

## Review

# Quality of life after spinal cord injury: a meta-synthesis of qualitative findings

K Whalley Hammell<sup>1,\*</sup>

<sup>1</sup>Oxbow, Saskatchewan, Canada

**Study design:** Meta-synthesis of qualitative research.

**Objectives:** To identify, compare and synthesize the factors found to contribute to, or detract from the experience of a life worth living following spinal cord injury (SCI).

**Methods:** Published articles were identified from the Medline, CINAHL and Sociological Abstracts databases, a hand search through selected journals published since 1990, and from reference lists. These were assessed for their relevance to the focus of interest and appraised for rigour and quality. The key themes that emerged from the data were summarized, compared and synthesized.

**Results:** The search located 64 papers and four books, of which seven papers met the review criteria for relevance and rigour, and in which 10 main concepts were identified: (1) body problems, (2) loss, (3) relationships, (4) responsibility for, and control of one's life, (5) occupation, and ability to contribute, (6) environmental context, (7) new values/perspective transformation, (8) good and bad days, (9) self-worth, (10) self-continuity.

**Conclusions:** This study demonstrates the utility of synthesizing qualitative research to provide a greater depth of insight into the factors that contribute to, and detract from, quality of life (QOL) after SCI. It also provides a more nuanced understanding of the experience of QOL following SCI than is achievable by quantitative methods. Future qualitative research is required to probe further the concepts and connections identified in this study, and to identify how rehabilitation services might best address these issues.

**Sponsorship:** N/A.

*Spinal Cord* (2007) 45, 124–139. doi:10.1038/sj.sc.3101992; published online 7 November 2006

**Keywords:** spinal cord injury; quality of life; rehabilitation outcomes; qualitative research; meta-synthesis

## Introduction

Quality of life (QOL) is both the ultimate goal of rehabilitation following spinal cord injury (SCI) and a key outcome to be used in determining the effectiveness of rehabilitation programmes.<sup>1–3</sup> However, while the need to understand more about the perceptions and determinants of life's quality held by people with SCI is undisputed, there have been difficulties in studying a concept that lacks a clear definition and that is perceived differently by different people, in differing circumstances and at different times of their lives.<sup>3,4</sup>

The vast majority of research into QOL following SCI has adopted a quantitative approach,<sup>3</sup> reflecting researchers' assumptions that quality can be measured quantitatively; that the determinants of QOL following SCI can be reliably predicted by able-bodied research-

ers; and that the subjective experience of a life can be objectively and accurately discerned by another person. These assumptions have been challenged<sup>5–10</sup> and it has been argued that the results of these studies are both misleading and of questionable value.<sup>11</sup> Indeed, it has been suggested that how someone attempts to 'measure' QOL says more about their own values, priorities and fundamental orientation to life than it does about the QOL of the people whose lives are ostensibly being studied.<sup>3,12</sup>

Quantitative research is hypothesis-driven, requiring researchers to predetermine the variables to be measured and thus to identify in advance those factors that are relevant and important to the issue under investigation. This inevitably limits the range of possible findings. For example, if 'pain' is not included as a variable in a quantitative study of QOL then pain will not be found to influence QOL. Quantitative methods are therefore

\*Correspondence: KW Hammell, Box 515, Oxbow, Saskatchewan, Canada S0C 2B0; published online 7 November 2006

best suited to studying relationships between variables that are already well known. However, research, by definition, is a process of discovery – of exploring what is not known – and indeed, it has been argued that intellectuals should be challenging (not reinforcing) the paradigms inherent in their field, raising questions and unmasking and contesting conventional and accepted ideas.<sup>13</sup> This would seem to support an exploratory, rather than a hypothesis-driven, approach to researching an issue that is as complex as QOL,<sup>3,4</sup> especially when seeking to understand the QOL perceived by those whose lives may differ from the researchers', by virtue of such factors as gender, class, 'race', sexual orientation, age, religion, (dis)ability, citizenship status, education, professional status, economic status, role expectations, interests, priorities and values.

Recognizing the inherent problems with attempts to quantitatively measure QOL among people with SCI many researchers have advocated the use of qualitative methods that can explore both the meaning of QOL for people with SCI and the factors they identify as contributing to the experience of quality in their lives.<sup>4,12,14–20</sup> Different research methods generate different types of knowledge<sup>21</sup> and qualitative research can make a valuable contribution to evidence-based healthcare by probing 'taken for granted' and conventional ideas, and exploring the experiences, perspectives and contexts of peoples' lives.<sup>22,23</sup> Accordingly, qualitative methods have been employed in several studies into the experience of life after SCI.<sup>3</sup>

However, most qualitative research is undertaken with a small number of participants, leading to perceived difficulties with generalizing the findings.<sup>24–26</sup> The interpretive nature of data analysis can lead to perceptions of researcher bias and because most qualitative researchers attempt to allow their interpretations to emerge from their study data, few translate the themes they identify into the concepts previously employed by other qualitative researchers, thereby limiting comparisons between studies.<sup>27</sup> Further, while there has been 'an unprecedented accumulation of qualitative studies in the health sciences' there has been 'as yet, little accumulation of the understandings gained from these studies'.<sup>25</sup> These perceived shortcomings can be addressed through a rigorous process of meta-synthesis that combines the results of several qualitative studies on a specific theme to achieve a level of understanding and conceptual development that is greater than the sum of its parts.<sup>28</sup>

Qualitative evidence is increasingly being used as a basis for evidence-based practice.<sup>28,29</sup> For example, both the British National Health Service Centre for Reviews and Dissemination and the Cochrane Collaboration have recognised the importance of qualitative evidence in systematic reviews.<sup>30,31</sup> The systematic review is a rigorous and explicit research method which aims to locate, critically appraise and synthesize the findings of multiple studies pertaining to a specific research question. This might be through the use of a meta-analysis of

quantitative data (eg Dijkers,<sup>32</sup> Evans *et al*<sup>33</sup>) or a meta-synthesis of qualitative data.<sup>34</sup>

### *The meta-synthesis*

Meta-synthesis is the examination, critical comparison and synthesis of published qualitative studies that concern a common topic.<sup>27</sup> The meta-synthesis aims to advance knowledge by accomplishing a greater depth of understanding and degree of conceptual development than can be attained from a single study.<sup>28,35</sup> In effect, by utilizing multiple studies the meta-synthesis constitutes a form of triangulation in that it incorporates each of the four methods of triangulation identified in the qualitative research literature,<sup>36,37</sup> drawing from multiple: sources (informants), methods, theories and investigators. The process of meta-synthesis entails identifying relationships between the findings of existing studies and undertaking interpretations across comparable studies.<sup>38</sup>

Hammell<sup>3</sup> suggested the use of meta-synthesis to identify those factors that people with SCI perceive as contributing to, or detracting from the experience of a life worth living and proposed that this might provide an evidence-based foundation for future rehabilitation practice and for future research into life after SCI. The current review is focused on addressing this suggestion.

### *Focus of review*

The purpose of this meta-synthesis was to identify those factors that community-dwelling people with SCI perceive as contributing to, or detracting from the experience of a life worth living and to synthesize these factors into a coherent representation. The following research question was established: What does the published qualitative research literature contribute to understanding the determinants of QOL after SCI?

## **Methods**

The process of meta-synthesis comprises five phases: identification of the focus of review; identification of published papers and determination of their relevance; appraisal of the papers for research rigour and quality; identification and summary of key themes from each paper that can be verified against the primary data (participants' perspectives); comparison of key themes between the papers such that the findings are linked across studies and synthesized into new concepts.<sup>24,25,28,38–40</sup>

### *Identifying published papers and determining their relevance*

Published articles were identified from the Medline, CINAHL and Sociological Abstracts databases, crossindexing the text phrases: 'spinal cord injury'

and 'qualitative'. This search was augmented by a hand search through the following relevant journals published since 1990 and by papers identified through reference lists.

- *American Journal of Occupational Therapy*
- *American Journal of Physical Medicine and Rehabilitation*
- *Archives of Physical Medicine and Rehabilitation*
- *British Journal of Occupational Therapy*
- *Canadian Journal of Occupational Therapy*
- *Occupational Therapy Journal of Research*
- *Qualitative Health Research*
- *Rehabilitation Nursing*
- *Rehabilitation Psychology*
- *SCI Psychosocial Process*
- *Social Science and Medicine*
- *Sociology of Health and Illness*
- *Spinal Cord*
- *Topics in Spinal Cord Injury Rehabilitation*

It was anticipated that qualitative researchers would have employed different methods, reflecting their different philosophical positions and epistemological assumptions (eg phenomenology, grounded theory, discourse analysis, ethnographic interviews). However, these various forms of research are all interpretive, in that they seek to understand and explain the experiences and perspectives of the group of people being studied.<sup>38</sup> Further, as Jensen and Allen<sup>39</sup> observed, it is not the study in and of itself that is of interest, but rather, the experience that is explicated in these studies: 'Each source of data sheds some light onto the understanding of the meaning of the experience' (p. 558). Accordingly, papers were neither selected nor rejected on the basis of the specific qualitative methods employed. However, articles that described a mixed method study that included a small qualitative component to augment a predominantly quantitative research design were not included in the review. To eliminate inappropriate papers, the basic question: Is this really qualitative research? was posed at the outset.<sup>28</sup>

Anthropologists and disability researchers have demonstrated that Western conceptions of QOL reflect culturally specific and not universal values.<sup>3</sup> To enhance comparability, studies were therefore excluded if they had been undertaken outside the context of the 'Western' (minority) world. Articles were not included if their study sample was not exclusively spinal cord injured. The relevance of each paper was determined by whether it explored determinants of QOL for people with SCI who were living in the community. For the purposes of this review, 'quality of life' was conceptualized as the experience of a life worth living.

