-free ageing is not achievable for the majority of older people, and those who consider themselves to be ageing successfully do not meet this researcher-defined, biomedical-based criteria (Von Faber *et al.*, 2001; Strawbridge *et al.*, 2002; Phelan *et al.*, 2004; Bowling and Dieppe, 2005; Montross *et al.*, 2006; Young *et al.*, 2009; McLaughlin *et al.*, 2012; Tate *et al.*, 2013; Moody and Sasser, 2020). Especially for people with SCI, ageing-related changes and challenges may be more highly connected to the number of years living with their disabilities rather than their age *per se* (Krause and Coker, 2006). Successful ageing measures based on longevity or clinical outcomes may therefore fail to capture the more complete ageing experience of older people, many of whom demonstrate considerable resilience in the face of physical and cognitive decline (Manning *et al.*, 2016) and engage in compensatory strategies to maintain their preferred lifestyles with varying degrees of success (Glass, 2003; Martin *et al.*, 2015). Unfortunately, individuals with disabilities have been overtly and specifically excluded from empirical studies of successful ageing (Molton and Yorkston, 2017).

Compared to researcher-defined, clinical-based successful ageing criteria, the older population's subjective judgement and self-perception of their current life situation and goals achieved, based on their own personal standards and expectations, are being regarded as more realistic indicators for successful ageing (Von Faber *et al.*, 2001; Strawbridge *et al.*, 2002; Bowling and Dieppe, 2005; Montross *et al.*, 2006; Young *et al.*, 2009; McLaughlin *et al.*, 2012). Specifically, the use of bio-medical markers for successful ageing is especially problematic for people with disabilities, such as persons with SCI. For example, according to Rowe and Kahn's (1987, 1997) model, people who age successfully need to avoid disease and disability and have high cognitive and physical functioning in later life. However, people with disabilities, especially with SCI, cannot satisfy these two dimensions in this model. Functional limitations are often unstable across the lifespan of this population, where living with a disability for many years contributes to premature declines in health (Imai *et al.*, 2004). Yet research has shown that life satisfaction can improve following the injury, and achieving this perceived status is a goal of SCI rehabilitation (Jørgensen *et al.*, 2021). Successful ageing measures based on longevity or clinical outcomes may therefore fail to capture the more complete and complex ageing experience compared to those subjective, self-reported

judgements. Longevity has been connected to more positive self-perceptions of ageing, where Levy *et al.* (2002) found that older individuals holding more positive self-perceptions of ageing lived over seven years longer than those with more negative attitudes. It is possible that using self-reported and self-evaluated health conditions and active engagement in life could better describe the ageing experience of people with disabilities.

Among the indicators applied in previous studies, life satisfaction has been typically used as the empirically based operationalisation of successful ageing (Thomas and Chambers, 1989). From some perspectives, satisfaction in various realms of life experience has been viewed as equal to successful ageing on many fronts (Havighurst, 1961; Williams and Wirths, 1965; Ryff, 1982; Caspi and Elder, 1986). For example, Cosco *et al.* (2014) identified physiological status (which includes health, functionality or longevity), wellbeing (affect and life satisfaction), active engagement with life (with social support systems and social interaction), personal resources (coping and resilience) and extrinsic factors (such as environment and economic status) as the most used components of research on successful ageing. Kleineidam *et al.* (2019) found that a well-constructed operationalisation of successful ageing includes measurements of physiological health, wellbeing and social engagement with both subjective and objective aspects. Among numerous indicators, life satisfaction can thus be considered as an important outcome associated with successful ageing, and an essential element of the subjective dimension of ageing (Bowling and Dieppe, 2005). As a successful ageing criterion, therefore, life satisfaction is as relevant as objective measures such as health status or cognitive functioning (Blazer, 2006). Life satisfaction is the precursor or crucial criterion of successful ageing, or even its equivalent, and thus serves as an accurate criterion for successful ageing (Ryff, 1982; Caspi and Elder, 1986; Thomas and Chambers, 1989; Kanning and Schlicht, 2008).

Previous literature has suggested that several demographic characteristics (including gender, income status, education level and marital status), self-reported health condition, participation in recreational activities and social engagement can contribute to the life satisfaction of people with SCI (LoBello *et al.*, 2003; Krause and Coker, 2006; Li *et al.*, 2021). Although extensive research has investigated life satisfaction for people with SCI, limited studies have examined the long-term changes of life satisfaction predicting factors. Among those variables, recreational participation has been rarely included in longitudinal life satisfaction studies among SCI populations, while it has been proven to have positive impacts on people's ageing and life satisfaction (Rantanen *et al.*, 2019; Reich *et al.*, 2020; Yoon *et al.*, 2020, 2021). In addressing injury-related secondary complications that develop in the years after injury, studies have found psycho-social changes in perceived life satisfaction (Kennedy and Rogers, 2000; Krause *et al.*, 2000; Elliott *et al.*, 2002; Charlifue *et al.*, 2004; Kennedy *et al.*, 2006; Van Leeuwen *et al.*, 2012; Dorsett *et al.*, 2017), where predictors such as demographic and injury characteristics change over time. Due to these dynamics, there is great need to understand what factors contribute to life satisfaction of people ageing with SCI, and how they change with time.

As researcher-defined, biomedical-based criteria cannot capture the entire ageing experience, particularly for people with disabilities, and various ageing theories

(e.g. activity theory, continuity theory and disengagement theory) offer diverse explanations when studying changes in predictors of life satisfaction, such as recreation participation and social engagement during ageing, more empirical study is needed to identify the patterns of change in these factors as predictors of life satisfaction, especially for individuals with disabilities.

