1. Introduction and rationale
Quality of life (QoL) is important for all people. This is because our QoL affects our health and wellbeing. It is vital for us to live a fulfilling and enriching existence. Spinal cord injured people are no exception in this case. They are living longer and achieving greater functional independence. With greater life expectancies, the focus of rehabilitation and intervention for people with spinal cord injury (SCI) has shifted from medical management of the acute condition to issues that affect QoL and community participation. But, what do we know about the QoL among spinal injured people?

Aims and objectives
The primary aim of this scoping study is to generate knowledge on QoL among spinal injured people. Specifically, the objectives of the study were to:
• Explore what is QoL;
• Describe how spinal injured people’s QoL is understood by researchers;
• Identify what impacts on the QoL of people with SCI;
• Identify implications for policy;
• Identify future research directions to inform policy and best practice.

2. Methodology
A scoping method was used to meet the aims and objectives. This method is a way of systematically reviewing the literature. It aims to map the key concepts underpinning a research area (e.g. QoL) and the main sources and types of evidence available.

The rationale for using a scoping method is grounded in the following. Most kinds of methods for reviewing literature funnel down on a narrow research question. These methods only examine research data that has been collected using certain techniques (e.g. quantitative questionnaires or qualitative interviews). Many reviews also do not go beyond the research findings nor seek to identify research gaps in the existing literature or problems with the research.
Scoping studies, however, include and disseminate findings from a range of different methods. They critically address broader topics where many different study designs might be applicable. Other reasons for using a scoping study are described by Arksey and O’Malley (2005):

A key strength of the scoping study is that it can provide a rigorous and transparent method for mapping areas of research...This analysis in turn makes it possible to identify the gaps in the evidence base, as well as summarising and disseminating research findings. By presenting the results in an accessible and summarised format, policy makers, practitioners and consumers are better placed to make effective use of the findings. (p. 30)

There are five stages that constitute a scoping study. These are outlined in Table 1.

<table>
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<th>Table 1: Stages of scoping</th>
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<td>Stage 1: Identifying the research question.</td>
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Specifically:

**Stage 1: Identify the research question.**

The research question here is: ‘What is known from the existing literature about spinal injured people's QoL?’

**Stage 2: Identifying relevant studies.**
To identify studies on QoL, different sources were searched: electronic databases, reference lists, key journals in university libraries, and using existing networks, relevant organisations and conferences. The search strategy for electronic databases used the following procedure to ensure consistency and rigour. An electronic search of the CINAHL, AMED, EMBASE, MEDLINE, and GOOGLE SCHOLAR databases using key words related to the project (i.e. spinal cord injury and quality of life).

**Stage 3: Study selection.**
What was deemed irrelevant and relevant was guided by the following exclusion and inclusion criteria.

- The research does not focus explicitly on spinal injury people themselves and QoL.
- The research was not published in a peer reviewed journal.
- The research was published in 2002 or thereafter. However, significant papers published before this were included.
- There is clear evidence that the results were grounded in well gathered data.

**Stage 4: Charting the data.**
‘Charting’ describes the technique for synthesising and interpreting data by sifting,
charting and sorting material according to key issues and themes.

Stage 5: Collating, summarising and reporting the results. Here data was described as well as analytically interpreted.

3. Results

Reviewing over 200 papers, the scoping study produced the following results.

What is QoL?

There are numerous descriptions of QoL in the literature. Because it means different things to different researchers, no single or universal definition of QoL on which everyone agrees exists. Although researchers and others cannot all agree on a common definition of QoL, the review of empirical papers and theoretical position pieces suggested that there is a major approach to understanding emerging. This is known as subjective QoL. It is also the approach recently advocated in a paper by the International Spinal Cord Society (International SCI QoL Basic Data Set; Charlifue et al., 2012).

Subjective quality of life is defined as the fit between a person’s aspirations / expectations (e.g. wishes, goals, values, desires, standards of comparison) and their achievements / accomplishments (e.g. possessions, statuses, roles,) as perceived by the person. Subjective QoL is thought to consist of a cognitive and an affective part. The cognitive part is the evaluation of one’s life, mostly measured as the satisfaction with one’s life as a whole or with certain domains (e.g. family life, personal development, employment). The affective part consists of both positive (e.g. joy, positive mood) and negative emotions (e.g. depressive feelings, anxiety). Depending on the congruence or gap between expectations and achievements, the cognitive and/or emotional reaction is one of satisfaction (dissatisfaction) or happiness (sadness). Following this approach, subjective QoL can be described as:

QoL is a reflection of "an individual's overall perception of and satisfaction with how things are in their life" (Wood-Dauphinee et al. 2002).