#### *Appraising the papers for research rigour and quality*

Researchers undertaking meta-analyses of quantitative studies have encountered significant methodological deficiencies. For example, researchers undertaking a

meta-analysis into the effectiveness of exercise in the management of depression were unable to draw any conclusion due to the methodological weaknesses of all 14 studies under analysis.<sup>41</sup> Unfortunately, many published qualitative studies are also of poor quality and lacking in rigour.<sup>24</sup> Therefore, as part of the process of the meta-synthesis, the quality of relevant studies was evaluated using predetermined criteria.<sup>21,30</sup>

Krefting<sup>42</sup> observed that 'too frequently, qualitative research is evaluated against criteria appropriate to quantitative research and is found to be lacking'. This is not due to an inherent inadequacy, but rather to the inappropriate imposition of criteria developed for a different form of inquiry.<sup>30</sup> A number of guidelines exist for evaluating qualitative research.<sup>21,26,36,43,44</sup> However, the procedure for critiquing qualitative research is not one of judging rigid adherence to rules or specific prescriptive criteria,<sup>45,46</sup> but is a process of weighing the various elements of the research in an effort to determine their appropriateness given the purpose and context of the study.<sup>44</sup> Sandelowski *et al*<sup>25</sup> recommend using very general criteria for quality in evaluating the studies relevant to the systematic review. Researchers contend that the most important indicator of quality for papers to be included in a meta-synthesis is clear evidence (through documentation of participants' perspectives) that the themes reported by the original researchers were rooted in the data.<sup>21,24,28,39</sup> Thus, papers were only included in the review if they included participants' words to support the researchers' interpretations (the 'audit trail'), and if they met those guidelines for rigour that are listed below. For the purposes of this review the following criteria were employed to gauge the quality of the studies, and were the guidelines for rigour that underpinned the present study. These criteria were formulated with reference to the work of scholars from the qualitative tradition<sup>21,26,36,43</sup> and to the Critical Appraisal Skills Programme.<sup>28</sup>

1. Information on the purpose and relevance of the study (including literature review),<sup>26,44,47</sup>
2. Information demonstrating the appropriateness of the methodology and methods;<sup>26,44,47,48</sup>
3. Information of appropriate methods of sampling and recruitment of participants;<sup>26,43,44</sup>
4. Information regarding transferability. (If qualitative findings are to be relevant to other settings researchers need to provide information concerning the transferability of the findings.) Transferability is dependent upon information concerning the representativeness of the informants;<sup>26,49,50</sup>
5. Evidence of data quality: appropriate collection process, methods and documentation;<sup>43,49,51</sup>
6. Examples of participants' perspectives and evidence that participants' perspectives have been accorded primacy: the 'primary marker' of quality in qualitative research;<sup>21,51,52</sup>
7. Evidence of plausibility (audit trail): whether researchers' interpretations and analyses can be seen

- to have arisen from the data and whether they fit the data from which they are derived;<sup>26,43,44,50</sup>
- Evidence that conclusions are consistent with, and justified by the data.<sup>44</sup>

#### *Summarizing themes*

Lists summarizing the findings of each paper were drawn up and compared with lists summarizing the other papers, using condensing labels. This followed the procedure used by Campbell *et al.*<sup>28</sup> For example, the observation that: 'When I'm not able to contribute, that's going to be the end [of QOL]'<sup>53</sup> was labelled 'Contributing'. This process drew upon those issues raised by study participants and on those themes that constituted the researchers' interpretations. The researchers' terminology and interpretations were cross-checked (by KWH) against their cited data to determine whether and how these fit with the terminology previously employed by other authors. To ensure the inclusion of all relevant findings, careful attention was paid to the details in the individual accounts and to issues that may not have been identified explicitly by the original researchers because while some issues may have appeared of minor concern within one study, the recurrence of these issues across studies strengthens their importance and relevance to the topic under study.<sup>28,39</sup>

#### *Comparison of themes and conceptual synthesis*

As the themes and issues arising from each paper were charted under unifying labels, relationships were identified that enabled the formation of concepts that synthesized the findings of all the papers included in the review.

## Results

#### *Identifying published papers and determining their relevance*

Sixty-four articles and four books were identified through the literature searches. Three papers<sup>54-56</sup> were rejected because qualitative research comprised a mere adjunct to a predominantly quantitative study. The question posed at the outset – Is this really qualitative research? – resulted in the elimination of one study<sup>57</sup> that claimed to employ a qualitative design but which reflected few of the criteria that characterize rigorous qualitative research. One paper<sup>58</sup> was omitted because it explored QOL in a majority ('developing') world context (see Discussion). The four books used interview data to explore the experience of SCI for men<sup>59</sup> and women<sup>60</sup> in the UK, and Australia,<sup>61,62</sup> but included insufficient information for appraisal of methodological rigour.

The remaining 59 papers were appraised for their relevance to the review question (see Table 1). Eleven papers were identified as having substantial relevance to the review question and were moved to the next phase of the review: the appraisal for rigour and quality. To

maintain the number of papers to be synthesized at a feasible number<sup>25,28,38</sup> those papers with only indirect bearing on the review question were omitted.

#### *Result of appraisal for rigour and quality*

One paper<sup>74</sup> was excluded because the researcher had imposed her assumption that men with SCI would be socially isolated on her interpretation of the data, despite acknowledging that her expectations were not verified by the study participants. Thus, only data that could be co-opted to justify this preconception had been presented in the paper. Three further studies<sup>64,89,90</sup> were excluded because few of the researchers' analyses and interpretations were supported by participants' words, making it impossible to identify an 'audit trail', appraise the plausibility of the researchers' interpretations, tease apart the participants' and researchers' perspectives or draw together the perspectives of the participants in these studies with those in other studies. The remaining seven papers satisfied those criteria for rigour and quality in the research process that had been established in the review guidelines. The demographic data of these studies are presented together in Table 2. These seven studies involved a total of 120 participants.

#### *Summary of themes that emerged from the data*

It was apparent that while many participants across the different studies had raised the same issues – frequently using the same phrases – these issues had been interpreted differently by different researchers. For example, Bach and McDaniel<sup>69</sup> noted the importance to their participants of having control over their lives and had interpreted this in terms of 'Inner strength/survival'. In a later study, Hammell<sup>12</sup> also identified the frequent occurrence of comments pertaining to the importance of having control of one's own life but interpreted these in terms of 'Autonomy'. Accordingly, the synthesis relied primarily upon the original data (participants' reports) to ensure consistency of interpretation.

#### *Comparison and synthesis of themes*

As the labels that summarised the key themes were listed with similar themes from other papers, it was possible to merge – or synthesize – these into concepts. Table 3 illustrates this stage of the synthesis.

Relationships between the concepts were examined and some were linked on the basis of their shared characteristics. Specifically, 'control' was linked to 'responsibility' (ie the responsibility to assume control), the importance of doing things that 'contribute' was linked with other forms of doing through 'occupation', and the development of 'new values' and the unfolding of 'perspective transformation' were linked together. Ten main concepts were identified through the synthesis and these are outlined below, with representative quotes. Six of the concepts were identified within at least six of the seven studies. The remaining four

**Table 1** Results of identifying the relevance of the studies

<i>Authors</i>	<i>Background</i>	<i>Focus of interest</i>	<i>Data concerning QOL?</i>
Dewis <sup>63</sup> Spencer <sup>64</sup>	Nursing OT	The meaning of body changes for adolescents Dimensions of occupation and health	Indirect: desire to feel normal and valued Importance of engaging in purposeful and personally meaningful activities; and of regaining control over everyday life
Mulcahey <sup>65</sup>	OT	Returning to school after SCI in adolescence	Indirect: importance of friends; themes of loss, self-image, physical access
Khalifa <sup>66</sup>	Nursing	Perceptions of home health care	Indirect: problems of impaired body; importance of family, friends and enabling environment
Laskiwski and Morse <sup>67</sup>	Nursing	The experience of being a patient on a SCI unit	None
Bates <i>et al</i> <sup>68</sup>	OT	Adapting to wheelchair use during rehabilitation	None
Bach and McDaniel <sup>69</sup>	Nursing	To explore the components contributing to QOL	Relationships, job and productivity, dependence/independence, finances, health, inner strength/survival, assertiveness and level of activity
Yoshida <sup>70</sup>	PT	Impact of SCI on identity and self-concept	Indirect: importance of redefining identity
Yoshida <sup>71</sup>	PT	Impact of rehabilitation on self-concept	None
Yoshida <sup>72</sup>	PT	Barriers to employment after SCI	None
Carpenter <sup>73</sup>	PT	The experience of living with SCI	Rediscovering self, redefining disability and establishing a new identity
Blake <sup>74</sup>	Nursing	Perceptions of social isolation after SCI	Problems of impaired body, finances, access, self-concept and social interaction
Spencer <i>et al</i> <sup>75</sup>	OT	The experience of in-patient rehabilitation	None
Creighton <i>et al</i> <sup>76</sup>	OT	Clinical reasoning by OTs during SCI rehabilitation	None
Quigley <sup>77</sup>	OT	Women's life roles after SCI	Indirect: interaction of daily routines, relationships and environment. Impact of SCI on sense of self
Bell and Hinjosa <sup>78</sup>	Unknown	Impact of assistive devices on daily life	Indirect: importance of choice and control, independence, feelings of usefulness
Kleiber <i>et al</i> <sup>79</sup>	Recreation and leisure studies	Impact of SCI on leisure	Indirect: themes of loss, relationship disruption, dependence on others, environmental barriers
Lee <i>et al</i> <sup>80</sup>	Leisure studies	Perceptions of return to valued activities	Indirect: importance of attaining continuity of, and participation in, valued activities
McAlonan <sup>81</sup>	OT	Perspectives of sexual rehabilitation services	None
Taylor and McGruder <sup>82</sup>	OT	The meaning of sea kayaking	Indirect: importance of re-defining self through competence in activities
Rintala <i>et al</i> <sup>83</sup>	Nursing	Role of family in early adjustment to SCI (in-patient rehabilitation)	None
Brillhart and Johnson <sup>84</sup>	Nursing	Factors contributing to motivation during rehabilitation	None
Lucke <sup>85</sup>	Nursing	Perceived consequences of caring relationships with rehabilitation staff	None
Lucke <sup>86</sup>	Nursing	As above	None
Datillo <i>et al</i> <sup>87</sup>	Leisure studies	Facilitators and barriers to engagement in leisure activities	Indirect: importance of relationships and of meaningful activities
Newman and Reed <sup>88</sup>	Psychology	Rehabilitation concerns of Mexican-American men	Indirect: importance of family and social support, problems of: the body, self-concept, sexual function, substance abuse
Boswell <i>et al</i> <sup>53</sup>	Exercise and sport science	Meaning of QOL after SCI, and the domains contributing to QOL	New values, new activities and new life focus. Three important QOL domains: attitude (to QOL and life), opportunities to work, level of resources