The specific aims of the study are to (a) examine the patterns of change in the self-rated health condition, recreational activity participation, social engagement and life satisfaction of people with SCI, and (b) determine how these changes can predict their life satisfaction. Results of the study can help identify whether and how these factors impact life satisfaction of people with SCI as they age. The variables selected in this study echo the argument in the previous paragraphs that an individual's self-reported, subjective measurements are more realistic indicators for evaluating successful ageing. In this study, participants' self-reported recreation participation time, social integration level and self-perceived health status were included in the model, corresponding to the three dimensions of Rowe and Kahn's (1987, 1997) model. Findings should offer insights for people with disabilities on how to age with grace, a sense of life fulfilment and contentedness, and provide foundations for future successful ageing model development.

Method

Study population

This study used secondary data collected from 11,405 people with SCI enrolled in Spinal Cord Injury Model Systems (SCIMS) sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, a centre within the Administration for Community Living, United States Department of Health and Human Services. The SCIMS of care was created in 1970, and its database, the world's largest and longest SCI research database, is managed by the National Spinal Cord Injury Statistical Center (NSCISC). This study included the longitudinal data collected from 1973 to 2021, and there are individuals enrolled into the database who have now been followed for 45 years after injury (Model Systems Knowledge Translation Center, 2023). Generally, for those participants in the database, their initial hospital care data were recorded, and the follow-up data post-injury were collected in years 1, 5, 10, *etc.*, every five years, for up to 45 years.

At the beginning of the study, 104,108 copies of post-injury surveys were received from the dataset. After data cleaning following the research objectives, there were total 11,405 individuals, with 68,431 copies of surveys included in this study. In order to answer the research questions, participants included in this study had to meet two selection criteria. First, participants needed to be at least 45 years old when they were injured or had lived with SCI for over or equal to 15 years. This data selection criterion was in place because signs of ageing show up earlier for people with SCI, who are more likely to experience age-related problems such as chronic pain, bone loss, pressure injury (pressure sores), and kidney and bladder stones (Thompson and Yakura, 2001; Hitzig *et al.*, 2011; Model Systems Knowledge Translation Center, 2021). These aged-related changes have been found to occur as early as 15 years after injury and around 45 years of age

(McColl *et al.*, 1995; Menter and Hudson, 1995). Second, all the participants needed to have had at least three follow-up surveys for longitudinal data analysis purposes. As life situations of this population change dramatically after injury, their perceived life satisfaction is often low initially after SCI, but generally improves to a higher and stable level as they adapt to the consequences of the injury (Mortenson *et al.*, 2014). Generally, the first survey was taken one year after the injury, and then every five years. To avoid the potential bias in data analysis caused by potential low life satisfaction in newly injured individuals adapting to life with SCI during the first few years, at least three rounds of surveys will be included.

Measurements

Dependent variable

Life satisfaction, as the dependent variable, was measured by the Satisfaction with Life Scale (Diener *et al.*, 1985), which has been widely used to assess subjective well-being. Study participants were asked to respond to five statements on a seven-point scale (1 = strongly disagree, 2 = disagree, 3 = slightly disagree, 4 = neither agree nor disagree, 5 = slightly agree, 6 = agree, 7 = strongly agree): (a) In most ways my life is close to my ideal; (b) The conditions of my life are excellent; (c) I am satisfied with my life; (d) So far, I have gotten the important things I want in life; and (e) If I could live my life over, I would change almost nothing. The total score of participants' life satisfaction, ranges from 5 to 35, with higher scores indicating higher levels of life satisfaction. The total scores of key variables in the study were calculated by the NSCISC. The detailed descriptive and calculation information of the variables used in this study can be found in SCIMS's Data Dictionary for the National Spinal Cord Injury Database provided by NSCISC.

Independent variable (fixed factors)

Self-perceived health status, which reflects participants' own thoughts on their physical, mental and social aspects of their health (Idler *et al.*, 1999), was measured using a five-point scale, where the following question was asked: In general, would you say that your health is excellent (= 1), very good (= 2), good (= 3), fair (= 4) or poor (= 5)?

Self-reported weekly recreation hours and social integration level were measured using the Craig Handicap Assessment and Reporting Technique short form (CHART-SF). The short form of CHART reproduces all the CHART subscales with at least 90 per cent accuracy (NSCISC, 2019). Participation in recreational activities was measured by hours per week, excluding hours of watching television and listening to radio. Recreational activities were determined by the participants themselves and may include hobbies, outdoor activities, reading, blogging and/or playing games online. The valid score of weekly recreation hours' range was 0 to 98, with higher scores meaning more recreation participation weekly.

Social integration level was measured as a total score using data collected from the CHART social integration variables: 'Live with a spouse/significant other', 'How many [roommates] are relatives', 'Number of business/organisational contacts/month', 'Number of contact/months with friends' and 'Stranger initiated contacts/month'. The valid score for social integration level ranges from 0 to 100, with higher scores representing higher levels of social integration.

Covariates

Demographic information including sex (female, male), family income (in US\$; 1 = <25,000, 2 = 25,000–49,999, 3 = 50,000–74,999, 4 = >75,000), marital status (1 = never married, 2 = married, 3 = divorced, 4 = separated, 5 = widowed, 6 = others, 7 = living with significant other) and education levels (1 = eighth grade or lower, 2 = ninth to 11th grade, 3 = high school diploma or GED, 4 = associate degree, 5 = bachelor degree, 6 = master degree, 7 = doctorate, 8 = other) were collected and updated at each follow-up survey. Participants who refused to answer the questions or did not know about the answers were treated as missing values in the analysis.

Data analysis

Data analysis was conducted using R (version 4.1.3). Descriptive statistics (e.g. mean, standard deviation (SD) and frequency) were used to describe demographics, including age, family income, education level, marital status, category of neurologic impairment and race. The descriptive analysis was calculated based on participants' first documented post-injury interviews. The change in patterns of participants' recreational participation hour, social integration level, self-perceived health status and life satisfaction across time were then visualised, respectively, using function 'ggplot ()' from R package 'ggplot2 (version 3.3.5)' (Wickham, 2016). Post-injury year was mapped to the *x*-axis, and participants' recreational participation hour, social integration level, self-perceived health status and life satisfaction were mapped to the *y*-axis separately, grouped by participants' ID. A summary function 'stat_summary()' was added to calculate and plot the means, with the points of mean displayed as a line in the figures.

