

## REVIEW

# An evidence-based review on the influence of aging with a spinal cord injury on subjective quality of life

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**Study design:** Systematic review.

**Objectives:** To identify changes in subjective quality of life (QoL) as one ages with a spinal cord injury (SCI).

**Setting:** Vancouver, Canada.

**Methods:** Electronic databases were searched for studies reporting on age-related QoL changes over time. Data from relevant studies were transcribed into data extraction forms and analyzed by years post injury (YPI) and chronologic age. Each study was assigned a level of evidence based on a modified Sackett scale.

**Results:** In all, 21 studies, each with a low level of evidence, were included for review. The results indicated that regardless of chronologic age, individuals with relatively new SCI have the potential to improve their QoL. Among individuals with advanced YPI, overall QoL is consistently reported as good or excellent over time, however, with variations in different QoL domains.

**Conclusion:** The QoL of individuals aging with a SCI has the potential to improve, and remain high and stable over time. As the identified studies provide low levels of evidence, more longitudinal research with greater methodological and measurement rigor is needed to corroborate the findings and conclusions of this review.

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**Keywords:** spinal cord injury; quality of life; aging; measurement; systematic review

## INTRODUCTION

In the general population, advancing into older adulthood is often portrayed as a period when individuals are faced with a unique array of physical, functional and environmental stressors. This is no different for individuals aging with a traumatic spinal cord injury (SCI), who are now living an average of 30–40 years post injury (YPI).<sup>1</sup> In fact, it has recently been established that SCI represents a model for premature aging in some body systems (for example, cardiovascular and endocrine, musculoskeletal, immune and respiratory systems),<sup>2</sup> thereby suggesting that the declines associated with natural aging are compounded by the injury, and are likely to present more quickly among individuals with SCI. Similarly, Gerhart *et al.*<sup>3</sup> established that increasing age was a significant predictor of functional decline among individuals with SCI, and that 22% of the study's sample reported declines over a 3-year period. Such declines have important implications on an individual's independence.<sup>4</sup> Further, as people age, their social support networks have been shown to change due to retirement and increasing frequency of death among friends and family. Changes in social support networks of individuals with SCI are also apparent, and most evident within personal networks where there exists a high likelihood of divorce.<sup>5</sup> The issues of aging are considerable, with some being clearly magnified by SCI (e.g., physical declines).

The physical, functional and environmental changes associated with aging are important considerations in its evaluation among individuals with a SCI; however, such knowledge is insufficient without indication of how people perceive the changes and how they adapt their lifestyles in response to such changes.<sup>4</sup> In attempts to gain such information, the evaluation of subjective quality of life (QoL) is often used to gain perspective of and contextualize the quality of a person's life. For this reason, QoL is often considered to be the ultimate goal of rehabilitation following SCI,<sup>6,7</sup> and a key outcome for program evaluation.

Subjective QoL is a multidimensional and dynamic construct that has the potential to be influenced by many physical, psychosocial and environmental factors.<sup>8</sup> It can be evaluated from either a global or a domain-specific perspective. A significant body of cross-sectional research has examined QoL among people with SCI. In 1991, Eisenberg and Saltz<sup>9</sup> published a study that reviewed the literature on the QoL of individuals with a SCI. The conclusion based from the two studies reviewed was that both young and old individuals with a SCI experience have a good QoL.<sup>9</sup> Despite such positive findings, the review was limited by only including survey and cross-sectional data, largely due to lack of studies and evidence at that time, which examined the relationship between chronologic age and QoL. Furthermore, research has revealed that the QoL of individuals with

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a SCI is generally lower than that of their able-bodied counterparts, albeit at levels considered not to be poor,<sup>10,11</sup> and that social support<sup>12</sup> and marital status,<sup>13</sup> self-perceived health,<sup>12,14</sup> independence,<sup>12</sup> mobility,<sup>12–14</sup> employment,<sup>12–14</sup> income<sup>15</sup> and community integration,<sup>12–15</sup> are all factors shown to influence QoL post SCI. Conversely, factors related to the injury itself, such as level and cause, appear to have little effect.<sup>16</sup> Overall, such evidence has contributed to an understanding of the relationships that exist between QoL and other variables at a given point in time. The cross-sectional nature of much of the evidence, however, fails to shed light on how QoL changes due to the aging process.

Given that more people with SCI are living longer, a greater understanding of the changes in QoL over time is important to ensure that people with SCI are not only living longer but also living well. Therefore, the purpose of this evidence-based review is to systematically evaluate the research reporting on the influence of aging on subjective QoL after SCI, with a specific objective to identify changes in QoL as one ages with a SCI.

## METHODS

### Study design

A systematic review of the literature focusing on the influence of aging on QoL after SCI was undertaken to address the objectives of this study.