**Table 1** Continued

<i>Authors</i>	<i>Background</i>	<i>Focus of interest</i>	<i>Data concerning QOL?</i>
Duggan and Dijkers <sup>89</sup>	Rehabilitation	Comparison of QOL among those injured by violence or other causes	Loss of self-esteem; problems of: impaired body, finances, physical environment, policies, social attitudes; importance of relationships, care and social support
Duggan and Dijkers <sup>90</sup>	Rehabilitation	Describe subjective QOL	Importance of financial security, material assets, meaningful social roles, length of time since injury. Personal growth and positive value changes
Duggan and Dijkers <sup>91</sup>	Rehabilitation	Meaning and assessment of QOL and its components	Loss importance of biographical connections; envisioning a productive future, relationships, sense of purpose, ability to contribute
Langeno <i>et al</i> <sup>92</sup>	Nursing	Experience of having a pressure sore	Indirect: negative impact of pressure sores on QOL
Chan <sup>93</sup>	Psychology	Impact of SCI on marital relationships	None
Dewar <sup>94</sup>	Nursing	Staff experiences of conveying bad news	None
Kleiber and Hutchinson <sup>95</sup>	Recreation and leisure studies	Analysis of dominant cultural representations of SCI	Indirect: need for rehabilitation to challenge narrow life 'frames' for men with SCI
Hutchinson and Kleiber <sup>96</sup>	Recreation and leisure studies	As above	As above
Sparkes and Smith <sup>97</sup>	Sport and health science	Exploration of masculinity, embodiment and athletic identity	Indirect: SCI's assault on valued dimensions of the self
Sparkes and Smith <sup>98</sup>	Sport and health science	As above	As above
Low and Zubir <sup>99</sup>	Health research	Sexuality and SCI	Indirect: association between diminished sexual ability and low self-esteem
Chapin and Kewman <sup>100</sup>	Psychology	Issues of employment access	None
Manns and Chad <sup>101</sup>	Kinesiology	The concept and experience of QOL	Physical function and independence, accessibility, emotional well-being, stigma, spontaneity, relationships and social function, occupation, financial stability and physical well-being
Sullivan <sup>102</sup>	Nursing	The experience of acute care after SCI	None
Duggan <i>et al</i> <sup>103</sup>	Rehabilitation	Impact of nursing home environment on QOL	None
Pentland <i>et al</i> <sup>104</sup>	Rehabilitation	Impact of ageing on women with SCI	Indirect: concerns about deteriorating body and needs for enhanced environmental supports
Barclay <sup>105</sup>	OT	Factors influencing goal setting during rehabilitation	None
Houlihan <i>et al</i> <sup>106</sup>	Health outcomes	Effect of Internet access on health-related QOL	Indirect: correlation of Internet use and QOL
Bloemen-Vrencken and de Witte <sup>107</sup>	Nursing	Identification of nursing problems after discharge	Indirect: problems associated with physical limitations, pain and dependency
Carpenter <sup>108</sup>	PT	Programme evaluation	Indirect: importance of self-esteem, family and friends; of physical access, financial, medical, technological and care supports
Carpenter and Forman <sup>109</sup>	PT/CPA	Programme evaluation	As above
Smith and Sparkes <sup>110</sup>	Sport and health science	Reconstructing identity and masculinity	3 dominant cultural narratives: restitution, chaos and quest
Hammell <sup>12</sup>	OT	Perceptions of QOL	Refocusing values/re-affirming the value of myself; autonomy, choice and control; meaningful use of time; relationships; contextual issues: access to economic, health care, physical and

Table 1 Continued

Authors	Background	Focus of interest	Data concerning QOL?
Levins <i>et al</i> <sup>11</sup>	PT	Individual and environmental influences on physical activity	social resources, 'fighting the system'; coping with physical impairment
Henwood and Ellis <sup>112</sup>	Rehabilitation	Experience of chronic pain	Indirect: loss of able identity and redefinition of self; environmental and attitudinal barriers
Lohne and Severinsson <sup>113</sup>	Nursing	Experience of hope during rehabilitation	Indirect: negative impact of pain on all aspects of life
Lohne and Severinsson <sup>114</sup>	Nursing	Experience of hope during rehabilitation	None
Lohne and Severinsson <sup>115</sup>	Nursing	Experience of hope and suffering after SCI	None
Ville <sup>116</sup>	Health sciences	Return to employment after SCI	Indirect: need to engender hope to counter psychological suffering
Warms <i>et al</i> <sup>117</sup>	Nursing	Experience of research concerning pain following SCI	None
Isaksson <i>et al</i> <sup>118</sup>	Health sciences	Social networks and women with SCI	None
Kinder <sup>119</sup>	Nursing	Coping with SCI	Indirect: relationship between social support and ability to engage in meaningful occupations
			Indirect: desire for choice, importance of environmental barriers, participation, self-esteem, relationships

CPA = Canadian Paraplegia Association; OT = occupational therapy; PT = physiotherapy

concepts were identified within at least three of the studies (Table 4).

*Environment: physical, economic, political, legal, social, cultural* Every study reported dimensions of the environment that either enabled or constrained the quality of the lives of people with SCI. The *physical* environment was important in terms of physical access, urban infrastructure and the availability and accessibility of transportation. For example: 'I have to contend with everyday barriers placed by society'.<sup>110</sup> 'It would be nice not to have to wonder if you are going to be able to get around'.<sup>69</sup> The natural environment was also important: 'It's almost like come spring, I get out of jail and I've been in jail for the last 7 months [due to cold temperatures and snow]'.<sup>101</sup> The *economic* context was important: 'Finances are a big problem'; 'Our cost of living is extremely high';<sup>69</sup> 'We almost lost everything because of this accident. Financially'.<sup>91</sup> It was apparent that the economic context was closely tied to policy: to the *political and legal* context in which SCI was experienced, notably in terms of unmet needs for care-assistance and the complexities of attaining medical care. In the USA, the following remark was typical: 'We almost have to work part-time just to keep medical insurance'.<sup>69</sup> 'Without having a quality attendant caregiver, my ability to do much of anything is severely restricted'.<sup>53</sup> In Canadian studies<sup>12,101</sup> finances were identified as constraints to the purchase of adapted vans or the pursuit of expensive leisure activities but not to attaining health-care or a meaningful every-day life: 'There's funds available [and] the technology's available to keep you mobile and healthy ...[when] I did work I participated in support of the system and now that I need it, it's working for me'.<sup>12</sup> In both the US and Canada it was noted that the *social* environment could exert a negative impact on those with SCI, taking the form of bureaucratic 'red tape'<sup>91</sup> or 'power trips'<sup>12</sup> – 'Freedom is still extremely limited. There's always somebody winding up to play a bit of a power trip somewhere'<sup>12</sup> – or overt stigma and discrimination: 'I see that barrier [of stigma] everywhere I go... 'You are different''.<sup>91</sup> Studies from Canada and the UK<sup>73,110</sup> identified the impact of the *cultural* environment in shaping taken-for-granted beliefs and assumptions, for example: 'I was...programmed with a whole set of rules and beliefs, positive and negative stuff...we sort of unthinkingly accept it and keep perpetuating the same old stuff. Well, the accident happened and I had to do some major rethinking, because none of that stuff was any help in this situation'.<sup>73</sup>

*Problems associated with an impaired body* It was apparent that the problems associated with an impaired body – notably pain, fatigue, urinary tract infections, spasticity and susceptibility to pressure sores – had a significant impact upon the lives of many people with SCI. For example: 'Really the biggest drawback is you

**Table 2** Studies included in review

	No. of participants	Age at time of study (years)	Years since injury	Level of injury	Men:women	Location
Bach and McDaniel <sup>69</sup>	14	21–53	1–15	C4–C8	12:2	Mid-west USA
Carpenter <sup>73</sup>	10	21–39	3–5	Cervical and thoracic	9:1	BC, Canada
Boswell <i>et al</i> <sup>53</sup>	12	26–66	>1	Paraplegic and tetraplegic	8:4	USA
Duggan and Dijkers <sup>91</sup>	40	Mean = 43	6 months–12 years	Paraplegic and tetraplegic	23:17	Mid-west USA
Manns and Chad <sup>101</sup>	15	22–63	Mean = 13	8 paraplegia, 7 tetraplegia	9:6	Rural and urban Canada
Smith and Sparkes <sup>110</sup>	14	26–51	—	—	14:0	England
Hammell <sup>12</sup>	15	21–50	4–28	C1–C4	11:4	BC, Canada
Total	120					

have no control over your body’;<sup>12</sup> ‘Everything about your body has to be relearned, just like a child, only a thousand times more difficult’.<sup>73</sup> Above all, SCI was hugely inconvenient, frustrating and thwarting spontaneity: ‘after all these years, I still find it very frustrating to do some of the things that should be so simple yet they take so much energy’.<sup>101</sup> The synthesis identified the need to assume responsibility for planning, organizing and orchestrating one’s days in light of significant impediments to spontaneity in daily living.<sup>101</sup> Of fundamental concern was the impact of the impaired body on the ability to engage in desired activities, for example: ‘I used to cut the grass and do all that. And now my wife and my kids have to do it...I want to...do something to help them out’; ‘It’s hard to see people bathing [my baby] and changing her...I wanted to do it myself’.<sup>91</sup>

*Assuming responsibility and seizing control* A recurrent theme within six of the seven studies was the idea that at some point following SCI, the study participants had made a conscious decision to assume responsibility for their own lives. For example: ‘It became blindingly clear soon after the accident that I was the only one who could see me through this, that where I go in the future and what I do with my life was entirely up to me’;<sup>73</sup> ‘Quality of life is what you make it’;<sup>69</sup> ‘You can maintain a very high quality of life, just the same as before...It’s just however you want to limit yourself, [that] is the only thing stopping you’.<sup>12</sup> There was an apparent relationship between assuming responsibility and attaining control over one’s own life. For example: ‘You have to take control as much as you can...I direct my own care’.<sup>12</sup> Countering rehabilitation’s preoccupation with physical independence, the review identified the importance of independence in terms of freedom of decision-making and the power of self-determination,<sup>73</sup> demonstrating that control of one’s life is not predicated on physical ability. However, control of one’s own life

was dependent upon physical location: ‘I was kind of scared that I might be stuck in institutions for the rest of my life...[where] you had no freedom’;<sup>12</sup> [living in the community] ‘you’re running your own life’.<sup>12</sup>