A multilevel modelling, also known as linear mixed model (LMM) method was then applied to explore the growth curve in participants' recreational time, social integration level, self-perceived health status and life satisfaction, where participants' year living with SCI ('post-injury-year') was added as the time indicator to examine variables' growth trends. Participants' ID was treated as the random factor in the models in order to observe the longitudinal patterns on individual level. Multilevel models are often used to examine individual differences in change over time, where time-points are nested within individuals (such as their growth curve models), for which assumptions of independence are likely to be violated (Hoffman and Rovine, 2007). The model used in this analysis had two levels, with life satisfaction as an example:

$$\text{Level 1: } y_{ti} = \pi_{0i} + \varepsilon_{ti}. \quad (1)$$

$$\text{Level 2: } \pi_{0i} = \beta_{00} + \mu_{0i}. \quad (2)$$

Here, the equation in level 1 means participant 'i's' life satisfaction score (*y*) is equal to the participant's life satisfaction score averaged over time (π_{0i}) plus a time-specific deviation (ε_{ti}) from that mean. It showed within-group variation of the model. Equation 2 means participant 'i's' mean life satisfaction score (π_{0i}) is equal to the grand mean of all participants' mean life satisfaction scores plus the deviation (μ_{0i}) of that participants' score from the grand mean of participant means. It represented the modelling variation in intercepts.

Finally, the same method, the LMM, was applied to see how recreation, social integration level and self-perceived health status impact life satisfaction over time. SCI individuals' patient ID was treated as a random factor in the model. Participants' recreation time, self-perceived health status and social integration level were added to the model as the independent variables (fixed effects). To address potential bias, a null model (Table 3, Model 1) was conducted with only the random factor (SCI individuals' patient ID) and covariates. Independent variables including recreation time (Table 3, Model 2), self-perceived health status (Table 3, Model 3) and social integration level (Table 3, Model 4) were added in the model, using forward selection, to see their individual contribution to the model. In the model, 't' (= 1, 5, 10 ..., 45) and 'i' (= 1 ..., N) represented the repeated measurements 'post-injury-year' and participants' ID, respectively. Using participants' ID as the random factor grouped data on the individual level. β values were the effects of independent variables (fixed effects) in the model, interpreted as the difference in life satisfaction between two individuals that differ by 1 unit of dependent variables. u_{ti} was the individual random effect, that tells the variability between individual participants. Since the study did not intend to explore the difference between individuals, the u_{ti} was not reported and analysed. R package 'lme4' (Bates *et al.*, 2015) (version 1.1–30) was the main package used. The R function used for the LMM model was 'lmer()'. The final LMM equation was:

$$\begin{aligned} \text{Life satisfaction}_{ti} = & \beta_0 + \beta_1 \text{Recreation}_{ti} + \beta_2 \text{Self-perceived health}_{ti} \\ & + \beta_3 \text{Social integration}_{ti} + u_{ti} \text{ID} + \beta_5 \text{Gender} + \beta_6 \text{Income} + \beta_7 \text{Education} \\ & + \beta_8 \text{Marital status} + \varepsilon_{ti}. \end{aligned}$$

Results

Socio-demographic information is listed in Table 1. Among the 11,450 selected SCI participants, 8,972 (78.7%) were male and 2,433 (21.3%) were female. Their average age at injury was 33.5 years (SD = 15.54). In this study, 47.4 per cent of the participants' neurologic impairments were diagnosed as paraplegia, and the other 52.9 per cent were diagnosed as tetraplegia. According to the first available post-injury survey from the dataset, 41.2 per cent of the participants had never married, and 37.2 per cent were married; over half of the participants had at least a high school diploma. Only 55.3 per cent of participants reported their family annual income levels, which were mostly under US\$50,000. Among the participants, 44.6 per cent who reported family incomes had less than \$25,000 per year, with 24.3 per cent ranging from \$25,000 to 49,999 annually. More detailed demographic information can be found in Table 1.

As seen in Figure 1, SCI individual's total life satisfaction (Figure 1A) had a notable growth between the first and second post-injury survey waves compared to other waves. After that, the growth line tended to be mild and stable except after the 35-years-of-injury time-point, where the curve had a notable rise again. From the growth curve multilevel model, each SCI individual's average life satisfaction score across time was found to be around 21.57 of the maximum total score of

Table 1. Demographic information

| Variables | N | % |
|---|-------|------|
| Gender: | | |
| Male | 8,972 | 78.7 |
| Female | 2,433 | 21.3 |
| Category of neurologic impairment: | | |
| Paraplegia, incomplete | 2,082 | 18.3 |
| Paraplegia, complete | 3,303 | 29.0 |
| Paraplegia, minimal deficit | 6 | 0.1 |
| Tetraplegia, incomplete | 3,754 | 32.9 |
| Tetraplegia, complete | 2,244 | 19.7 |
| Tetraplegia, minimal deficit | 15 | 0.1 |
| Normal neurologic | 1 | 0.0 |
| Race: | | |
| White, Caucasian | 8,314 | 75.8 |
| Black, African American | 2,181 | 19.9 |
| American Indian, Alaska Native | 77 | 0.7 |
| Asian, Pacific Islander | 186 | 1.7 |
| Other, multiracial | 214 | 2.0 |
| Marital status: | | |
| Never married (single) | 4,671 | 41.2 |
| Married | 4,218 | 37.2 |
| Divorced | 1,838 | 16.2 |
| Separated | 291 | 2.6 |
| Widowed | 254 | 2.2 |
| Other, unclassified | 12 | 0.1 |
| Living with significant other | 42 | 0.4 |
| Education: | | |
| Eighth grade or lower (includes ages 0–5) | 427 | 3.8 |
| Ninth to 11th grade | 1,555 | 13.8 |
| High school diploma or GED | 5,856 | 51.9 |
| Associate degree | 786 | 7.0 |
| Bachelor's degree | 1,707 | 15.1 |
| Master's degree | 551 | 4.9 |
| Doctorate (PhD, MD, law degrees, etc.) | 232 | 2.1 |
| Other, unclassified | 170 | 1.5 |