### Inclusion and exclusion criteria

For papers to be included for review, they had to: (1) be published in English and in a peer-reviewed journal; (2) be published between 1980 and September 2011; (3) have a sample with at least half comprised of adult ( $\geq 18$  years) participants with a traumatic SCI; and (4) evaluate the effects of aging on subjective QoL by longitudinal (including retrospective cohort data) or prospective research designs that had observations of at least 1 year. Studies evaluating health-related QoL were excluded for review, however, the subjective data from studies using a combined health-related and subjective QoL measure were included.

### Search strategy

Studies were found using two search strategies. First, trained research assistants searched through the MEDLINE/PubMed, CINAHL, EMBASE and PsycINFO online databases. The key word ‘spinal cord injury’ and its variants were used to narrow the search along with the terms: aging, years post injury, chronologic age, quality of life and QoL. The research assistants then reviewed the reference lists of each relevant paper and identified additional articles that the online database search missed.

### Study selection process

The list of identified papers, including the titles and abstracts, was then sent to the authors for review. The authors identified papers for inclusion, and any discrepancies were resolved through discussion.

## Data extraction and analysis

Because both YPI and chronologic age are aspects of aging,<sup>17</sup> each were considered in the data extraction and analyses. The papers selected for review first had the relevant data transcribed into data extraction forms developed by the Spinal Cord Injury Rehabilitation Evidence research team (<http://www.scireproject.com>).<sup>18</sup> To facilitate QoL comparisons between samples with similar aging parameters, the longitudinal data were categorized, first by YPI and then by mean chronologic age at baseline. The first YPI category was *a priori* determined to be  $\leq 5$  YPI to reflect the amount of time commonly perceived as needed to adapt to the initial injury.<sup>19</sup> Subsequent YPI categories increased by 10 years over the previous. The first age category was 18–29 years, with each following category increasing by a decade. To further structure the data for analyses, the studies were each assigned a level of evidence, based on a modified Sackett scale (Table 1).<sup>2</sup> Levels of evidence indicating better research design were given primacy when formulating conclusions. Lastly, for studies using the same QoL outcome measure comprised of different subscales, data were extracted by domain, and sub-analyses were done to identify domain-specific QoL trends.

## RESULTS

The search strategy resulted in 246 papers of possible interest. After detailed examination of the identified and initially reviewed abstracts, 21 papers were selected for review (See Tables 2–4). Most studies were from the United States ( $n = 14$ ). Studies were also from Britain ( $n = 3$ ), the Netherlands ( $n = 2$ ), Canada ( $n = 1$ ) and Sweden ( $n = 1$ ). All studies provided level 4 evidence.

The outcome measures used in each of the studies are also identified in Tables 2–4. Overall, eight different QoL outcome measures were used, with many differing in both their definition of and approach to assessing QoL. For example, the use of a single question to measure perceived global QoL was used in several studies, whereas other studies derived QoL composite scores from the evaluation of several purported domains of QoL. Only two measures have had independent evaluation of their psychometric properties of reliability and validity among individuals with SCI, including the SWLS (Satisfaction with Life Scale),<sup>20</sup> and the QLI (Quality of Life Index).<sup>21</sup> No instrument has had its responsiveness data evaluated among individuals with SCI.

The length of observations in the studies ranged from 1<sup>22,23</sup> to 30<sup>24</sup> years. The sample sizes ranged from a low of 17 to a high of 6451 subjects,<sup>25,26</sup> and the mean age of the samples at the beginning of each of the studies ranged from 18.1 to 51.9 years.<sup>27,28</sup> The mean YPI in each of the studies ranged from around  $>0.9$  to 26.8 years.<sup>23,29</sup> Because of the few studies reporting on samples with mean YPI and age greater than 16 and 50 years, respectively, the last data extraction category in each of the two areas include all of those papers with samples characterized by  $\geq 16$  YPI and  $\geq 50$  years, resulting in three YPI and three age categories. The following summarizes the findings in each of the studies.

**Table 1** Levels of evidence

Evidence level	Description
Level 1	Not applicable given there are no studies with a design that is equivalent to a randomized controlled trial.
Level 2	Longitudinal studies that include a control group (for example, able-bodied group) as they are considered cohort studies where one group is exposed to a particular condition (in this case, a spinal cord injury).
Level 3	Longitudinal studies, which include historical controls (from chart review or database).
Level 4	Longitudinal studies including at least a baseline and follow-up evaluation (at least equivalent to before–after studies).
Level 5	Not applicable given cross-sectional studies were excluded for review.