*The importance of occupation* For the purposes of this synthesis, *occupation* was defined as being anything that people do in their daily lives.<sup>120</sup> This was evidently an important concept: ‘If you’re happy with what you’re doing, that’s about as far as you can go’.<sup>91</sup> Numerous comments referred to the needs: to be busy, to have something to wake up for, to explore new opportunities, to envision a future engaged in meaningful activities, to participate and to be involved in meaningful roles. For example: ‘I think my quality of life opened up, or actually increased because of what happened to me...I went back to school and became involved in sports. It opened up a lot of avenues’;<sup>53</sup> ‘Having a job makes you get up and gives you something to look forward to’;<sup>101</sup> ‘I guess [life’s] pretty rewarding. I keep pretty busy’;<sup>12</sup> ‘[after a while] you realize that you’ve got options and you’ve got something that you can wake up for every day – I’ve got to DO something today’.<sup>12</sup> ‘I’m going for my dreams and goals – and that’s school and getting a good education to have a good job’.<sup>12</sup>

It was evidently important to be able to do things that contributed something to others – to be useful and valuable: ‘If you feel like you are contributing in a worthwhile manner, then I think your quality of life is rather adequate’;<sup>69</sup> ‘When I’m not able to contribute, that’s going to be the end [of QOL]’;<sup>53</sup> ‘I’m making a contribution. I’m making a difference’.<sup>91</sup> Engagement in meaningful occupations was connected to a sense of self-worth: ‘I set my own goals...when I achieve them it makes me feel good about myself’;<sup>73</sup> ‘I’m doing something good with my life...and I have more self-esteem which is important to me’.<sup>12</sup>

Echoing and overlapping the previous theme, engagement in occupations following injury had evidently

**Table 3** Tabulation of key findings

<i>Relationships</i>	<i>Contributing</i>	<i>Occupation</i>	<i>Environmental context</i>
Social support <sup>91</sup>	Ability to give back <sup>12</sup>	Ability to do <sup>12,53,91</sup>	Housing <sup>53,69,91</sup>
Families <sup>12,69,73,91,101</sup>	Opportunity to contribute <sup>12,53,69</sup>	Able to do what you do <sup>12,69,101</sup>	Physical access <sup>69,73,91,101,110</sup>
Friends <sup>12,69,73,91,101</sup>	Need to contribute <sup>12</sup>	Something to do/get up for <sup>12,101</sup>	Social barriers <sup>110</sup>
Partners <sup>12,73,101</sup>	Feeling needed <sup>69</sup>	Being busy/active <sup>12,69</sup>	Transportation <sup>53,69,91,101</sup>
Emotional support <sup>73</sup>	Contributing <sup>53,69</sup>	Occupying time <sup>69,101</sup>	Care assistants <sup>53,69,91,101</sup>
Importance <sup>69,73,101,110</sup>	Able to contribute <sup>53,69,91</sup>	Meaningful work roles <sup>53,91</sup>	Finances/living costs <sup>53,69,91,101</sup>
Cultivating <sup>73,101</sup>	Able to make a difference <sup>91</sup>	New opportunities <sup>12,53,73</sup>	Basic needs must be met <sup>53</sup>
See I'm the same <sup>73</sup>	Inherent need to contribute <sup>12</sup>	New 'I ams' <sup>73</sup>	Cold/snow <sup>101</sup>
Treat me the same <sup>73</sup>	Need to give back <sup>12,69</sup>	Anticipation <sup>12,69,73,91,101</sup>	Stigma/negative attitudes <sup>73,91,101</sup>
My life is valued by others <sup>12,73,91</sup>		Work is important <sup>53,69,91,101</sup>	Bureaucracy/red tape <sup>12,69,91</sup>
More empathy now <sup>53</sup>		Need to be productive <sup>69,101</sup>	Discrimination <sup>73,101</sup>
QOL is caring people <sup>91</sup>		Not being bored <sup>69,101</sup>	Disabling policies <sup>12,69,91,101</sup>
Not taken for granted <sup>73,101</sup>		Creativity <sup>53</sup>	Medical insurance <sup>69</sup>
Interacting with others <sup>69,73</sup>		Doing what you want to do <sup>12,53</sup>	Urban infrastructure <sup>101</sup>
Learning from peers <sup>73,91,101,110</sup>		Doing things benefits health <sup>101</sup>	Access to equipment <sup>69</sup>
		Need to do things <sup>12</sup>	Inability to control <sup>110</sup>
		Life is boring <sup>110</sup>	Enabling policies <sup>12</sup>
		Focus on what you can do <sup>12</sup>	Cultural expectations <sup>73</sup>
		Happy with what I do <sup>91</sup>	Cultural ideals of perfection <sup>110</sup>
<i>Self-worth</i>	<i>Body problems</i>	<i>Control</i>	<i>Responsibility</i>
Financial security <sup>69</sup>	Living with new body <sup>73,110</sup>	Feel control over life <sup>12,69,73,91</sup>	Ignore what I can't do <sup>12,73,101</sup>
Being competent <sup>73</sup>	Time consuming <sup>53,73,101</sup>	Ability to direct others <sup>12</sup>	You make your own QOL <sup>12,53</sup>
Being productive <sup>53,73</sup>	Huge energy demands <sup>53,101</sup>	Power – self-determination <sup>12,73</sup>	Make the best of it <sup>69,101</sup>
Meaningful roles <sup>73,91</sup>	Pain <sup>91,101,110</sup>	Ability to make decisions <sup>12,73</sup>	QOL is what you make it <sup>69</sup>
Self-esteem <sup>12,73,91,101</sup>	Fatigue <sup>53</sup>	No control over body <sup>12</sup>	Learning to get back out there <sup>69</sup>
New 'I ams' <sup>73</sup>	Body less resilient <sup>69</sup>	Ability to drive <sup>91,101</sup>	Acknowledge responsibility <sup>73</sup>
Sense of self <sup>91</sup>	Everything is difficult <sup>73,101</sup>	Have to plan everything <sup>73,101</sup>	It's my life – it's up to me <sup>53,73</sup>
Achieving goals <sup>73,91</sup>	Body is frustrating <sup>12,101,110</sup>	Ability to make choices <sup>12</sup>	Positive attitude <sup>53</sup>
Realizing strengths <sup>91,101</sup>	Always waiting for help <sup>69,91,101</sup>	Have to take control <sup>12</sup>	Asking for help <sup>69</sup>
I felt useless <sup>12</sup>	Can't care for myself <sup>91</sup>	Independent mobility <sup>12,69,91</sup>	Being assertive <sup>69</sup>
Self-image <sup>12,101</sup>	Everything is done for me <sup>91</sup>	Desire control <sup>110</sup>	My body – my responsibility <sup>73</sup>
Self-concept <sup>91</sup>	No spontaneity <sup>101</sup>	Deinstitutionalization <sup>12</sup>	I find a way to do things <sup>91</sup>
Self-satisfaction <sup>53</sup>	Body not taken for granted <sup>91</sup>	Directing personal care <sup>12</sup>	I have carved a life for myself <sup>12</sup>
Self-confidence <sup>101</sup>	UTIs/bowel problems <sup>101,110</sup>		Just have to get on with it <sup>12,69</sup>
Employment <sup>101</sup>	Spasticity <sup>12,75,101</sup>		Accept loss of body control <sup>110</sup>
Ability to contribute <sup>12,53</sup>	Pressure sores <sup>12,53,91,101</sup>		
Pride in achievements <sup>91</sup>	No control over body <sup>12,101,110</sup>		
<i>Self-continuity</i>	<i>Perspective transformation</i>	<i>New values</i>	<i>Loss</i>
Adapt old interests <sup>73</sup>	Challenging stereotypes <sup>73</sup>	Redefining one's values <sup>12,73</sup>	Depression <sup>12,73,91,101</sup>
Get back on track <sup>73,110</sup>	New meaning of disability <sup>12,73,91</sup>	New values <sup>53,73</sup>	SCI was overwhelming <sup>73,91,110</sup>
Self coherence <sup>73</sup>	New meaning of normality <sup>73</sup>	Developing life purpose <sup>73,91,101</sup>	What might have been <sup>101</sup>
Expand options <sup>73</sup>	Focus on capabilities <sup>12,73,101</sup>	Focus on important things <sup>12,53,101</sup>	Wanted to die after SCI <sup>91</sup>
Life clicks in place <sup>73</sup>	Don't view self as disabled <sup>12,73</sup>	Appreciating life <sup>12,91,101</sup>	Lost a lot due to SCI <sup>73,91,110</sup>
I'm the same <sup>73,91,101</sup>	SCI assimilated into life <sup>12,73</sup>	Personal growth <sup>12,53,73,101,110</sup>	Can't do anything I used to do <sup>91,110</sup>
Enjoy same things <sup>73</sup>	Not walking is not so bad <sup>73,101</sup>	New perceptions of QOL <sup>12,53,73</sup>	World has become small <sup>91</sup>
Not a huge change <sup>73,101</sup>	It's like you grew up <sup>53,73</sup>	New important things <sup>12,53,73,101</sup>	Hard to rely on others <sup>91</sup>
Body is part of me <sup>73,110</sup>	New opportunities <sup>73,110</sup>	Positive life changes <sup>53,73,110</sup>	Feel I'm not a real man <sup>91,110</sup>
Not defined by SCI <sup>73</sup>	Life more meaningful/better <sup>12,73</sup>	Values less superficial <sup>12,73,110</sup>	I'll never accept it <sup>101</sup>
Reconstruct self <sup>110</sup>	Desire to die was mistake <sup>91</sup>	Old values no help now <sup>12,73</sup>	Don't want to stay paralyzed <sup>110</sup>
Link past to present <sup>91</sup>	SCI was turning point <sup>91</sup>	Life not taken for granted <sup>12,53,110</sup>	I can't live like this <sup>110</sup>
Reassemble pieces <sup>91</sup>	Ignore what cannot do <sup>12,73,101</sup>	Had to reframe values <sup>12</sup>	My life is a mess – it's over <sup>110</sup>
Life continuum <sup>73</sup>	My attitudes have changed <sup>110</sup>	Had to learn new outlook <sup>12,91</sup>	SCI was devastating <sup>12,110</sup>
I do not feel disabled <sup>73</sup>	Focus on what you can do <sup>12</sup>	Looked at deeper issues <sup>12</sup>	Initially felt useless <sup>12</sup>
	New priorities <sup>12,53,73</sup>	Initially felt life had no value <sup>12</sup>	Felt life was over <sup>12</sup>
	New chance at life <sup>110</sup>	Non-physical values now <sup>73</sup>	Want to return to who I was <sup>110</sup>
	Lost less than it seemed <sup>73</sup>		
<i>Good days/bad days</i>			
Mix good/bad days <sup>12,53,101,110</sup>			