(Continued)

Table 1. (Continued.)

| Variables | N | % |
|-----------------------|-------|------|
| Family income (US\$): | | |
| <25,000 | 2,761 | 44.6 |
| 25,000–49,999 | 1,507 | 24.3 |
| 50,000–74,999 | 821 | 12.3 |
| 75,000+ | 1,103 | 17.8 |

35. At the first-year post-injury interview, participants' life satisfaction was 19.77 ($p < 0.001$) and grew 0.14 ($p < 0.001$) point at each later post-injury interview over time.

SCI individuals' weekly recreation activity participation (Figure 1B), social integration level (Figure 1C) and self-perceived health (Figure 1D) status had no obvious change across the ageing process. But when turning to the 30-year post-injury anniversary, SCI individuals' weekly participation in recreational activities dropped gradually. Especially for those who had SCI for over 35 years, their recreation activity participation and self-perceived health status notably dropped. The average weekly recreation participation hour, self-perceived health status and social

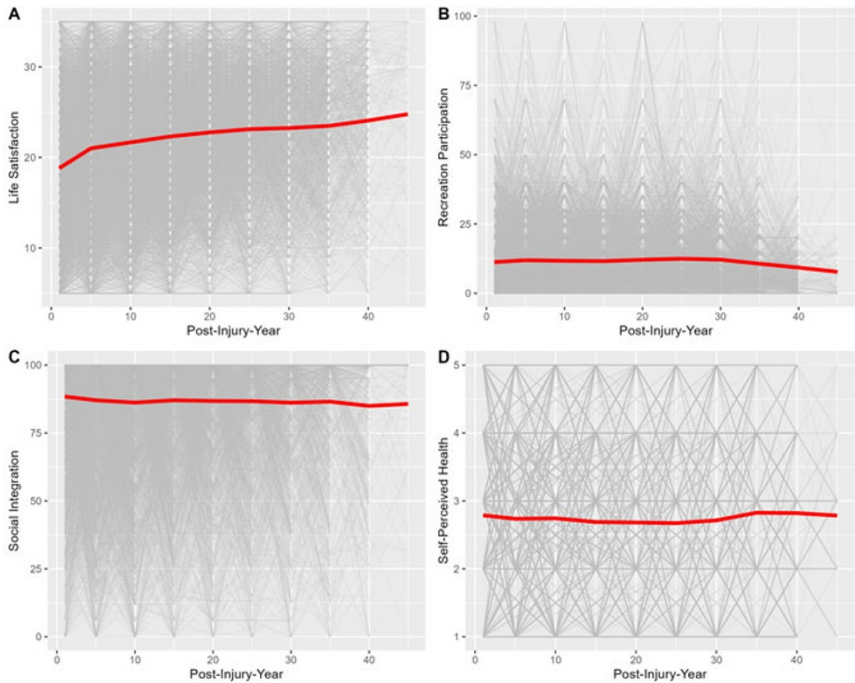


Figure 1. Growth curves of life satisfaction (A), recreation participation (B), social integration (C) and self-perceived health status (D).

Table 2. Multilevel models for factors' post-injury growth

| Factors | Parameter | Estimate | SE | 95% CI |
|---|------------------|----------|------|----------------|
| Life satisfaction GM = 21.57 | Intercept | 19.77** | 0.08 | 19.61–19.93 |
| | Post-injury-year | 0.14** | 0.00 | 0.13–0.14 |
| | Random effect | 30.16** | | |
| Recreation participation GM = 11.59 | Intercept | 11.64** | 0.12 | 11.40–11.89 |
| | Post-injury-year | –0.00 | 0.03 | –0.02–0.01 |
| | Random effect | 33.94 | | |
| Self-perceived health status GM = 2.76 | Intercept | 2.70** | 0.01 | 2.67–2.72 |
| | Post-injury-year | 0.01** | 0.01 | 0.00–0.01 |
| | Random effect | 0.47** | | |
| Social integration GM = 86.25 | Intercept | 88.56** | 0.24 | 88.08–89.03 |
| | Post-injury-year | –0.18** | 0.01 | –0.20 to –0.15 |
| | Random effect | 245.51** | | |

Notes: SE: standard error. CI: confidence interval. GM: grand mean.

Significance level: ** $p < 0.001$.

integration score of SCI individuals were 11.59 ($p < 0.001$), 2.76 ($p < 0.001$) and 86.25 ($p < 0.001$), respectively, across the post-injury ageing period (Table 2). Participants' weekly recreation activity participation hours at first post-injury interview was about 11.63 hours on average. Though it had a notable drop from graphi (Figure 1B), the declining trend of weekly recreation participation for people with SCI while ageing was not statistically significant ($\mu_{01} = -0.00$, $p = 0.60$). On the other side, results of self-perceived health status and total social integration score were statistically significant. The average social integration score amongst SCI individuals was 86.25 ($p < 0.001$) at the first post-injury year, and then gradually decreased 0.18 ($p < 0.001$) point every five years. After living with SCI for about one year, individuals considered their health status as between good and very good, around 2.70 ($p < 0.001$). The scale then increased 0.01 ($p < 0.001$) at every five-year interview frequency.