**Table 2 Longitudinal QoL and aging studies:  $\leq 5$  year post injury by age (years)**

Author/Study details/Length of observation	Sample characteristics	Methodology—data collection time points	QoL outcome measures	Outcomes
<i>Samples with mean ages <math>\leq 29</math> years and <math>\leq 5</math> YPI</i>				
Chen <i>et al.</i> <sup>27</sup> USA N = 278 9 years	Mean age (range) = 18.1 (15–28) Mean YPI (range) = 3.8 (at injury–21) Male = 184 Tetraplegia = 161 Other = 117	Up to eight time points (median 4, range 2–8), between 1996 and 2006.	SWLS	(1) Overall, SWLS scores slightly increased per year (n.s.). (2) Life satisfaction increased for those employed or students ( $P=0.02$ ), lived independently ( $P=0.05$ ), injury level at T7–S5 ( $P=0.006$ ) and had medical problems in the past year ( $P=0.02$ ).
Bushnik <sup>30</sup> USA N = 58 13–14 years	Mean age (range) = 29.0 (16–58) Mean YPI (range) = 4.5 (1–10) Male = 49 Tetraplegia = 58 Paraplegia = 0	Three time points: (1) 1984–1985; (2) 1992–1994; (3) 1997–1999.	Single item to measure perceived QoL	(1) The percentage of people rating their QoL as good or excellent steadily increased from 62, 72, to 78% at each time point (n.s.) (2) Individuals with access to modified vans for transportation had greater QoL at time points 2 and 3, than those without access ( $P<0.02$ , $P<0.01$ ).
Bushnik and Charlifue <sup>31</sup> USA N = 63 13–14 years	Mean age = 29.2 Mean YPI (range) = 4.9 (1–10) Male = 54 Tetraplegia = 63 Paraplegia = 0	Three time points: (1) 1984–1985; (2) 1992–1994; (3) 1997–1999.	Single item to measure perceived QoL	(1) Individuals most frequently reported good or excellent QoL at all points. (2) The percentage of individuals who rated good or excellent QoL increased from 58 to 77 to 76% ( $P<0.04$ ).
Krause and Coker <sup>24</sup> USA N = 78 30 years	Mean age = 25.7 Mean YPI = 5.8 Male = 67 Tetraplegia = 53 Paraplegia = 25	Three time points: (1) 1973; (2) 1988; and (3) 2002.	LSQ	(1) During the first 15-year period, increases were observed in satisfaction with social and sex lives, and employment. (2) During the last 15-year period, declines were noted in satisfaction with social life and sex life.
<i>Samples with mean ages 30–39 years and <math>\leq 5</math> YPI</i>				
Mortenson <i>et al.</i> <sup>23</sup> Canada N = 93 1 year	Mean age (range) = 39.6 (18–78) Mean YPI = $>0.25$ post discharge Male = 83 ASIA A = 28 ASIA B = 11 ASIA C = 9 ASIA DE = 45	Two time points between 1999 and 2003: (1) 3 months post discharge; and (2) 15 months post discharge.	QLI	(1) No QoL differences were observed between time points ( $P=0.85$ ). (2) Average QLI scores were 19.66 out of 30.
Stensman <sup>25</sup> Sweden N = 17 5 years	Mean age = 32.4 Mean YPI = 0.5 Male = 15 Tetraplegia = 10 Paraplegia = 7	Six time points: (1) 0.5 YPI; (2) 1 YPI; (3) 2 YPI; (4) 3 YPI; (5) 4 YPI; (6) 5 YPI.	Single item to measure perceived QoL	(1) 5 subjects had consistently high QoL. (2) 6 had low QoL between 0.5 and 3 years, and improvements thereafter. (3) 2 had variable QoL over time, influence by variable pain. (4) 4 had consistently low QoL, influenced by constant pain.
Putzke <i>et al.</i> <sup>22</sup> USA N = 270 1 year	Mean age = 35.7 YPI = 1.0 Male = 210 Tetraplegia = 132 Paraplegia = 134 Other = 4	Two time points between 1998 and 2000: (1) 1 YPI; and (2) 2 YPI; among 4 groups.	SWLS	(1) Older individuals were more likely to report pain in both years than younger individuals ( $P<0.001$ ). (2) SWLS scores decreased in the group with pain only in year 2. (3) SWLS scores increased in the group with pain only in year 1.
Kalpakjian <i>et al.</i> <sup>26</sup> USA N = 6141 15 years	Mean age = 39.0 Mean YPI = 1.0 Male = 4864 Tetraplegia complete = 1147 Tetraplegia	One to $>5$ time points at 1 and 5 YPI, and every 5 years after.	SWLS	(1) Life satisfaction was shown to improve over time. (2) Life satisfaction of those separated or divorced increased over time and do so to a greater degree for women ( $P=0.03$ ).