**Table 4** Summary of concepts identified through the synthesis

Environment: physical, economic, political, legal, social, cultural <sup>12,53,69,73,91,101,110</sup>
Problems associated with an impaired body <sup>12,53,69,73,91,101</sup>
Assuming responsibility and seizing control <sup>12,53,69,73,91,101</sup>
Importance of engaging in, and contributing through occupation <sup>12,53,69,73,91,101</sup>
Development of new values and perspectives <sup>12,53,73,91,101,110</sup>
Self-worth <sup>12,53,69,73,91,101,110</sup>
Renewed importance of relationships <sup>12,69,73,91,101</sup>
Injury and loss <sup>12,91,101,110</sup>
Continuity of biography <sup>12,73,101</sup>
Good days and bad days <sup>12,53,101,110</sup>

required a conscious act: a deliberate decision to overlook one's inabilities and focus instead on residual abilities – on what is, not what was<sup>73</sup> – for example: 'There's a lot of things that I miss of course, but if you concentrate on what you are able to do and focus towards that, and forget about what you're not able to do, it's a lot easier';<sup>12</sup> 'You've got the rest of your life in front of you...you can't spend a lot of time worrying about what you can't do. Figure out what you can do and focus on that'.<sup>12</sup> Sudden confrontation with the fragility of life forced a revision of the values that informed the use of time. This shifting perspective is reflected further in the following concept.

*Development of new values and perspectives* The severe biographical disruption<sup>12,91,110</sup> occasioned by SCI had shattered the illusion of a predictable future and prompted many people to reflect both on the value of life itself and on the values and priorities with which they informed their lives: 'All the things I thought were really important before, I now find were not...You think at first that you've lost more than you have';<sup>73</sup> 'My basic lifestyle has changed. Most of my life revolved around physical things before, pretty superficial really; now all that's changed...in the way I think about my life, my job, the way I treat people who are close';<sup>73</sup> 'I took life for granted, and then boom, I got a big awakening';<sup>53</sup> 'The injury makes you think about what's important and what's not important...you learn to appreciate a lot of different things';<sup>101</sup> 'The person you were pre-injury is the person you are going to be post-injury – with different values'.<sup>12</sup>

*Self-worth* While many of the concepts overlapped with others, it was noted that several aspects of the previous concepts pertained directly to rebuilding a sense of 'self-worth': a concept that incorporates the idea of re-acquiring 'value' and that recurred in every study. For example, while some people identified feelings of helplessness, uselessness, valuelessness and worthlessness following SCI<sup>12,91</sup> that persisted among

some people<sup>110</sup> many identified ways in which a positive sense of self-worth – of being capable, valuable and useful – had been re-established through renewed participation in meaningful occupations<sup>12,73,101</sup> ('I don't feel disabled any more...I have a job like everyone else'<sup>73</sup>), contributing to others,<sup>53</sup> attaining financial security 'and not just living off the government',<sup>69</sup> 'getting involved', becoming competent and capable,<sup>73</sup> achieving goals, feeling productive and taking pride in accomplishments.<sup>53,73,101</sup> For example: 'It takes a long time to see value and self-worth are continuing and not tied to physical status';<sup>12</sup> 'It's ok to resign yourself to the fact that you're going to be like this probably for the rest of your life...If something better comes along that's good, but don't depend on it. Work towards your own self-employment or your own self-worth'.<sup>12</sup> By letting go of some 'I ams' (such as 'I am an athlete') and developing others (such as 'I am a father'), a sense of self-worth was enhanced.<sup>73</sup>

*Renewed importance of relationships* Central to the process of re-establishing a sense of self-worth was recognition of the value of relationships with partners, family members, friends and assistants; in terms of the material and emotional support provided by special people; the affirmation that one's life held value for others and that the important people in one's life recognized that SCI had not changed 'who I am'. For example: 'Relationships are really important';<sup>69</sup> 'You really get to appreciate people more ...I put a lot more effort into my friendships these days';<sup>73</sup> '[family and friends] saw that I was the same person as before';<sup>73</sup> 'Your family and friends see you as having value and able to contribute even though you may have written yourself off as having no value. They think you are worth it and you see that you are valued and start to value yourself'.<sup>12</sup> The ability and opportunity to contribute to others<sup>12,53</sup> was an important dimension of meaningful relationships.

*Injury and loss* It was apparent that for a significant number of people, the months and years since SCI were characterized by a preoccupation with loss, reflected in narratives of shattered dreams, crushing and persistent depression and of an inability to attain valued ideals of masculinity. For example: 'If I wouldn't have ended up in this thing [wheelchair] I would have been married, I would have had three kids...things would have just been totally different than they are now';<sup>101</sup> 'My life is a mess...Before the accident I was happy and life was good. The injury and everything that has happened since has choked any life and happiness out of me. I have nothing now. Am nothing...It's over...My life is in darkness...I'm shattered';<sup>110</sup> 'There's times I feel like I'm not a full man'.<sup>91</sup> For some, this overwhelming sense of loss led to a preoccupation with being cured, such that current lives appeared to be 'placed on hold' awaiting a return to lost lives. 'I do think that I'll make

a comeback and walk again at some point in time. I won't stop fighting until I can do that';<sup>110</sup> 'I don't want to stay like this. I want to walk...I'll keep going until a cure is found. I will win and walk again'.<sup>110</sup>

*Continuity of biography* In contrast to the narratives of those whose biographies remained mired in disruption and disarray, other studies revealed biographies that had, over time, attained a sense of continuity and this sense of continuity was important. For example: 'It took at least 4 years before things began to click into place, and life goes on fairly normally'; '[it's good to be] getting back on track'.<sup>73</sup> By focusing on capability and competence rather than inadequacy and limitation, it was possible to view oneself as able, not *disabled*. For example: 'I'm the same person that I was before the accident except that now I have to get around a little bit differently';<sup>101</sup> 'I live a normal life. I don't feel disabled any more...I have a job like everyone else. I enjoy the same things I always did, do the same chores, have the same problems everyone else does'.<sup>73</sup> Even those with the very highest cord lesions noted: 'I don't really look at myself any different. I just need somebody to be my hands and feet for me';<sup>12</sup> 'I don't look at you as able-bodied and me as disabled...We're [all] doing the best we can with what we have'.<sup>12</sup>

*Good days and bad days* Although not a QOL determinant *per se*, a recurrent theme, expressed in identical terms, was identifiable within four of the papers. This pertained to people's perceptions that their lives since SCI were characterised by good days and bad days *and that this was normal*: that their own mixture of good and bad days was just like that of other people and not specific to those with SCI. For example: 'There is always the good and the bad';<sup>53</sup> 'I had good days and bad days when I was walking and I have good days and bad days now';<sup>101</sup> 'It's a mixture of good days and some bad ones';<sup>110</sup> 'Like anybody else I guess, you have good days and bad days'.<sup>12</sup> Boswell *et al*<sup>53</sup> noted that both negative and positive aspects of life were identified by their study participants as being essential life ingredients.

## Discussion

DeLisa<sup>121</sup> astutely noted that 'the assumptions of those of us who are able-bodied bear little relationship to the realities of life for people with spinal cord injury'. Research has demonstrated that health-care professionals frequently hold misconceptions about life with a SCI,<sup>122,123</sup> that they convey these misconceptions to newly injured people<sup>124,125</sup> and that there are few resources in the research literature from which more valid conceptions might be drawn.<sup>122,126</sup> Gerhart<sup>123</sup> argued that people with SCI need accurate information about the possibilities for quality living following injury: 'They need it from their providers, they need it from

other survivors, and they need it first hand – gleaned from others' experiences living with a disability. We must educate ourselves, our clients, and the society in which we live' (p. 83). This meta-synthesis contributes to this process.

This synthesis reaffirms the findings of quantitative studies that have noted the importance to QOL of the following: perceived social support, social integration, access to the physical environment, health-care, adequate income, perceptions of having control over one's life; and of satisfaction with relationships, community participation and occupational engagement.<sup>3</sup> It also provides evidence to support previous findings that correlate low life satisfaction with pain, pressure sores, spasticity, inadequate income, boredom, reduced mobility, dissatisfaction with occupations and perceptions of having reduced control over life.<sup>3</sup> Moreover, while the meta-synthesis identified and thus reinforced all of these issues, it also began the work of identifying relationships *between* them, such as between engagement in meaningful occupations and perceptions of self-worth. Indeed, the importance of affirming self-worth has not been emphasized in most previous studies, nor has the need for a sense of biographical continuity been specifically highlighted.

The findings of the synthesis can be related to medical sociologists' theories of biographical disruption and reconstruction (indeed, this theoretical framework had been employed by some of the studies' authors<sup>12,91</sup>). Before injury the able body and life itself were taken for granted.<sup>12,91</sup> SCI was experienced, not just as a physical transformation, with its significant problems, frustrations and difficulties, but as a major life disruption that precipitated a sense of devastating loss.<sup>12,91,110</sup> This disruption to daily activities, valued occupations, life-plans and 'the seductive predictability' of every-day life<sup>127</sup> has been conceptualized in terms of *biographical disruption*.<sup>128</sup> Biographical disruption is understood to comprise three dimensions – the body, conceptions of self, and time – suggesting that an injury that leads to an inability to perform valued activities of every-day life may lead to a loss of certain aspects of the self, such as perceptions of competence and self-worth.<sup>129</sup> The theory of biographical disruption neatly encapsulates the findings of this meta-synthesis, which identified recurrent findings pertaining to the relationship of the body to the self, for example, the overwhelming sense of loss among those preoccupied with bodily dysfunction (for whom the impaired body represented a flawed self).