As seen in the LMMs (Table 3), participants' recreational participation, self-perceived health status and social integration level had positive impact on life satisfaction during the ageing process. The null model had marginal $R^2 = 0.083$ and conditional $R^2 = 0.547$, indicating that with only controlled variables, the whole model can explain 54.7 per cent of the life satisfaction variance during ageing. Recreational participation (Model 2) showed its statistical significance to life satisfaction along with the controlled variables and the random factor, with coefficient $\beta = 0.06$ ($p < 0.001$, 95% confidence interval (CI) = 0.05–0.07). When SCI individuals had 0.06 more hours per per week of recreation, their life satisfaction score increased one point. The model had marginal $R^2 = 0.093$ and conditional $R^2 = 0.548$. Those values indicated that recreational participation alone with the controlled variables can explain 9.3 per cent of the life satisfaction variance, and the whole model including fixed and random factors can explain 54.8 per cent of the variance.

SCI individuals' self-perceived health status was then added to the model (Table 3, Model 3). Model 3 showed marginal $R^2 = 0.202$ and conditional $R^2 = 0.565$, where this variable can explain 10.9 per cent of the variance with the controlled variables and recreational participation. The two fixed factors of recreation participation and self-perceived health status, with controlled variables, can explain 20.2 per cent of the life satisfaction variance. The two fixed factors together with the random factor can explain 56.5 per cent of the life satisfaction variance. Each level was found to have statistical significance. When SCI individuals thought they had better health status, their life satisfaction increased; and the healthier they thought they were, the higher impact this perception had on their life satisfaction.

The last fixed factor, social integration scores, explained 1.5 per cent of the variance of life satisfaction (Table 3, Model 4). The model had marginal $R^2 = 0.217$ and conditional $R^2 = 0.569$. With the controlled variables, the three fixed factors can explain 21.7 per cent of the variance. In considering recreational participation, self-perceived health status, controlled variables and random variable, the whole model can explain 56.9 per cent of the life satisfaction variance. The coefficient $\beta = 0.04$ ($p < 0.001$, 95% CI = 0.03–0.04) indicated that with 0.04 point of social integration score increasing, the SCI individuals' total life satisfaction can improve one point.

Overall, results of the LMMs indicated that SCI participants' recreational participation, self-perceived health status and social integration levels have statistical significances to their overall life satisfaction. When their weekly recreation activity participation and social integration level increased over time, their overall life satisfaction increases. Also, when SCI individuals believed that they had a better health status, their life satisfaction increases.

According to the LMM analysis, the intercept-only model has its between-group variance of $\tau_{00} = 30.92$. After adding the controlled variables and fixed factors into the models, the τ_{00} decreases from 27.06, 26.47, 20.59 to 20.00, respectively, which indicated the mean difference of life satisfaction among each SCI participant became smaller.

Discussion

This study reports how life satisfaction changes when people living with SCI age, as measured across a 45-year time period. The evidence from this study suggests that life satisfaction for this population increases gradually and steadily after discharge from the hospital, which is different from the previous panel studies on general ageing populations. There is both limited and contradictory evidence on long-term life satisfaction change in the general population, and even fewer numbers of longitudinal studies on life satisfaction for people with SCI while ageing. As the world has increasingly larger older populations, understanding how people age and how to age successfully, gracefully and achieve life satisfaction is a promising and important topic for future exploration.

In this study, after examining the changes of potential predictive factors of life satisfaction of people with SCI during the ageing process, results show that participating in recreational activities, having high self-perceived health status and being involved in more social interactions positively impact life satisfaction across SCI individuals' ageing process when selected socio-demographic variables were controlled. Unlike the decreasing trends of weekly recreational hours, social interactions

Table 3. Generalised linear mixed models

| | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
|----------------------------|----------------|-------------|----------------|-------------|----------------|----------------|----------------|----------------|
| | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI |
| Fixed factors: | | | | | | | | |
| Intercept | 16.64 (0.41)** | 15.83–17.45 | 16.16 (0.41)** | 15.36–16.97 | 20.85 (0.41)** | 20.05–21.64 | 17.87 (0.44)** | 17.00–18.74 |
| Year-post-injury: | | | | | | | | |
| 5 | 2.31 (0.15)** | 2.02–2.60 | 2.25 (0.15)** | 1.96–2.54 | 2.16 (0.14)** | 1.88–2.44 | 2.26 (0.14)** | 1.98–2.54 |
| 10 | 3.06 (0.15)** | 2.77–3.36 | 3.03 (0.15)** | 2.74–3.33 | 3.03 (0.15)** | 2.74–3.31 | 3.17 (0.15)** | 2.88–3.45 |
| 15 | 3.71 (0.16)** | 3.40–4.02 | 3.7 (0.16)** | 3.39–4.00 | 3.61 (0.15)** | 3.32–3.91 | 3.76(0.15)** | 3.47–4.06 |
| 20 | 3.99 (0.17)** | 3.66–4.31 | 3.94 (0.17)** | 3.62–4.26 | 3.95 (0.16)** | 3.64–4.26 | 4.16 (0.16)** | 3.84–4.47 |
| 25 | 4.2 (0.18)** | 3.84–4.56 | 4.12 (0.18)** | 3.76–4.48 | 4.17 (0.17)** | 3.83–4.51 | 4.40 (0.18)** | 4.06–4.75 |
| 30 | 4.32 (0.20)** | 3.92–4.71 | 4.27 (0.20)** | 3.88–4.67 | 4.55 (0.19)** | 4.17–4.93 | 4.79 (0.19)** | 4.41–5.17 |
| 35 | 4.12 (0.21)** | 3.70–4.54 | 4.12 (0.21)** | 3.70–4.54 | 4.69 (0.20)** | 4.29–5.09 | 4.93 (0.20)** | 4.53–5.33 |
| 40 | 4.61 (0.27)** | 4.07–5.14 | 4.7 (0.27)** | 4.16–5.23 | 5.24 (0.26)** | 4.73–5.75 | 5.54 (0.26)** | 5.03–6.05 |
| 45 | 5.25 (0.64)** | 4.00–6.49 | 5.39 (0.64)** | 4.14–6.64 | 5.99 (0.61)** | 4.79–7.19 | 6.21 (0.61)** | 5.01–7.40 |
| Gender: | | | | | | | | |
| Female | 0.57 (0.16)** | 0.26–0.87 | 0.64 (0.15)** | 0.33–0.94 | 0.55 (0.14)** | 0.27–0.82 | 0.49 (0.14)** | 0.22–0.77 |
| Education: | | | | | | | | |
| Ninth to 11th grade | −0.24 (0.43) | −1.08–0.60 | −0.43 (0.43) | −1.27–0.40 | 0.98 (0.40)* | −1.76 to −0.20 | −0.91 (0.40)* | −1.69 to −0.13 |
| High school diploma or GED | 0.35 (0.40) | −0.43–1.14 | 0.09 (0.40) | −0.69–0.87 | −0.87 (0.39) | −1.60 to −0.14 | −0.97 (0.37)** | −1.70 to −0.24 |
| Associate degree | 0.48 (0.43) | −0.36–1.32 | 0.23 (0.43) | −0.60–1.07 | −0.76 (0.40) | −1.54–0.02 | −0.93 (0.40)* | −1.71 to −0.15 |