**Table 2 (Continued)**

Author/Study details/Length of observation	Sample characteristics	Methodology—data collection time points	QoL outcome measures	Outcomes
	incomplete = 2107 Paraplegia complete = 1706 Paraplegia incomplete = 1181			
DeVivo and Chen <sup>32</sup> USA N = 1591 30 years	Mean age = 39.5 Mean YPI = 1.0 Injury severity = no data	Seven time points at 1, 5, 10, 15, 20, 25 and 30 YPI.	SWLS	(1) There were decreasing numbers of respondents at each follow-up. There was a low of N = 486 at 30 YPI. (2) Life satisfaction consistently increased over the 30 years of observation.
<i>Samples with mean ages 40–49 years and ≤ 5 YPI</i>				
van Koppenhagen <i>et al.</i> <sup>33</sup> Netherlands N = 222 > 1 year	Mean age (range) = 41.5 (18–65) YPI = < 0.9 Male = 165 Tetraplegia complete = 54 Paraplegia complete = 96 Other = 38	Four time points: (1) start of rehabilitation; (2) 3 months after 1; (3) discharge; (4) 1 year post discharge	Two study specific questions: (1) current life satisfaction; and (2) life satisfaction now versus before SCI.	(1) Individuals unsatisfied with their life decreased from 74.6% at time 1 to 49.3% at time 4. (2) Individuals with deterioration in life satisfaction after SCI decreased from 85.8% at time 1 to 75.3% at time 4. (3) There was a significant increase in life satisfaction total scores between times 1 and 3, and stable scores from times 3 to 4.
van Leeuwen <i>et al.</i> <sup>34</sup> Netherlands N = 206 5 years	Mean age (range) = 41.5 (26.2–56.9) Mean YPI = during rehabilitation Male = 153 Tetraplegia complete = 50 Tetraplegia incomplete = 26 Paraplegia complete = 91 Paraplegia incomplete = 39	Six time points: (1) start of rehabilitation; (2) 3 months after 1; (3) discharge; (4) 1 year post discharge; (5) 2 years post discharge; (6) 5 years post discharge	Two study specific questions: (1) current life satisfaction; and (2) life satisfaction now versus before SCI.	1. 56 subjects had consistently low, yet improving, life satisfaction. 2. 34 subjects had consistently high life satisfaction. 3. 63 subjects had intermediate scores. 4. 48 subjects improved their life satisfaction. 5. 5 subjects had deteriorating life satisfaction.

Abbreviations: LSQ, Life Situation Questionnaire; n.s., not significant; QLI, Quality of Life Index; QoL, quality of life; SCI, spinal cord injury; SWLS, Satisfaction With Life Scale; YPI, years post injury.

**QoL and aging ≤ 5 years post SCI**

Table 2 identifies the 11 studies reporting on individuals who were at 5 or less YPI. Among the four studies with samples with mean ages in the late teens and 20s, both overall QoL and various domains of QoL were shown to significantly increase with age.<sup>24,27,30,31</sup> For example, in individuals with pediatric-onset SCI, Chen *et al.*<sup>27</sup> observed significant increases in life satisfaction, as measured by the SWLS, over the course of 9 years of follow-up. The rate of change, however, was not different by socio-demographic variables, medical complications or physical and psychosocial functioning.<sup>27</sup> Further, in two studies using a single item to rate QoL, Bushnik<sup>30</sup> and Bushnik *et al.*<sup>31</sup> observed the majority of their common sample, which were comprised of persons with high-level tetraplegia, consistently rated their QoL as either good or excellent over time, and the frequency of those rating their QoL as good or excellent increased at each follow-up over 14 years.<sup>30,31</sup> Finally, in a 30-year longitudinal study, Krause *et al.*<sup>24</sup> found satisfaction with employment, social and sex lives as measured by the Life Situation Questionnaire (LSQ) to improve during the first 15 years, at which time satisfaction with social and sex lives began to deteriorate over another 15 years of observation. Satisfaction with employment similarly decreased over the second 15-year period, but the satisfaction level remained higher than that at baseline.<sup>24</sup>

For those individuals in the age of 30s, at the beginning of study observation, QoL was shown to remain stable,<sup>23,25</sup> improve,<sup>22,25,26,32</sup> or decline<sup>22</sup> in five studies. More specifically, QoL, as measured by the QLI, was shown to remain stable for 1 year among individuals 3 and 15 months post discharge from rehabilitation,<sup>23</sup> and to vary, as measured by a single QoL item and the SWLS, among individuals who were experiencing pain and interference with pain.<sup>22,25</sup> Further, life satisfaction as measured by the SWLS was shown to consistently improve at 5 YPI intervals over 30 years,<sup>32</sup> and another study using the same measure showed life satisfaction to generally improve with YPI and to improve to a greater degree for those women who were separated/divorced than for men.<sup>26</sup>

Finally, among individuals in their 40s, van Koppenhagen *et al.*<sup>33</sup> observed QoL, as assessed by a two-item study-specific measure, to improve during rehabilitation, and to remain stable from discharge to 1 year post discharge. In a follow-up study, van Leeuwen *et al.*<sup>34</sup> observed five different QoL trajectories over 5 years, with most having either consistently low or intermediate QoL trajectories, followed by individuals with either consistently high or improving trajectories. Few individuals (*n* = 5) had trajectories that diminished over the 5 years.<sup>34</sup> That is, these individuals showed high life satisfaction at the beginning of the study and declines thereafter.