Somner and Baumeister<sup>130</sup> theorized that restoration of a sense of self-worth is fundamentally important to the experience of a life worth living – a finding supported by this review. The present findings also support the linkage between engagement in valued occupations – using time in personally meaningful ways – and perceptions of self-worth: of perceiving oneself to be able, competent, capable and valuable.<sup>82</sup> There appears to be a relationship between a sense that 'I can' and a sense of who 'I am'.<sup>131</sup>

Supporting the findings of this synthesis, research into the experience of various forms of impairment has confirmed the importance of being able to contribute to others in reciprocal relationships that foster perceptions of value and competence, connecting and belonging.<sup>132</sup> Corbin and Strauss<sup>133</sup> noted that with a supportive social network and appropriate material resources, lifestyles can be adopted that enable a shift from an image of a disabled self to one of a capable self. This observation was reflected in findings relating to the importance of relationships that affirmed one's self-worth.<sup>12</sup> A significant body of literature has explored the social support perceived by those with spinal cord lesions.<sup>134–137</sup> However, the need to *give* as well as receive support – to participate in webs of reciprocity – is less commonly acknowledged or researched, yet this dimension of social networks is clearly of importance to people with SCI, and is associated with lower levels of depression, higher self-esteem and fewer health problems.<sup>138–140</sup>

Lucke<sup>85</sup> noted that people with SCI defined the 'major work' of the rehabilitation process as 'getting back together', or reintegrating the self. This synthesis identified the importance of rethinking one's biography following injury in terms of priorities and values, and of achieving a sense of continuity between past and present lives and selves<sup>91</sup> (through visualizing a productive and purposeful future<sup>12,91</sup> and enhancing important relationships<sup>91</sup>). It has been suggested that the concept of continuity might be a more useful avenue for rehabilitation than the traditional preoccupations with loss and change, enabling people to see 'that there are many important areas of their life that have been unchanged since the injury'.<sup>141</sup> The need for a sense of continuity – of connecting one's present and future lives to one's past life – has been a recurrent research finding.<sup>64,75,77</sup>

The synthesis noted the interrelationship between the resources of the environment (physical, economic, political, legal, social and cultural) and the ability both to engage in meaningful occupations and to assume responsibility and control over one's life. The importance of re-engaging in occupations, already noted in relation to self-worth, has long been recognized by the rehabilitation professions and it has been proposed that occupation should be understood as a context for appreciation and enjoyment of living, an opportunity for experiencing meaning in everyday endeavours and the basis for establishing self-identity, gaining a sense of control and achieving biographical continuity.<sup>142</sup> It is because ability is of little value without opportunity that the rehabilitation professions also acknowledge the need to address the social, political and physical environments that often restrict opportunities for a range of everyday endeavours to those in the dominant population.<sup>143</sup>

Autonomy, or the ability to control and direct one's own life, was linked by the study participants to the opportunity to live in the community, to direct their own personal care, to make decisions and to act on choices. However, while 'controlling one's life is

essential to maintaining personal dignity, independence, and quality of life',<sup>144</sup> it is important to note that 'control is more than choice. People may make choices but have little control to act on these choices. Control is dependent upon opportunities provided by the environment'.<sup>144</sup> People are unable to assert any meaningful control of their lives in the absence of a supportive political, social, economic and legal/policy environment.

Bury<sup>145</sup> theorized that the 'meaning' of an impairment will lie in its *consequences* (its impact on everyday life activities and relationships) and in its *significance* (its social connotations). The rehabilitation professions have tended to focus exclusively on the consequences of SCI while ignoring the impact of its significance: the influence of stigma, cultural norms and ideas of competence and social worth for the individual's sense of self.<sup>145</sup> Research suggests that people who make a good adjustment to the sudden onset of impairment are those who are able to redefine their values, broaden the range of things that are cherished and decrease the emphasis on physique as a measure of the self.<sup>146,147</sup> Sartre<sup>148</sup> observed that one does not examine one's values or beliefs when engaged in the predictable routine of daily activities – when cultural values appear so natural and self-evident as to be indiscernible – but when crisis compels reflection. The present synthesis supports the premise that the biographical disruption occasioned by SCI had prompted a reassessment of values and a reappraisal of life priorities, time use and occupational choices. As a component of this process of reassessment disability was redefined by some people with SCI, not as inability, but as a dimension of ability with comparisons between self and others, then and now, through the 'good days, bad days' theme.

It cannot be assumed that the findings of this meta-synthesis of qualitative research undertaken among people with SCI in the 'Western', or minority, world have any relevance to people with SCI in the majority (or 'developing') world, for whom interdependence, harmonious living and belonging, for example, may be more highly valued than independence, autonomy and personal achievement.<sup>149,150</sup> However, although a qualitative study exploring dimensions of QOL for adults with SCI in China identified two unique issues – world peace and harmonious relationships with neighbours – many themes reflected those identified in this synthesis, such as the role of the political, social, economic and physical environment, self-concept, the ability to contribute to others, family relationships and participation in social activities.<sup>58</sup>

Using accepted methods<sup>24,25,28,38–40</sup> this study has demonstrated the utility of the meta-synthesis in drawing together the findings of a number of published studies. Unlike meta-analyses of quantitative data, a meta-synthesis is interpretive rather than aggregative,<sup>28,39</sup> with concepts created by the synthesizer from data presented in published papers. This need to 'root' interpretations in existing data<sup>24,39</sup> effectively limits the availability of papers for synthesis. More studies would be available for synthesis if qualitative researchers

demonstrated a greater commitment to documenting participants' perspectives, thereby providing evidence that their interpretations are plausible; and that their conclusions are justified by their findings.<sup>24</sup>

Although it is not uncommon for meta-analyses of quantitative studies to be undertaken by a single researcher, for example Dijkers,<sup>32</sup> it is less common for a qualitative meta-synthesis to be undertaken in this way. Accordingly, a substantial quantity of data has been provided to justify the linkages that were made between data and concepts and to support the credibility of the interpretations. However, Jensen and Allen<sup>39</sup> claimed that 'a meta-synthesis is credible when it re-presents such faithful descriptions or interpretations of human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own' (p. 556). The failure to facilitate a peer-review by people with SCI<sup>36,44,151</sup> is a major limitation of this study.

## Conclusion

This study has demonstrated the utility of synthesizing qualitative research to provide a greater depth of insight into the factors that contribute to, and detract from, QOL after SCI; providing a more nuanced understanding of the experience of QOL following SCI than is achievable by quantitative methods. QOL was found to be diminished by problems associated with the impaired body; and by a sense of loss. The experience of a life worth living (QOL) was found to be enhanced by meaningful relationships; the assumption of responsibility for, and opportunity to exert control over, one's own life; and the ability to engage in personally meaningful occupations. The review also identified the importance of developing new values and perspectives (by which good and bad days could be viewed as 'normal'); the importance of reconstructing a positive sense of self-worth; and of attaining a sense of biographical continuity. By highlighting the impact of social, cultural, physical, legal, political and economic environments the findings of this review support the premise that the experience of SCI is inseparable from the context in which it occurs. Future qualitative research is required to probe further the concepts and connections identified in this study, and to identify how rehabilitation services might best address these issues.

## References

- Manns PJ, Chad KE. Determining the relation between quality of life, handicap, fitness, and physical activity for persons with spinal cord injury. *Arch Phys Med Rehab* 1999; **80**: 1566–1571.
- May LA, Warren S. Measuring quality of life of persons with spinal cord injury: external and structural validity. *Spinal Cord* 2002; **40**: 341–350.
- Hammell KW. Exploring quality of life following high spinal cord injury: a review and critique. *Spinal Cord* 2004; **42**: 491–502.
- Tate DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. *Arch Phys Med Rehab* 2002; **83**(Supp 2): S18–S25.
- Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994; **272**: 619–626.
- Dijkers M. Quality of life after spinal cord injury. *Am Rehab* 1996; **Autumn**: 18–24.
- Dijkers M. Measuring quality of life: methodological issues. *Am J Phys Med Rehab* 1999; **78**: 286–300.
- Johnston M, Nissim E, Wood K, Hwang K, Tulskey D. Objective and subjective handicap following spinal cord injury: interrelationships and predictors. *J Spinal Cord Med* 2002; **25**: 11–22.
- Loew L, Rapin H. The paradoxes of quality of life and its phenomenologic approach. *J Palliat Care* 1994; **10**: 37–41.
- Woodend AK, Nair RC, Tang AS. Definition of life quality from a patient versus health care professional perspective. *Int J Rehab Res* 1997; **20**: 71–80.
- Dale AE. A research study exploring the patient's view of quality of life using the case study method. *J Adv Nurs* 1995; **22**: 1128–1134.
- Hammell KW. Quality of life among people with high spinal cord injury living in the community. *Spinal Cord* 2004; **42**: 607–620.
- Said EW. *Representations of the Intellectual*. Random House: New York 1996.
- Fuhrer MJ. The subjective well-being of people with spinal cord injury: relationships to impairment, disability and handicap. *Topics Spinal Cord Inj Rehab* 1996; **1**: 56–71.
- Dijkers M. Correlates of life satisfaction among persons with spinal cord injury. *Arch Phys Med Rehab* 1999; **80**: 867–876.
- The Consortium for Spinal Cord Medicine. *Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health Care Professionals*. The Consortium and the Paralyzed Veterans of America, Washington 1999.
- Whiteneck GG. Outcome evaluation and spinal cord injury. *Neurorehabilitation* 1992; **2**: 31–41.
- Whiteneck GG. Measuring what matters: key rehabilitation outcomes. *Arch Phys Med Rehab* 1994; **75**: 1073–1076.
- Whiteneck GG. Evaluating outcome after spinal cord injury: what determines success? *J Spinal Cord Med* 1997; **20**: 179–185.
- Widerström-Noga EG, Felipe-Cuervo E, Broton JG, Duncan RC, Yezierski RP. Perceived difficulty in dealing with consequences of spinal cord injury. *Arch Phys Med Rehab* 1999; **80**: 580–586.
- Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; **8**: 341–351.
- Popay J, Williams G. Qualitative research and evidence-based healthcare. *J Royal Soc Med* 1998; **91**: 32–37.
- Hammell KW. Using qualitative research to inform the client-centred evidence-based practice of occupational therapy. *Br J Occup Ther* 2001; **64**: 228–234.
- Estabrooks CA, Field PA, Morse JM. Aggregating qualitative findings: an approach to theory development. *Qual Health Res* 1994; **4**: 503–511.
- Sandelowski M, Docherty S, Emden C. Qualitative metasynthesis: issues and techniques. *Res Nurs Health* 1997; **20**: 365–371.