How is QoL understood?

Three methodological approaches exist for understanding QoL. The first is a quantitative methods approach. Here, people self-rate their QoL on a predetermined instrument. There are numerous self-report QoL instruments. Each is different. Each one asks people to self-rate their QoL in relation to a set of questions designed by the
researcher(s) that reflect one or more conceptual domains (e.g. family life, personal development, physical health, psychological health).

A quantitative approach has numerous strengths. It provides researchers and clinicians with a quick and easily administered way to understand a spinal cord injured person’s QoL. The problems with it are that:

• The researcher imposes what they see as QoL rather than letting the spinal injured person articulate what they themselves – as the experts – see as important for QoL. We might therefore end up with a rather limited picture of QoL. We do not know what is meaningful for a high QoL for spinal injured people themselves.

• There are over ten measures that have been used to assess spinal injured people’s QoL. All claim to be a reliable, valid, and responsive measure of QoL. Yet, each one measures different domains of QoL. Some measure one conceptual domain (e.g. psychological health) others four, five, six, seven, or eight domains. For example, the Life Satisfaction Questionnaire contains one question about global life satisfaction (life as a whole) and eight questions about domain-specific life satisfaction: self-care ability, leisure situation, vocational situation, financial situation, sexual life, partnership relation, family life, contacts with friends and acquaintances. In contrast, the SCI QL-23 questionnaire has four domains: functioning (ten items assessing physical and social limitations), mood (six items concerning distress and depressive feelings), SCI-related problems (six items regarding difficulty with loss of independence and other issues relating to injury, such as bladder and bowel function), and global Health Related QoL (assessed using a visual analogue scale). The many different measures mean that not only is the QoL field ‘difficult to navigate’, but how we can best promote QoL is empirically difficult to judge. The empirical evidence generated will often produce contradictory results, thereby making it difficult for health professionals or disability organisations to have faith in applying ideas to practice.

To address the many different ways QoL can be measured while reducing measurement error and maintaining consistency in these evaluations, the International SCI QoL Basic Data Set was recently developed by the International Spinal Cord Injury Society. The
QoL data set consists of 3 variables that spinal injured people rate their QoL on: 1) ratings of satisfaction with general quality of life, 2) satisfaction with physical health, and 3) satisfaction with psychological health. All variables are rated on a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied) (see Appendix).

The data set and variables is not without problems. The labels are conceptually inaccurate. What is termed psychological health here is in fact measuring what is called subjective wellbeing. That is, in the psychology literature subjective wellbeing refers to affective states coupled with life satisfaction, whereas psychological wellbeing refers to existential engagement with life, purpose, autonomy, and mastery. That said, the simplicity of the scales hold much value. The aspiration to gather a body of evidence using one measurement tool is another strong point.

The second way to understand QoL is through qualitative methods. Much of the literature uses quantitative methods, but there has been a growing appreciation and uptake of qualitative methods (e.g. interviews). A strength of qualitative methods is that, unlike quantitative methods, what can be known is driven by spinal cord injured persons themselves – they are the experts on QoL. It identifies what is meaningful for a high or low QoL for spinal injured people themselves.

Qualitative methods also provide rich descriptions of QoL that are generalisable. They are generalisable in naturalistic ways (i.e. ways that resonate with other spinal injured people).

Like all methods however there are weaknesses with qualitative methodologies:

- It is a time consuming method for collecting and analysing data.
- Researchers need to be highly trained in qualitative methodology.
- The dominant way to collect data is just through interviews. This is limited. Researchers also need to harness the power of new, innovative methods. Many of these methods are ideally suited for gathering longitudinal and detailed information of QoL.

The third way to understand QoL is through mixed-methods research. Here, qualitative and quantitative methods are combined. One benefit of mixed-methods research is that researchers can harness together all of the strengths noted above of quantitative and qualitative methods. But, there are problems with mixing methods.
• There is little evidence of QoL mixed methods researchers genuinely integrating their findings, or paying sufficient attention to the writing up of qualitative research findings in nuanced ways.

• Mixed methods research is highly contested. There is a lack of engagement in the QoL literature with key questions, including: When or where in the design of a study is the mixing carried out (i.e., when is the mixing stage)? How should mixed methods be used in QoL research – sequentially (i.e. each conventional method implementation represents a separate study)?; in a nested fashion (i.e. one method is dominant, and the other used infrequently)?; or in a fully integrated design (i.e. both methods are employed concurrently to explore questions and hypotheses throughout the phases of a study)? Finally, how does one assess the quality (e.g., credibility, trustworthiness, validity) of mixed methods research?