**Table 3 Longitudinal QoL and aging studies: 6–15 years post injury by age (years)**

Author/Study details/ Length of observation	Sample characteristics	Methodology—data collection time points	QoL outcome measures	Outcomes
<i>Samples with mean ages ≤29 years and 6–15 YPI</i>				
Krause and Broderick <sup>35</sup> USA N = 95 25 years	Mean age = 28.8 Mean YPI = 7.2 Male = 79 Tetraplegia = 64 Paraplegia = 30	Two time points: (1) 1974; and (2) 1998.	LSQ	(1) Participants were less satisfied with their social life ( $P < 0.01$ ), sex life ( $P < 0.05$ ) and health ( $P < 0.05$ ). (2) Participants had greater satisfaction with employment ( $P < 0.01$ ).
Krause <sup>36</sup> USA N = 114 20 years	Mean age = 29.9 Mean YPI = 8.7 Male = 95 Tetraplegia = 67 Paraplegia = 47	Four time points: (1) 1974; (2) 1985; (3) 1989; (4) 1994.	LSQ	(1) Satisfaction with employment increased over 20 years ( $P < 0.05$ ). (2) Satisfaction with living arrangements improved at each time point and general health worsened (n.s.). (3) Satisfaction with finances, social and sex lives worsened overall (n.s.).
<i>Samples with mean ages 30–39 years and 6–15 YPI</i>				
Krause <sup>38</sup> USA N = 135 15 years	Mean age = 30.6 Mean YPI = 9.2 Male = 110 Tetraplegia = 91 Paraplegia = 44	Two time points: (1) 1974; (2) 1989.	LSQ	(1) Satisfaction with employment and finances increased ( $P < 0.05$ ). (2) Satisfaction with social life and general health decreased (n.s.).
Charlifue <i>et al.</i> <sup>40</sup> USA N = 315 5 years	Mean age = 37.1 Mean YPI = 9.3 Male = 253 Tetraplegia ABC = 133 Paraplegia ABC = 147 Tetra/Para D = 35	Two time points: (1) 1990–1995; (2) 1995–1998;	Single item to measure perceived QoL	(1) QoL improved over 5 years (n.s.). (2) No QoL differences were observed by neurologic, age or YPI group.
Crewe and Krause <sup>37</sup> USA N = 154 11 years	Mean age = 32.0 YPI = 10.0 Male = 124 Tetraplegia = 95 Paraplegia = 58	Two time points: (1) 1974; (2) 1985.	LSQ	(1) Satisfaction with employment increased over 11 years ( $P < 0.01$ ). (2) Satisfaction with living arrangements, finances and social life (n.s.). (3) Satisfaction with sex life remained the same, and satisfaction with general health worsened (n.s.).
Krause <sup>39</sup> USA N = 235 9 years	Mean age = 35.7 Mean YPI = 12.6 Male = 195 Tetraplegia = 143 Paraplegia = 92	Two time points: (1) 1985; and (2) 1994.	LSQ	(1) Satisfaction related to: social and sex lives, family relationships, emotional adjustment and control over life significantly declined. (2) Problems related to: pain, control, making friends, depression, family and attitudes toward disabled people significantly increased.
<i>Samples with mean ages 40–49 years and 6–15 YPI</i>				
Krause <i>et al.</i> <sup>41</sup> USA N = 250 6 years	Mean age = 42.5 YPI = 14.0 Male = 142 Tetraplegia = 133 Paraplegia = 117	Two time points 6 years apart.	LSQ-R	(1) Differences in the satisfaction domain did not systematically or significantly increase or diminish over time.

Abbreviations: LSQ, Life Situation Questionnaire; LSQ-R, Life Situation Questionnaire-Revised; n.s., not significant; QoL, quality of life; SCI, spinal cord injury; YPI, years post injury.

### QoL and aging 6–15 years post SCI

The seven studies reporting on samples with mean YPI ranging between 6 and 15 years are shown in Table 3. Those individuals in their 20s at baseline showed improved satisfaction with employment after 25 years, in addition to lowered satisfaction with social and sex lives, and general health as assessed by the LSQ.<sup>35</sup> Satisfaction with living arrangements and finances remained unchanged.<sup>35</sup> In a 20-year study with three follow-up time points, Krause<sup>36</sup> similarly found satisfaction with employment to improve, whereas satisfaction

in the other five areas assessed by the LSQ (that is, living arrangements, finances, social life, sex life, general health) remained unchanged.

Four studies reported on samples with a mean age in the 30s. In the two studies that used the LSQ, satisfaction with employment was shown to improve after both 11<sup>37</sup> and 15<sup>38</sup> years. Satisfaction with finances was also shown to improve after 15 years.<sup>38</sup> One study used an expanded version of the LSQ which included five new life satisfaction items (that is, family relationships, recreational