- 26 Mays N, Pope N. Quality in qualitative health research. In: Pope C, Mays N (eds). *Qualitative Research in Health Care*. BMJ: London 2000, pp 89–101.
- 27 Morse J. Qualitative verification. In: Morse J, Swanson J, Kuzel A (eds). *The Nature of Qualitative Evidence*. Sage: London 2001, pp 203–220.
- 28 Campbell R *et al*. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med* 2003; **56**: 671–684.
- 29 Hammell KW, Carpenter C. *Qualitative Research in Evidence-Based Rehabilitation*. Churchill Livingstone, Edinburgh 2004.
- 30 Dixon-Woods M, Fitzpatrick R. Qualitative research in systematic reviews. *BMJ* 2001; **323**: 765–766.
- 31 Cochrane Qualitative Methods Group. [http://mysite.free-serve.com/Cochrane\\_Qual\\_Method/index.htm](http://mysite.free-serve.com/Cochrane_Qual_Method/index.htm) Accessed 28 November 20002.
- 32 Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. *Spinal Cord* 1997; **35**: 829–840.
- 33 Evans RL, Hendricks RD, Connis RT, Haselkorn JK, Ries KR, Mennet TE. Quality of life after spinal cord injury: a literature critique and meta-analysis (1983–1992). *J Am Para Soc* 1994; **17**: 60–66.
- 34 Bannigan K. Clinical effectiveness: systematic reviews and evidence-based practice in occupational therapy. *Br J Occup Ther* 1997; **60**: 479–486.
- 35 Sandelowski M. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Adv Nurs Sci* 1993; **16**: 1–8.
- 36 Law M, Stewart D, Letts L, Pollock N, Bosch J, Westmorland M. *Guidelines for Critical Review of Qualitative Research* 1998 Available at <http://www.fhs.mcmaster.ca/rehab/ebp/>.
- 37 Brechin A, Sidell M. Ways of knowing. In: Gomm R, Davies C (eds). *Using Evidence in Health and Social Care*. Sage and The Open University: London 2000, pp 3–25.
- 38 Noblit GW, Hare RD. *Meta-Ethnography: Synthesizing Qualitative Studies*. Sage: London 1988.
- 39 Jensen LA, Allen MN. Meta-synthesis of qualitative findings. *Qual Health Res* 1996; **6**: 553–560.
- 40 Jensen LA, Allen MN. A synthesis of qualitative research on wellness-illness. *Qual Health Res* 1994; **4**: 349–369.
- 41 Lawlor DA, Hopker SW. The effectiveness of exercise as an intervention in the management of depression: systematic review and meta-regression analysis of randomised controlled trials. *BMJ* 2001; **322**: 763–767.
- 42 Krefling L. Rigor in qualitative research: the assessment of trustworthiness. *Am J Occup Ther* 1991; **45**: 214–222.
- 43 Baxter J, Eyles J. Evaluating qualitative research in social geography: establishing ‘rigour’ in interview analysis. *Trans Inst Br Geog* 1997; **22**: 505–525.
- 44 Hammell KW. Informing client-centred practice through qualitative inquiry: evaluating the quality of qualitative research. *B J Occup Ther* 2002; **65**: 175–184.
- 45 Hasselkus BR. Beyond ethnography: expanding our understanding and criteria for qualitative research. *Occup Ther J Res* 1995; **15**: 75–84.
- 46 Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; **322**: 1115–1117.
- 47 Hammersley M. *What’s Wrong with Ethnography?* Routledge: London 1992.
- 48 Sandelowski M. The problem of rigor in qualitative research. *Adv Nurs Sci* 1986; **8**: 27–37.
- 49 Lincoln YS, Guba EG. *Naturalistic Inquiry*. Sage: Beverley Hills, CA 1985.
- 50 Robson C. *Real World Research. A Resource for Social Scientists and Practitioner-Researchers*. Blackwell: Oxford 1993.
- 51 Carpenter C, Hammell KW. Evaluating qualitative research. In: Hammell KW, Carpenter C, Dyck I (eds). *Using Qualitative Research. A Practical Introduction for Occupational and Physical Therapists*. Churchill Livingstone: Edinburgh 2000, pp 107–119.
- 52 Kirsch GE. *Ethical Dilemmas in Feminist Research. The Politics of Location, Interpretation and Publication*. State University of New York Press: Albany, NY 1999.
- 53 Boswell BB, Dawson M, Heining E. Quality of life as defined by adults with spinal cord injuries. *J Rehab* 1998; **64**: 27–32.
- 54 Payne JA. The contribution of group learning to the rehabilitation of spinal cord injured adults. *Rehab Nurs* 1993; **18**: 375–379.
- 55 Allotey P, Reidpath D, Kouamé A, Cummins R. The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon. *Soc Sci Med* 2003; **57**: 949–958.
- 56 Boschen KA, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. *Int J Rehab Res* 2003; **26**: 157–164.
- 57 Rogers B, Kennedy P. A qualitative analysis of reported coping in a community sample of people with spinal cord injuries: the first year post discharge. *SCI Psychosoc Proc* 2000; **13**: 4144–4963.
- 58 Hampton NZ, Qin-Hilliard DB. Dimensions of quality of life for Chinese adults with spinal cord injury: a qualitative study. *Disab Rehab* 2004; **26**: 203–212.
- 59 Oliver M, Zarb G, Silver J, Moore M, Salisbury V. *Walking into Darkness. The Experience of Spinal Cord Injury*. Basingstoke: Macmillan 1988.
- 60 Morris J. *Able Lives. Women’s Experience of Paralysis*. Women’s Press: London 1989.
- 61 Seymour W. *Bodily Alterations*. Allen & Unwin: Sydney 1989.
- 62 Seymour W. *Remaking the Body. Rehabilitation and Change*. Routledge: London 1998.
- 63 Dewis ME. Spinal cord injured adolescents and young adults: the meaning of body changes. *J Adv Nurs* 1989; **14**: 389–396.
- 64 Spencer EA. Toward a balance of work and play: promotion of health and wellness. *Occup Ther Health Care* 1989; **5**: 87–99.
- 65 Mulcahey MJ. Returning to school after a spinal cord injury: perspectives from four adolescents. *Am J Occup Ther* 1992; **46**: 305–312.
- 66 Khalifa M. Inducing the quality of home health care theory through the use of grounded methodology. *Int J Nurs Stud* 1993; **30**: 269–286.
- 67 Laskiwski S, Morse JM. The patient with spinal cord injury: the modification of hope and expressions of despair. *Can J Rehab* 1993; **6**: 143–153.
- 68 Bates PS, Spencer JC, Young ME, Rintala DH. Assistive technology and the newly disabled adult: adaptation to wheelchair use. *Am J Occup Ther* 1993; **47**: 1014–1021.
- 69 Bach CA, McDaniel RW. Quality of life in quadriplegic adults: a focus group study. *Rehab Nurs* 1993; **18**: 364–367, 374.

- 70 Yoshida KK. Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociol Health Ill* 1993; **15**: 217–245.
- 71 Yoshida KK. Institutional impact on self-concept among persons with spinal cord injury. *Int J Rehab Res* 1994; **17**: 95–107.
- 72 Yoshida KK. Employment among persons with spinal cord injury: work trajectories, resources and barriers. *Res Sociol Health Care* 1994; **11**: 151–171.
- 73 Carpenter C. The experience of spinal cord injury: The individual's perspective – implications for rehabilitation practice. *Phys Ther* 1994; **74**: 614–629.
- 74 Blake K. The social isolation of young men with quadriplegia. *Rehab Nurs* 1995; **20**: 17–22.
- 75 Spencer J, Young ME, Rintala DH, Bates S. Socialization to the culture of a rehabilitation hospital: an ethnographic study. *Am J Occup Ther* 1995; **49**: 53–62.
- 76 Creighton C, Dijkers M, Bennett N, Brown K. Reasoning and the art of therapy for spinal cord injury. *Am J Occup Ther* 1995; **49**: 311–317.
- 77 Qigley MC. Impact of spinal cord injury on the life roles of women. *Am J Occup Ther* 1995; **49**: 780–786.
- 78 Bell P, Hinjosa J. Perception of the impact of assistive devices on daily life of three individuals with quadriplegia. *Assist Technol* 1995; **7**: 87–94.
- 79 Kleiber DA, Brock SC, Lee Y, Datillo J, Caldwell L. The relevance of leisure in an illness experience: realities of spinal cord injury. *J Leis Res* 1995; **27**: 283–299.
- 80 Lee Y, Datillo J, Kleiber DA, Caldwell L. Exploring the meaning of continuity of recreation activity in the early stages of adjustment for people with spinal cord injury. *Leis Sci* 1996; **18**: 209–225.
- 81 McAlonan S. Improving sexual rehabilitation services: the patient's perspective. *Am J Occup Ther* 1996; **50**: 826–834.
- 82 Taylor LPS, McGruder JE. The meaning of sea kayaking for persons with spinal cord injuries. *Am J Occup Ther* 1996; **50**: 39–46.
- 83 Rintala DH, Young ME, Spencer JC, Bates PS. Family relationships and adaptation to spinal cord injury: a qualitative study. *Rehab Nurs* 1996; **21**: 67–74.
- 84 Brillhart B, Johnson K. Motivation and the coping process of adults with disabilities: a qualitative study. *Rehab Nurs* 1997; **22**: 249–256.
- 85 Lucke KT. Knowledge acquisition and decision-making: spinal cord injured individuals perceptions of caring during rehabilitation. *SCI Nurs* 1997; **14**: 87–95.
- 86 Lucke KT. Outcomes of nurse caring as perceived by individuals with spinal cord injury during rehabilitation. *Rehab Nurs* 1999; **24**: 247–253.
- 87 Datillo J, Caldwell L, Lee Y, Kleiber DA. Returning to the community with a spinal cord injury: implications for therapeutic recreation specialists. *Ther Rec J* 1998; **First quarter**: 13–27.
- 88 Newman JA, Reed BJ. Mexican-American males with a spinal cord injury. *SCI Psychosoc Proc* 1998; **11**: 14–19.
- 89 Duggan CH, Dijkers M. Etiology, disablement, and quality of life: interpersonal violence versus other causes of spinal cord injury. *Topics Spinal Cord Inj Rehab* 1999; **4**: 65–85.
- 90 Duggan CH, Dijkers M. Quality of life after spinal cord injury: a qualitative study. *Rehab Psychol* 2001; **46**: 3–27.
- 91 Duggan CH, Dijkers M. Quality of life – Peaks and valleys: a qualitative analysis of the narratives of persons with spinal cord injuries. *Can J Rehab* 1999; **12**: 181–191.
- 92 Langemo DK, Melland H, Hanson D, Olson B, Hunter S. The lived experience of having a pressure ulcer: a qualitative analysis. *Adv Skin Wound Care* 2000; **13**: 225–235.
- 93 Chan RC. How does spinal cord injury affect marital relationship? A story from both sides of the couple. *Disab Rehab* 2000; **22**: 764–775.
- 94 Dewar A. Nurses' experiences in giving bad news to patients with spinal cord injuries. *J Neurosci Nurs* 2000; **32**: 324–330.
- 95 Kleiber DA, Hutchinson SL. Heroic masculinity in the recovery from spinal cord injury. In: Sparkes A, Silvennoinen M (eds) *Talking Bodies: Men's Narratives of the Body and Sport*. SoPhi University of Jyväskylä: Jyväskylä, Finland 1999, pp 135–155.
- 96 Hutchinson SL, Kleiber DA. Heroic masculinity following spinal cord injury: implications for therapeutic recreation practice and research. *Therap Rec J* 2000; **First quarter**: 42–54.
- 97 Sparkes A, Smith B. Disrupted selves and narrative reconstructions. In: Sparkes A, Silvennoinen M (eds). *Talking Bodies: Men's Narratives of the Body and Sport*. SoPhi, University of Jyväskylä: Jyväskylä, Finland 1999, pp 76–92.
- 98 Sparkes A, Smith B. Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity. *Men Masculin* 2002; **4**: 258–285.
- 99 Low WY, Zubir TN. Sexual issues of the disabled: implications for public health education. *Asia Pac J Public Health* 2000; **12**(Suppl): S78–S83.
- 100 Chapin MH, Kewman DG. Factors affecting employment following spinal cord injury: a qualitative study. *Rehab Psychol* 2001; **46**: 400–416.
- 101 Manns PJ, Chad KE. Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury. *Qual Health Res* 2001; **11**: 795–811.
- 102 Sullivan J. Surviving uncertainty and projecting recovery: a qualitative study of patients' and family members' experiences with acute spinal cord injury. *SCI Nurs* 2001; **18**: 78–86.
- 103 Duggan CH, Lysack C, Dijkers M, Jeji T. Daily life in a nursing home: impact on quality of life after a spinal cord injury. *Topics Spinal Cord Inj Rehab* 2002; **7**: 112–131.
- 104 Pentland W, Walker J, Minnes P, Tremblay M, Brouwer B, Gould M. Women with spinal cord injury and the impact of aging. *Spinal Cord* 2002; **40**: 374–387.
- 105 Barclay L. Exploring the factors that influence the goal setting process for occupational therapy intervention with an individual with spinal cord injury. *Aus Occup Ther J* 2002; **49**: 3–13.
- 106 Houlihan BV, Drainoni ML, Warner G, Nesathurai S, Wierbicky J, Williams S. The impact of Internet access for people with spinal cord injury: a descriptive analysis of a pilot study. *Disab Rehab* 2003; **25**: 422–431.
- 107 Bloemen-Vrencken JHA, de Witte LP. Post-discharge nursing problems of spinal cord injured patients: on which fields can nurses contribute to rehabilitation? *Clin Rehab* 2003; **17**: 890–898.
- 108 Carpenter C. Using qualitative focus groups to evaluate health programmes and service delivery. In: Hammell KW, Carpenter C (eds). *Qualitative Research in Evidence-Based Rehabilitation*. Churchill Livingstone: Edinburgh 2004, pp 51–64.
- 109 Carpenter C, Forman B. Provision of community programs for clients with spinal cord injury: use of