What impacts on QoL?
The review found several key factors or domains that impact on spinal injured persons QoL. In what follows we present each general domain and offer more specific examples under it for ease of reference. It should be noted that in practice each domain might overlap. They can also affect each other. For example, when people exercise in an active rehabilitation programme they may increase their bodily control as well as develop different types of relationships that offer social support. They might also build confidence, which can be important for returning to employment.

The Environment
The environment surrounding a person enables or limits QoL. This includes:

• The physical/structural environment. Inaccessible environments limit QoL.

• Housing. A person needs appropriate housing to have QoL.

• The social environment. Society needs to be structured in a way that supports people with SCI. This means providing equal opportunities.

• The political/economic environment. People may need monetary benefits from the government to support their needs as well as have good healthcare available.

Relationships
Building meaningful relationships with others is fundamental for QoL whether it is with family, friends, and/or a partner. They are important for:
• Providing different types of social support. These include emotional, informational, and esteem support.

• A sense of belonging.

• Sexual desire.

• Feeling socially meaningful and being able to help others.

Control
A balance is needed between gaining control and recognising that *total* control over the physical body and social environment is often impossible. Control:

• Helps people to plan day to day life and prepare for different scenarios.

• Enables greater independence and confidence.

• Facilitates feelings that one can make a personal decision on one’s own and/or can take responsibility for these decisions.

• Helps in managing inaccessible and oppressive physical environments.

• Helps plan a social life and place it into one’s daily routine.

• Provides people with a sense that they can meaningful use their time.

It is important to re-emphasise that not everything can be controlled. The unexpected may happen. We also as human beings cannot control everything. This needs embracing as part of being human and for enhancing QoL.

Physical/Impaired body
Regaining partial function can lead to greater independence thereby improving QoL. Specifically:

• Functioning of the body, such as bowel, bladder, arms, and hands, can impact on QoL.

• Sexual function can influence on QoL.

• Body image issues can enhance or worsen QoL.

• QoL can be impacted on by pain (e.g. neuropathic or shoulder), fatigue, pressure sores, urinary tract infections, respiratory problems, and spasticity.

• The bed rest that arises from the above.

• The time taken to daily manage the impaired body can impact on QoL.

Occupation/Finance
A person’s occupation as well as financial security is important in terms of promoting or hindering QoL. In particular:

• Following SCI, it can be important to have an occupation as quickly as possible. An occupation, whether it is a job, or a volunteer role in society, provides a person with a sense of responsibility, purpose and meaning.
• Having a secure financial income is important to being able to afford everything needed to live healthily and maintain well-being.

• People who return to work quickly tend to return to the same job that they did before they were injured. Thus people may need guidance if they cannot return to this job or were not previously employed. Availability of retraining courses is therefore imperative.

It must be remembered that finding an occupation following injury takes time so financial assistance is important following injury to help with QoL.

**Identity**

Identities are valuable for how we see ourselves and how we wish to be portrayed to others. QoL can be affected in different ways:

• For some, a lack of continuity with the self that one had before injury can impact negatively on QoL.

• For others, SCI is an opportunity to leave behind certain identities and develop a new self. Over time this new self has a positive effect on QoL.

**Mental Factors**

The way in which a person feels and thinks about things is very important to both their physical and mental health. Specifically, QoL can be influenced by:

• Having a positive attitude towards life.

• Acceptance of SCI.

• Not blaming oneself or others for the occurrence of SCI.

• Developing coping strategies.

• Feeling a sense of confidence and value in oneself and ones activities.

• Not ruminating on any sense of loss.

• Resilience.

• Feeling that one has gown as a person.

It is important to remember that these all can be learned.

**Growth**

Following SCI people can develop in positive ways that impact on QoL. Growth can include:

• Having a meaningful life. This may consist of finding a purpose, developing new priorities or values, and creating an increased focus on things that are personally important. People can find that they are less superficial and able to think more deeply following SCI.

• An increased appreciation and a new chance of life. People may begin to see what they can do and focus on their capabilities. This may also include a greater appreciation of simplicity and
existential and aesthetic qualities of life.

- New opportunities and friendships.
- A positive change to who one is. This can consist of people feeling they are more humble, understanding of others, and patient following SCI.
- Developing a political view. People can challenge oppressive practices and pre-existing stereotypes of disability along with creating new meanings of normality. This can positively affect QoL.

**Sport and Physical Activity**
Regularly taking part in sport or being physically active can positively impact on QoL. Although there is a lack of good studies, some possible reasons for this are:

- People who exercise generally report significantly less pain, stress and depression after exercise and score higher on satisfaction with physical function, level of perceived health and overall QoL.
- Active rehabilitation results in significant gain in both physical and psychological wellbeing, including self-esteem, confidence, body image, and happiness.
- Exercise is important to functional recovery. However more facilities / programmes are required as often many people have no access to exercise facilities.