**Table 4 Longitudinal QoL and aging studies:  $\geq 16$  years post injury by age (years)**

Author/Study details/Length of observation	Sample characteristics	Methodology—data collection time points	QoL outcome measures	Outcomes
<i>Samples with mean ages 40–49 years and <math>\geq 16</math> YPI</i>				
Savic <i>et al.</i> <sup>29</sup>	Mean age = 48.0	Six time points: (1) 1990; (2) 1993; (3) 1996; (4) 1999; (5) 2002; and (6) 2006	Single item to measure perceived QoL LSI	(1) 76% consistently rated good or excellent QoL over 16 years. (2) Differences in life satisfaction was observed over the 16-year period ( $P=0.0057$ ). (3) Life satisfaction was highest in the 2006 follow-up.
Britain	Mean YPI = 26.8			
N = 122	Male = 103			
16 years	Tetraplegia ABC = 44 Paraplegia ABC = 55 Tetra/Para D = 23			
<i>Samples with mean ages <math>\geq 50</math> years and <math>\geq 16</math> YPI</i>				
Charlifue and Gerhart <sup>42</sup>	Mean age (range) = 50.4 (44–74)	Four time points: (1) 1990; (2) 1993; (3) 1996; and (4) 1999.	Single item to measure perceived QoL LSI	(1) 78% consistently rated good or excellent QoL over 9 years. (2) LSI scores differed significantly over time by age and YPI, but there were no clear trends.
Britain	Mean YPI (range) = 25.0 (20–46)			
N = 189	Male = 162			
9 years	Tetraplegia ABC = 61 Paraplegia ABC = 91 Tetra/Para D = 37			
Charlifue <i>et al.</i> <sup>28</sup>	Mean age = 51.9	Two time points: (1) 1990; and (2) 1993.	Single item to measure perceived QoL LSI	(1) 76% consistently rated good or excellent QoL over 3 years. (2) There were no QoL differences for injury severity, age, or YPI. (3) LSI scores significantly decreased over time for older individuals, YPI (i.e. $<30$ years and $>40$ years), and those with complete paraplegia.
Britain	Mean YPI = 26.6			
N = 227	Male = 196			
3 years	Tetraplegia ABC = 67 Paraplegia ABC = 112 Tetra/Para D = 48			

Abbreviations: LSI, Life Satisfaction Index; n.s., not significant; QoL, quality of life; SCI, spinal cord injury; YPI, years post injury.

opportunities, life opportunities, emotional adjustment, control over life) in addition to the original six items.<sup>39</sup> Findings revealed that satisfaction with social and sex life, family relationships, recreational and life opportunities, emotional adjustment and control over life all diminished after 9 years. In the one study that assessed global QoL with one item, Charlifue *et al.*<sup>40</sup> found most individuals to report good or excellent QoL at both baseline and the 5-year follow-up. During this time, however, QoL remained stable as the frequency of individuals reporting good or excellent QoL neither significantly improved nor diminished.

Finally, among individuals in their 40s, Krause *et al.*<sup>41</sup> found differences in QoL as assessed by LSQ-R (a revised version of the LSQ) at baseline between various ethnic groups in the United States, with higher QoL found among Caucasians. At a 6-year follow-up, the differences were still observed, and there were no significant changes in QoL, indicating that QoL levels remain stable over time.

#### QoL and aging $\geq 16$ years post SCI

Three studies reported on individuals with at least 16 YPI and are detailed in Table 4. The mean ages of each of the samples in the three studies were either in the 40s or 50s. All studies reported on the same British cohort at two, four and six time points over 3, 6 and 16 years.<sup>28,29,42</sup> A single item was used to measure QoL, and life satisfaction was assessed with the Life Satisfaction Index. In all three studies, at least 76% of the respondents consistently reported good or excellent QoL at all time points. Life satisfaction was variable over the years, however, after 16 years, the reported life satisfaction was higher than at earlier follow-ups.<sup>29</sup>

#### QoL trends by domain

Six studies used the LSQ, which include questions pertaining to satisfaction in six different areas of life.<sup>24,35–39</sup> These studies used the data from the same cohort, however, analyses were done on different lengths of follow-up. Table 5 details the reported changes over time and identifies any significant changes and/or trends. The changes are also noted by age and YPI in the results above.

#### DISCUSSION

This paper sought to systematically review the current literature reporting on age-related changes (that is, chronologic age, YPI and age of SCI onset) in subjective QoL among individuals with a SCI. One consistent finding from the studies included for review is that regardless of chronologic age, individuals with relatively new SCI (that is,  $\leq 5$  YPI) have the potential to improve their overall QoL and/or various QoL domains.<sup>22,24–27,30–34</sup> Age of SCI onset therefore does not appear to preclude high QoL, however, within the various age categories there are likely differing age-related factors that may potentially influence QoL. For example, in studies with samples with mean ages  $\leq 29$  years, individuals were found to have greater improvements in life satisfaction and QoL if they were students, lived independently, had a lower level injury, had overcome past medical problems and if they had accessible vans for transportation. Among individuals in their 30s, both Putzke *et al.*<sup>22</sup> and Stensman<sup>25</sup> found QoL to be influenced by amount of pain and interference with pain, and Kalpakjian *et al.*<sup>26</sup> found the relationship between life satisfaction and YPI to be moderated by marital status and sex.