- qualitative research to evaluate the role of the British Columbia Paraplegic Association. *Topics Spinal Cord Inj Rehab* 2004; **9**: 57–72.
- 110 Smith B, Sparkes A. Men, sport, and spinal cord injury: an analysis of metaphors and narrative types. *Disab Soc* 2004; **19**: 613–626.
- 111 Levins SM, Redenbach DM, Dyck I. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study. *Phys Ther* 2004; **84**: 496–509.
- 112 Henwood P, Ellis JA. Chronic neuropathic pain in spinal cord injury: the patient's perspective. *Pain Res Manag* 2004; **9**: 39–45.
- 113 Lohne V, Severinsson E. Hope and despair: the awakening of hope following acute spinal cord injury – an interpretive study. *Int J Nurs Stud* 2004; **41**: 881–890.
- 114 Lohne V, Severinsson E. Hope during the first months after acute spinal cord injury. *J Adv Nurs* 2004; **47**: 279–286.
- 115 Lohne V, Severinsson E. Patients' experiences of hope and suffering during the first year following acute spinal cord injury. *J Clin Nurs* 2005; **14**: 285–293.
- 116 Ville I. Biographical work and returning to employment following a spinal cord injury. *Sociol Health Illn* 2005; **27**: 324–350.
- 117 Warms CA, Marshall HM, Hoffman AJ, Tyler EJ. There are a few things you did not ask about my pain: writing on the margins of a survey questionnaire. *Rehab Nurs* 2005; **30**: 248–256.
- 118 Isaksson G, Skar L, Lexell J. Women's perceptions of changes in the social network after a spinal cord injury. *Disab Rehab* 2005; **27**: 1013–1021.
- 119 Kinder RA. Psychological hardiness in women with paraplegia. *Rehab Nurs* 2005; **30**: 68–72.
- 120 McColl MA, Law M, Stewart D. *Theoretical Basis of Occupational Therapy*. Slack: Thorofare, NJ 1992.
- 121 DeLisa JA. Quality of life for individuals with SCI: let's keep up the good work. *J Spinal Cord Med* 2002; **25**: 1.
- 122 Patterson DR, Miller-Perrin C, McCormick TR, Hudson LD. When life support is questioned early in the care of patients with cervical-level quadriplegia. *New Engl J Med* 1993; **328**: 506–509.
- 123 Gerhart KA. Quality of life: the danger of differing perceptions. *Topics Spinal Cord Inj Rehab* 1997; **2**: 78–84.
- 124 Hammell KW. From the neck up: quality in life following high spinal cord injury. PhD thesis. University of British Columbia: Vancouver, Canada 1998.
- 125 Corbet B. Bully pulpit: bound for glory. *New Mob* 2000; **11**: 4.
- 126 Gerhart KA, Corbet B. Uninformed consent: biased decision-making following spinal cord injury. *HEC Forum* 1995; **7**: 110–121.
- 127 Hockenberry J. *Moving Violations*. Hyperion: New York 1995.
- 128 Bury M. Chronic illness as biographical disruption. *Sociol Health Ill* 1982; **4**: 167–182.
- 129 Corbin J, Strauss AL. Accompaniments of chronic illness: changes in body, self, biography and biographical time. *Res Sociol Health Care* 1987; **6**: 249–281.
- 130 Somner KL, Baumeister RF. The construction of meaning from life events. In: Wong PT, Fry PS (eds). *The Human Quest for Meaning*. Erlbaum: Mahwah, NJ 1998, pp 143–161.
- 131 Thompson NJ, Coker J, Krause JS, Henry E. Purpose in life as a mediator of adjustment after spinal cord injury. *Rehab Psychol* 2003; **48**: 100–108.
- 132 Hammell KW. Dimensions of meaning in the occupations of daily life. *Can J Occup Ther* 2004; **71**: 296–305.
- 133 Corbin J, Strauss A. Comeback: the process of overcoming disability. *Adv Med Sociol* 1991; **2**: 137–159.
- 134 Hammell KW. Psychosocial outcome following spinal cord injury. *Paraplegia* 1994; **32**: 771–779.
- 135 Herrick SM, Elliott TR, Crow F. Social support and the prediction of health complications among persons with spinal cord injuries. *Rehab Psychol* 1994; **39**: 231–249.
- 136 McColl MA, Skinner H. Assessing inter- and intrapersonal resources: social support and coping among adults with a disability. *Disab Rehab* 1995; **17**: 24–34.
- 137 Laxton AW, Perrin RG. The relations between social support, life stress, and quality of life following spinal decompression surgery. *Spinal Cord* 2003; **41**: 553–558.
- 138 Anson CA, Stanwyck DJ, Krause JS. Social support and health status in spinal cord injury. *Paraplegia* 1993; **31**: 632–638.
- 139 Schwartz CE, Sendor M. Helping others helps oneself: response shift effects in peer support. *Soc Sci Med* 1999; **48**: 1563–1575.
- 140 Stewart R, Bhagwanjee A. Promoting group empowerment and self-reliance through participatory research: a case study of people with physical disability. *Disab Rehab* 1999; **21**: 338–345.
- 141 Boekamp JR, Overholser JC, Schubert DS. Depression following a spinal cord injury. *Int J Psych Med* 1996; **26**: 329–349.
- 142 Christiansen C. Defining lives: occupation as identity: an essay on competence, coherence, and the creation of meaning. *Am J Occup Ther* 1997; **53**: 547–558.
- 143 Hammell KW. *Perspectives on Disability and Rehabilitation: Contesting Assumptions, Challenging Practice*. Churchill Livingstone: Edinburgh 2006.
- 144 Canadian Association of Occupational Therapists. *Enabling Occupation. An Occupational Therapy Perspective*. Author: Ottawa, ON 1997.
- 145 Bury M. The sociology of chronic illness: a review of research and prospects. *Sociol Health Ill* 1991; **13**: 451–468.
- 146 Keany KC, Glueckauf RL. Disability and value change: an overview and reanalysis of acceptance of loss theory. *Rehab Psychol* 1993; **38**: 199–210.
- 147 Crewe NM. Gains and losses due to spinal cord injury: views across 20 years. *Topics Spinal Cord Inj Rehab* 1996; **2**: 46–57.
- 148 Sartre J-P. *Being and Nothingness*. (tr: H. Barnes). Washington Square: New York, NY 1956.
- 149 Miles M. Disability in an Eastern religious context: historical perspectives. *Disab Soc* 1995; **10**: 49–69.
- 150 Iwama M. The *Kawa* [river] model. In: Kronenberg F, Algado SS, Pollard N (eds). *Occupational Therapy Without Borders*. Elsevier: Edinburgh 2005, pp 213–227.
- 151 Yoshida K, Willi V, Parker I, Self H, Carpenter S, Pfeiffer D. Disability partnerships in research and teaching in Canada and the United States. *Phys Can* 1998; **Summer**: 198–205.