It is also important to note that leisure and recreational pursuits can enhance QoL.

**Narrative**
The kinds of stories people tell and have access to impact on QoL. This is because stories take care of people. For example:

- Some people tell stories that essentially go like this: ‘Yesterday I was able-bodied, today I’m disabled, but at some point in the future I will walk again’. Short term this can keep depression at bay. However, a strong hold on this story can negatively affect QoL in the long term.
- Some people tell stories in which they say: ‘Life is normal, just like before SCI’. These stories can impact positively on QoL. But, they can have a negative side. People can tell these stories to help others (e.g. family) deal with SCI. This can result in the spinal injured person bottling up emotions and hiding fears about their future. All this can significantly impact on their QoL over time.

**Individual Variables**
There are many personal factors that complicate all the information above. The literature also produces many uncertain results regarding how the nature of SCI impacts on QoL. These include:
• Some studies show that level of injury impacts on QoL; others show there is no influence on QoL.
• Current age, as well as age at the time of injury, can for some impact on QoL; however some studies show it might not.
• Some studies suggest that how much time has passed since injury is important; others say it is not important.
• Individuals have good days and bad days.

4. Implications for policy
• Individuals with SCI require information on what can sustain and improve their QoL.
• Rehabilitation and community practices need to continue with or develop programmes that can enhance QoL through attending to domains like relationships, growth, physical activity, and identity. For example, resilience and active rehabilitation need to be better promoted.
• Support, resources, and opportunities need to be in place for spinal injured people to be able to act on the information offered. For example, to enhance and sustain QoL, appropriate housing is required. People might be motivated to exercise. But, they need more accessible and safe active rehabilitation programmes in the community to access. More also is needed to be done in terms of making environments accessible and employment achievable in light of discrimination.
• Stories that care for people need to be encouraged. Like exercise or peer support, this is a very cost effective strategy. For example, spinal injured people, family, and health professionals need to reflect on what types of stories they tell as the story they told impacts positively or negatively on QoL.
• Policy strategies should educate the families of spinal injured people about their role in promoting QoL.

5. Future directions
Despite identifying various domains or factors that impact on QoL, as noted earlier, there is a lack of systematic work on SCI and QoL. The field on this topic is a mess; multiple definitions exist, competing measures are used, conceptual confusion over psychological wellbeing is widespread, and, for example, studies rarely ask about a person’s QoL before SCI. We should then be very cautious about what we know and what we can apply in practice. This includes the suggestions noted in section 4 above. Thus:
• Systematic research is needed that examines what best promotes the QoL of
spinal injured people living in the community. This research needs to examine QoL over time. It should take into account how people perceived their QoL before SCI. It should look at a hierarchy of QoL needs. It should use both innovative qualitative methods and quantitative methods. Innovative qualitative methods include timelining and ‘what if narration’. Quantitatively, the collection of the *International SCI QoL Basic Data Set* (see Appendix) variables should be a part of future studies on QoL to facilitate comparison of results across published studies. Additional standardised quantitative instruments to assess other aspects of QoL can be administered based on the purpose of a certain study.

- Systematic research is needed that identifies who the preferred *messengers* are (e.g. peer support or family) and what are the most effective methods (e.g. manuals, DVDs, education programs, and/or case study stories on websites) for conveying information on to how to enhance ones QoL.
- Research should take advantage of the Paralympics, legacy commitments, and the £8 million Sport England ‘inclusive sport’ funding initiative to examine the impact of physical activity on QoL and how best to promote being active (e.g. active rehabilitation and the ‘blue gym’).
- Research is needed that examines how spinal injury impacts on the QoL of family members.
- Research that is underpinned by theory is needed. QoL research tends to be non-theoretical.

**References**


**Acknowledgments**

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Appendix

INTERNATIONAL SPINAL CORD INJURY DATA SETS QUALITY OF LIFE BASIC DATA SET – DATA FORM (Version 1.0)

Date performed: (YYYYMMDD) / / Unknown

1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.

Completely dissatisfied Completely satisfied

[ ] 0 [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8 [ ] 9 [ ] 10

2. How satisfied are you with your physical health in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.

Completely dissatisfied Completely satisfied

[ ] 0 [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8 [ ] 9 [ ] 10

3. How satisfied are you with your psychological health, emotions and mood in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.

Completely dissatisfied Completely satisfied

[ ] 0 [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8 [ ] 9 [ ] 10

Source: Charlifue et al. (2012)