**Table 5 QoL trends by domain**

Satisfaction with:	Change over time	Author	1973–1974	1985	1988–1989	1994	1998	2002
Living arrangements	Stable	Crewe and Krause <sup>37a</sup>	3.23	3.36				
		Krause <sup>38a</sup>	3.30		3.30			
		Krause <sup>39</sup>		4.34		4.33		
		Krause <sup>36</sup>	4.27	4.49	4.38	4.45		
		Krause and Broderick <sup>35</sup>	4.30				4.52	
		Krause and Coker <sup>24</sup>	4.36		4.44			4.18
Employment	Increasing trend	Crewe and Krause <sup>37a,b</sup>	2.18	2.63				
		Krause <sup>38a,b</sup>	2.10		2.50			
		Krause <sup>39</sup>		3.49		3.56		
		Krause <sup>36b</sup>	3.09	3.65	3.45	3.54		
		Krause and Broderick <sup>35b</sup>	3.09				3.65	
		Krause and Coker <sup>24b</sup>	3.10		3.61			3.37
Finances	Stable/increasing trend	Crewe and Krause <sup>37a</sup>	2.13	2.34				
		Krause <sup>38a,b</sup>	2.20		2.50			
		Krause <sup>39</sup>		3.26		3.32		
		Krause <sup>36</sup>	2.83	2.63	2.50	2.57		
		Krause and Broderick <sup>35</sup>	3.19				3.43	
		Krause and Coker <sup>24</sup>	3.30		3.60			3.32
Social life	Decreasing trend	Crewe and Krause <sup>37a</sup>	2.94	2.95				
		Krause <sup>38a</sup>	3.00		2.90			
		Krause <sup>39b</sup>		3.97		3.78		
		Krause <sup>36</sup>	3.97	4.02	3.89	3.80		
		Krause and Broderick <sup>35b</sup>	3.93				3.59	
		Krause and Coker <sup>24b</sup>	3.97		4.11			3.61
Sex life	Decreasing trend	Crewe and Krause <sup>37a</sup>	2.28	2.28				
		Krause <sup>38a</sup>	2.20		2.20			
		Krause <sup>39b</sup>		3.20		2.99		
		Krause <sup>36</sup>	3.21	3.32	3.18	2.95		
		Krause and Broderick <sup>35b</sup>	3.16				2.77	
		Krause and Coker <sup>24b</sup>	3.24		3.32			2.54
General health	Stable/Decreasing trend	Crewe and Krause <sup>37a</sup>	2.80	2.74				
		Krause <sup>38a</sup>	2.80		2.70			
		Krause <sup>39</sup>		3.87		3.73		
		Krause <sup>36</sup>	3.89	3.89	3.79	3.81		
		Krause and Broderick <sup>35b</sup>	3.87				3.57	
		Krause and Coker <sup>24</sup>	3.96		3.91			3.64

Abbreviations: increasing or decreasing trend, more than one paper with significant increases or decreases; stable, no significant change over time identified in any paper; stable/decreasing or increasing trend, only one paper with significant increases or decreases, and the rest with no significant changes.

<sup>a</sup>LSA items were originally scored with 1 = very satisfied and 5 = very dissatisfied. For this table, scores have been converted to higher scores indicating greater satisfaction for comparison purposes with the other studies that used a response scale with 1 = very dissatisfied and 5 = very satisfied.

<sup>b</sup>Significant change.

The concept of response shift is a more general explanation for the reason individuals have been shown to improve their QoL after life-altering diseases and disabilities.<sup>43</sup> Sprangers and Schwartz<sup>43</sup> argue that to accommodate changes in health and/or physical functioning, individuals inherently undergo simultaneous changes in their internal standards (that is, scale recalibration, a change in the meaning of one's self evaluation), values and conceptualizations of life quality. That is, once individuals adapt to life with a SCI, their QoL has the potential to improve over time. In the one study that observed no changes in QoL among individuals with  $\leq 5$  YPI, Mortenson *et al.*<sup>23</sup> argued that the individuals may have already experienced a response shift, and thus readjusted the criteria they used to evaluate their QoL before baseline assessment. Conversely, individuals with low and

intermediate QoL trajectories as observed by van Leeuwen *et al.*<sup>34</sup> may have yet to experience a response shift, as the life satisfaction scores were generally consistent over time, but did show slight improvements.

Another common finding of this review is that among individuals with YPI between 6 and 15 years, and  $\geq 16$  years at the beginning of observations, overall QoL is consistently reported as good or excellent over time.<sup>28,29,40,42</sup> This is ironic because despite much evidence suggesting that individuals with SCI face an array of stressors, such as significant physical and functional impairments, high incidence of depression and anxiety<sup>44</sup> and a greater likelihood of divorce than the general population,<sup>5</sup> their QoL has the potential to remain high and stable over time. Such a phenomenon is similarly seen among individuals in the general population who are transitioning from

middle to older age.<sup>45,46</sup> Qualitative evidence indicates that after an adjustment period, individuals with SCI feel as though that they live a normal life, do not look at themselves any different than before, and have similar circumstances to everyone else.<sup>19</sup> As such, it is not surprising that many individuals aging with a SCI have similar subjective QoL experiences to those without a SCI.