(Continued)

Table 3. (Continued.)

| | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
|-------------------------------|---------------|------------|---------------|------------|----------------|----------------|----------------|----------------|
| | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI | Estimate (SE) | 95% CI |
| Bachelors degree | 1.11 (0.42)** | 0.29–1.93 | 0.87 (0.42)* | 0.05–1.69 | −0.54 (0.39) | −1.31–0.22 | −0.79 (0.39)* | −1.56 to −0.03 |
| Masters degree | 1.34 (0.45)** | 0.45–2.23 | 1.09 (0.45)* | 0.21–1.98 | −0.24 (0.42) | −1.06–0.59 | −0.49 (0.42) | −1.32–0.33 |
| Doctorate | 0.90 (0.54) | −0.16–1.96 | 0.66 (0.54) | −0.39–1.72 | −0.69 (0.05) | −1.68–0.29 | −0.85 (0.05) | −1.82–0.13 |
| Other, unclassified | 0.58 (0.51) | −0.43–1.59 | 0.24 (0.51) | −0.77–1.25 | −0.78 (0.49) | −1.73–0.17 | −0.95 (0.49) | −1.90 to −0.00 |
| Family income (US\$): | | | | | | | | |
| 25,000–49,999 | 1.19 (0.12)** | 0.95–1.44 | 1.18 (0.12)** | 0.94–1.42 | 0.80 (0.12)** | 0.57–1.03 | 0.64 (0.12)** | 0.40–0.87 |
| 50,000–74,999 | 1.9 (0.16)** | 1.59–2.21 | 1.88 (0.16)** | 1.57–2.19 | 1.30 (0.15)** | 1.00–1.59 | 1.08 (0.15)** | 0.78–1.37 |
| 75,000+ | 2.72 (0.16)** | 2.41–3.04 | 2.74 (0.16)** | 2.43–3.05 | 2.02 (0.15)** | 1.72–2.31 | 1.75 (0.15)** | 1.45–2.04 |
| Marital status: | | | | | | | | |
| Married | 1.41 (0.14)** | 1.13–1.68 | 1.53 (0.14)** | 1.25–1.80 | 1.78 (0.13)** | 1.53–2.04 | 1.51 (0.13)** | 1.25–1.77 |
| Divorced | 0.00 (0.16) | −0.32–0.31 | 0.07 (0.16) | −0.24–0.38 | 0.43 (0.15)** | 0.14–0.72 | 0.48 (0.15)** | 0.19–0.77 |
| Separated | 0.08 (0.32) | −0.56–0.71 | 0.23 (0.32) | −0.41–0.86 | 0.66 (0.31)* | 0.06–1.26 | 0.86 (0.31)** | 0.26–1.46 |
| Widowed | 1.16 (0.33)** | 0.52–1.79 | 1.28 (0.32)** | 0.64–1.91 | 1.83 (0.30)** | 1.23–2.42 | 2.11 (0.30)** | 1.52–2.71 |
| Other, unclassified | 0.51 (1.28) | −2.00–3.01 | 1.38 (1.31) | −1.19–3.95 | 1.58 (1.25) | −0.87–4.02 | 1.47 (1.24) | −0.96–3.90 |
| Living with significant other | 0.56 (0.34) | −0.10–1.23 | 0.66 (0.34) | −0.00–1.32 | 1.18 (0.32)** | 0.56–1.81 | 0.92 (0.32)** | 0.29–1.55 |
| Recreation | | | 0.06 (0.00)** | 0.05–0.07 | 0.04 (0.00)** | 0.03–0.05 | 0.03 (0.00)** | 0.03–0.04 |
| Self-perceived health status: | | | | | | | | |
| Very good | | | | | −1.50 (0.14)** | −1.77 to −1.23 | −1.51 (0.14)** | −1.78 to −1.23 |
| Good | | | | | −3.57 (0.14)** | −3.85 to −3.30 | −3.49 (0.14)** | −3.76 to −3.21 |

| | | | | | | |
|-----------------------------------|-------------|-------------|----------------|-----------------|----------------|----------------|
| Fair | | | −6.22 (0.16)** | −6.53 to −5.90 | −6.02 (0.16)** | −6.33 to −5.70 |
| Poor | | | −9.90 (0.24)** | −10.37 to −9.43 | −9.44 (0.24)** | −9.91 to −8.96 |
| Social integration | | | | | 0.04 (0.00)** | 0.03–0.04 |
| Random effects: | | | | | | |
| σ^2 | 26.46 | 26.24 | 24.69 | | 24.45 | |
| τ_{00} UNIQID | 27.06 | 26.47 | 20.59 | | 20 | |
| ICC | 0.51 | 0.50 | 0.45 | | 0.45 | |
| Marginal R^2 /conditional R^2 | 0.083/0.547 | 0.093/0.548 | 0.202/0.565 | | 0.217/0.569 | |