In the aging literature, the high QoL despite loss phenomenon is accounted for by the Life Span Development theory.<sup>47</sup> This theory postulates that human development occurs throughout the life course and is observed by way of individuals continuously adapting to changing external demands.<sup>47</sup> Central to this theory are the notions of successful aging, and the timing of events. Successful aging is said to occur when individuals compensate for physical or functional losses by engaging in and focusing on fewer yet more desired activities in attempts to enrich life. Although the SCI literature reports that QoL remains high and stable over time, findings have also shown variation in several QoL domains, such as increasing satisfaction with employment<sup>35–38</sup> and diminishing satisfaction with social and sex lives.<sup>35,39</sup> It is therefore plausible that increasing satisfaction with employment may compensate for decreasing satisfaction with social and sex lives, as per the Life Span Development theory. Such changes in QoL domains, however, are likely not specific to individuals with SCI. As people increase their years worked, they are more likely to experience promotions, increased wages and more vacation time, which may contribute to increased satisfaction with their employment. Similarly, when considering sex life, in the general population, aging has been associated with a decreasing desire for and frequency of sex,<sup>48</sup> which also negatively influences satisfaction with sex life.<sup>49</sup>

Furthermore, the notion of timing of events in the Life Span Development theory refers to the actual occurrence of an event relative to its expected occurrence.<sup>46</sup> Events occurring as expected are 'on-time', and are less problematic than 'off-time' events that occur when they are not expected.<sup>47</sup> This is corroborated by a large study on aging<sup>46</sup> that found any aspect of disability that could not be explained by a person's age to have greater negative effects on subjective well-being than those aspects that are expected with aging. Thus, if physical and functional limitations occur on-time, because they are perceived as being normal, individuals are able to accept the limitations and thereby continue to age successfully. Although the effects of events occurring off-time with expectation (for example, a traumatic SCI) are not well studied in the aging literature,<sup>50</sup> such effects are explained in the disability literature by Sprangers and Schwartz<sup>43</sup> response shift, as discussed above.

Overall, when considering the Life Span Development theory in combination with response shift, it is plausible that individuals with SCI are able to separate their compromised physical functioning from positive psychological well-being due to a response shift, and as these individuals age, if other health conditions arise and negative social changes occur but are as expected, compensatory actions may lead individuals to engage in fewer yet more life-enriching activities.

Despite this being a rigorous review to identify age-related subjective QoL changes among individuals with SCI, there are several limitations that should be noted. First, studies were organized by YPI and then chronologic age. This assumes YPI to be a more deterministic factor in QoL than chronologic age. Both YPI and chronologic age however, are considered in the analyses. Next, the issues associated with measuring QoL are perhaps the largest limitation of this review. Because there remains a general lack of consensus of what constitutes the quality of someone's life,<sup>8</sup> and how it should be measured, it is not surprising that many studies included for review used a variety of methodological approaches and measurement tools in their

examination of QoL. Of the eight QoL measures used in the reviewed studies, only two have had independent evaluation of their psychometric properties among individuals with SCI, and none of the measures have had their sensitivity or responsiveness over time evaluated. The latter finding is of specific concern when examining the influence of aging on QoL because of the fact that people perceive their life quality differently at different points in their lives.<sup>43,47</sup> Issues of response shift therefore should be considered when assessing QoL in persons with SCI, and several recommendations are put forth by Schwartz *et al.*<sup>51</sup> on how to address them. Because none of the studies accounted for changes in internal standards and personal values as a result of aging, caution must be exercised when interpreting the results. Another limitation is that the studies included for review may have been affected by the survivor effect. That is, the studies may not have captured the responses from persons with very low QoL, and those who died or were otherwise lost to follow-up due to poor QoL. Further, the fact that studies were only included if they were written and published in English is another limitation, as is the fact that several of the studies reported data from the same cohort, however, at different lengths of follow-up. As a result, included studies were only from Canada, United States, Britain, Sweden, and the Netherlands; populations that likely share similar perceptions of QoL. The results therefore cannot be generalized to individuals with SCI in countries that likely have different QoL perspectives. Finally, the studies found for review provide low levels of evidence. Nonetheless, this is the best evidence to date.

## CONCLUSION

The findings from this review have indicated that regardless of chronologic age, individuals with relatively new SCI have the potential to improve their overall QoL and/or various QoL domains. Furthermore, among individuals with YPI between 6 and 15 years, and  $\geq 16$  years at the beginning of observations, overall QoL is consistently reported as good or excellent over time, however, with variation in different QoL domains.

Finally, the levels of evidence being used to draw the conclusions are relatively low. Therefore, more research with greater methodological rigor is needed to corroborate the findings and conclusions of this review. Longitudinal studies with able-bodied comparison groups would provide the best evidence (that is, level 2) to validate the findings in this study, as would the longitudinal evaluation of QoL that include methods to account for changes in internal standards and conceptualizations of QoL.

## DATA ARCHIVING

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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