Notes: SE: standard error. CI: confidence interval. ICC: intraclass correlation coefficient. σ^2 : residual variance, which represents the variability in the outcome that is not explained by the fixed and random effects in the model. τ_{00} UNIQID: variance of the random intercepts for the participants' ID. It captures the variability in the baseline level of life satisfaction across different individuals. Significance levels: * $p < 0.05$, ** $p < 0.001$.

and self-perceived health status, life satisfaction for people with SCI increases over time, with two obvious waves of increase exhibited during SCI individuals' ageing process. The first increasing wave was between the first and second post-injury interview. This finding agrees with the results from previous studies (Mortenson *et al.*, 2014; Jørgensen *et al.*, 2021) that found life satisfaction of newly injured SCI patients would most likely be low during the first few years after injury, and then increase after they get used to living with the injury. This phenomenon has been widely discussed through the SCI studies since the challenges preventing adaptive adjustment after SCI are numerous. People with SCI may experience various linear stages of adjustment, such as denial, anger, depression and acceptance of reality after the severe loss, according to the stage theory by Trieschmann (2013). People after SCI need to re-evaluate and adjust their values and beliefs about their life choices and decisions which is closely connected to their quality of life (Sprangers and Schwartz, 1999). People with SCI in the face of the upheaval from the trauma event accepted the reality after few years of adjusting, and changed their perception of wellbeing and quality of life. Those findings of adjustment post-SCI injury can, to some extent, explain the first wave of increasing life satisfaction in this study.

The second notable climbing wave of life satisfaction happened at the 35-year post-injury period. With the average age at injury of people with SCI in this study being about 33.5 years old, results show that around 68 years old, the people with SCI's life satisfaction has a notable increase. The second climbing wave of life satisfaction during SCI participants' ageing process showed similarity when compared to the general population. For example, a U-shape age profile was found in some research to have a nadir located around ages in the forties or fifties, and then monotonically increased (Stone *et al.*, 2010; Blanchflower, 2020, 2021). This phenomenon, which is considered to be related to 'midlife crisis', has been confirmed in many datasets and across many countries (Diener, 1994; López Ulloa *et al.*, 2013; Gigantesco *et al.*, 2019; Blanchflower, 2020, 2021; Hudomiet *et al.*, 2021). But this phenomenon was not observed in this study. Further exploration is still needed, since inconsistent findings have been found on stability and change in life satisfaction in longitudinal ageing studies (Hudomiet *et al.*, 2021). As this phenomenon has not been widely discussed among the SCI population, nor people with other disabilities, future study could explore if people with SCI or other disabilities face the same middle-age crisis as the regular population when they have an early injury or disabilities onset.

As can be expected, the predictors of life satisfaction, both recreation participation hours and social integration level, have declining trends when people with SCI age, although their weekly recreational hours decrease without statistical significance. This decline is more aligned to the disengagement theory of ageing proposed by Cumming and Henry (1961), wherein ageing is inevitably linked to reduced social activity and older adults' withdrawal from society is natural, voluntary and acceptable. Moreover, for the SCI population, ageing is also accompanied by limited mobility, health complications and mental health problems, which negatively impact their social activities and integration (Barclay *et al.*, 2016; Piatt *et al.*, 2016). In proposing that withdrawal from social life due to ageing is normal and natural from this perspective, older adults are encouraged to follow their natural inclination towards solitude and greater inactivity.

Nevertheless, the LMMs indicate that recreational participation can positively impact life satisfaction while people with SCI age. For recreation participation, research has rarely been conducted under a longitudinal context and across a long (45-year) period. Results of the growth curve and LMMs show a contradictory situation, that recreation participation declined while life satisfaction grew across the 45-year period, though no statistically significant decline towards recreation participation hour was found over time. But recreation participation has a statistically positive impact on life satisfaction in the LMMs, which shows evidence that participating more in recreational activities can increase life satisfaction for people with SCI. One possible explanation here is that patterns of recreation participation for older people with SCI change over time. For example, the older participants did not engage in formal outdoor recreational activities, such as being a member of clubs and organisations, travelling with family and friends, and other social engagements due to the functional limitations caused by ageing, but spent more time indoors or in activities that can be carried out alone (Janke *et al.*, 2006; Fernández-Mayoralas *et al.*, 2015). Also participants may also have different standards on defining recreational activities, which makes them report their recreational hours with different standards.

People with SCI also have more limited physical functioning compared to the general population, and ageing-caused chronic disease may force them to make this transformation from outdoor to indoor recreational activities earlier, or even reduce their time in recreational activities. It is unclear if participants in this study had this tendency. Future research is needed to see if people with SCI change the ways they participate in recreational activities as they age, and to explore what types of recreational activities can both boost the quality of recreational participation and impact social integration. Also it is possible that some other factors have been missed in this model in terms of evaluating the pattern of recreation and social interaction changes.

This study offers a general idea of how recreational participation hour changes across time among people with physical disabilities, and specifically people with SCI. Since the 1970s, for example, leisure and tourism scholars have found activity theory and continuity theory more compelling than disengagement theory, since such studies have found activity in later life yields life satisfaction and wellness (Lemon *et al.*, 1972; Palmore, 1979; Steinkamp and Kelly, 1987; Adams *et al.*, 2011). The activity theory and continuity theory posit that older adults are happiest when they stay active and maintain social interactions or preserve existing internal and external life structures while ageing. This study also confirms that increasing recreation participation hour and social integration level can lead to improved long-term life satisfaction for people with SCI while ageing, as expected by activity and continuity theory. However, the growth curves depicted in Figure 1 show that people with SCI gradually decrease their weekly recreational hours as they age. Meanwhile, their overall life satisfaction slowly increases. These growth curves, along with the LMM model results, indicate that the disengagement theory seems to better fit the ageing situation of the people with SCI in this study.

The limitation in this study involves an unexplained discrepancy found in the growth curve models. These models show a decrease in recreation time alongside an increase in life satisfaction among people with SCI as they age. This finding

contradicts the positive long-term impact of recreation participation on life satisfaction, as revealed by the LMMs. Future studies could pay more attention to explore, among both the general ageing population and the ageing population with disabilities, if the phenomenon found in this study is consistent. If not, what could cause this discrepancy is worth investigating. More socio-cultural factors need to be considered in the future studies since, for example, the few studies that have confirmed the validity of disengagement theory were conducted in developing and less-developed countries (Crewdson, 2016). For example, Bernard (2013) observed that cities and social infrastructure in developed countries better support social engagement and physical activity compared to those in poor or developing countries. The nature of this support system in wealthier regions implies that people with disabilities may fit the disengagement theory better, since the environmental factors related to the development of infrastructure may not satisfy their needs for social engagement activities even in developed countries.

In this study, SCI individuals' self-perceived health status was found to be relatively high across the ageing period. The average score of self-perceived health status was 2.78, which indicates that most of the time, the participants considered themselves as having a good or even very good health status, especially after they have lived with SCI for over 35 years and are used to managing related challenges. In this study, the higher the people with SCI rated their health status, the higher life satisfaction score they had. This finding echoes the previous studies that found self-perceived health has strong internal correlation with life satisfaction (Diener and Chan, 2011; Sabatini, 2014; Tareque *et al.*, 2015). Also, among the three independent variables in the linear mixed models, self-perceived health status explains the highest portion of variance in life satisfaction. This finding echoes the previous discussion on whether researcher-defined, biomedical-based criteria can fully capture the ageing experience of individuals, or whether self-reported and self-evaluated assessments can better describe people's ageing experience, especially for those with disabilities. For individuals with physical disabilities, such as SCI, their positive attitude towards their health conditions is positively correlated with their life satisfaction over a 45-year period. This could provide insight for future successful ageing studies regarding which types of variables should be included. The medically defined 'health status' often applied in such research may not fully represent the health experiences of individuals with SCI in real life. This alternative perspective on the importance of self-perceived health status aligns with previous studies on life satisfaction and successful ageing, which suggest that self-reported or self-evaluated variables could be more reflective of the actual *status quo* of individuals' ageing experiences. Researchers could, therefore, be more confident in incorporating subjective measurements into future life satisfaction or similar studies.

The overall change of self-perceived health status across time among the SCI population found in this study fits previous studies. As health complaints increase with age, the subjective health complaints reported could be explained as a (negative but not unexpected) outcome of the natural developmental process of ageing (Haugland *et al.*, 2001). In this study, SCI individuals' self-perceived health status did not show a continuous declining trend, as noted in Figure 1, but overall, their self-perceived health status declined to at least some degree across time. Another issue here is the trend of fluctuation of self-perceived health status, where SCI individuals' self-

perceived health status did not decrease at all times during the ageing process. The most obvious declining wave happened after people had been living with SCI for over 30 years. What causes this changing pattern is worthy of further exploration.

Conclusion

This study illustrates that participating in recreational activities regularly; engaging in and maintaining certain levels of social relationships with family, friends, colleagues or even strangers in daily life; and having a high evaluation of self-health would positively impact life satisfaction for people with SCI when they are ageing. But SCI individuals' recreation time and social integration levels had notable decreasing trends when this population reached the 30-year post-injury time-point, where the declining curve became more distinctive when the 35-year post-injury point was reached. Also, SCI individuals' self-perceived health status had a similar changing pattern compared to the other variables. It is possible that when their physical and mental condition or surrounding social environment became worse due to ageing, they reflected the change in their own evaluation of their health status. In this case, self-perceived health status and objective health and environmental conditions cause people with SCI to reduce their recreational time and social integration levels. More research is needed to identify reasons or factors that influence the changes in recreational participation and social integration during ageing. Additionally, more variables that can predict life satisfaction should be included to better understand its characteristics, and to assist in further evaluations and predictions on how to age successfully and gracefully, especially for individuals with disabilities. In future development of successful ageing models, researchers can be more confident in adding self-reported, self-evaluated assessment variables, as well as socio-cultural and socio-environmental-related variables, to better capture the ageing experience.

Limitations

The study has limitations that indicate possible directions for future research. One of the limitations is that people with SCI entered the dataset at different time periods with different SCI onset ages. There is limited evidence on whether and how onset age of this population may create a different perspective on their life satisfaction, however. But one longitudinal study found that people injured before 50 years old reported higher life satisfaction scores than people injured at older ages (Post and Reinhardt, 2015), suggesting that it is easier for people injured at an early age to adjust to living with SCI. Another limitation is that there is a possible 'happy survivor' effect in this study, where in life satisfaction studies, older adults in general will report higher psychological wellbeing than younger adults due to their perceived success in reaching old age. This effect can happen when older people receive more positive feedback in their life experience, which is a phenomenon consistently mentioned in socio-emotional selectivity theory (Carstensen *et al.*, 1999). There are still limited studies on this topic, however. It is also possible that people with SCI with lower physical wellbeing die earlier after their injury, whereas when maintaining better overall wellbeing, they may have a lower risk of

mortality. Future research could examine how disability onset influences post-injury recreation participation, social integration and life satisfaction over time.

Competing interests. The authors declare no competing interests.

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