

REVIEW

The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review

J Lynch¹ and R Cahalan²

Study design: Literature review.

Objectives: To provide a detailed review of the literature regarding the impact of spinal cord injury (SCI) on the quality of life (QOL) of family members who have become the primary caregiver and to highlight potential interventions available.

Methods: Appropriate databases were searched for relevant peer-reviewed studies. Twenty-five studies (four qualitative and 21 quantitative) were identified which investigated the role that family members play in caring for people with SCI and the impact it has on their QOL.

Results: Depression, anxiety, physical symptoms and reduced satisfaction with life in primary family caregivers of patients with SCI were commonly reported across the literature. Isolation, loss of identity and role changes were also regularly reported as negative outcomes of caregiving for someone with an SCI. A range of interventions (including family training, problem-solving training and support groups) have been shown to have benefits for family caregivers' QOL.

Conclusion: SCI impacts significantly on the QOL of family caregivers, with major implications for physical, mental and social aspects of caregiver health. This review highlights that these important issues are problematic internationally and may persist over several decades. The need for focused interventions to support family caregivers of spinal cord injured persons, with particular emphasis on increasing patient/family education and access to support groups, is recommended.

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INTRODUCTION

Spinal cord injury (SCI) is a life-altering condition that significantly impacts upon the person affected, immediately altering their daily life, independence and role within their family and society.¹ In certain instances, SCI may render a person dependent on caregivers, with family members often forced to take on the role for a variety of social and economic reasons.^{2,3} Costs associated with SCI are higher than those of comparable conditions such as dementia, multiple sclerosis and cerebral palsy,¹ with annual healthcare and living expenses incurred approximating US\$185 000 in some cases.⁴ This financial burden in addition to any income forgone by the patient can have a significant effect on the entire family unit.⁵

The World Health Organisation (WHO) describes quality of life (QOL) 'as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment'.⁶ Within this broad definition are important areas including satisfaction with life, self-esteem, pain and mood. As such, QOL can be perceived as poor in certain domains and acceptable or good in others. The complexity of such a concept has resulted in a plethora of approaches to measuring QOL. In this study, QOL will focus on aspects including mental and physical health and life satisfaction.

There is much published evidence to highlight the impact of caregiving on the QOL of family members caring for people with a variety of conditions including cancer,⁷ stroke,⁸ traumatic brain injury,⁹ multiple sclerosis,¹⁰ Parkinson's disease,¹¹ dementia¹² and palliative conditions¹³ with common themes of increased anxiety, depression, burden and lower satisfaction with life frequently reported. The aim of this study is to review the published literature regarding the impact of SCI on the QOL of family caregivers, to highlight common themes addressed, to discuss outcome measures used and suggest possible interventions.

MATERIALS AND METHODS

Search strategy

In November 2016, a detailed search of electronic databases Medline, Amed, Cinahl Plus, SportDiscus, PsycArticles, PsycInfo, Embase, ScienceDirect, Pedro and Cochrane Library was conducted for published, peer-reviewed journals from 1979 to the present. The search terms applied were 'spinal cord inj*' AND 'care*' AND 'family' OR 'spouse'. Results were screened for relevance and reference lists of accepted studies were also searched.

Inclusion and exclusion criteria

Inclusion criteria

- Family members who are primary caregivers of adult (18 years+) SCI survivors.
- Studies assessing QOL or life satisfaction of caregiver.

¹Physiotherapy Department, National Rehabilitation Hospital, Dublin, Ireland and ²Health Sciences Building, Faculty of Education and Health Sciences, University of Limerick, Limerick, Ireland

Correspondence: J Lynch, Physiotherapy Department, National Rehabilitation Hospital, Rochestown Avenue, Dun Laoghaire, Dublin A96P235, Ireland.
E-mail: john.lynych@nrh.ie

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- Peer-reviewed, published journals from 1979 to present.
- English language full text available.

Exclusion criteria

- Unable to isolate SCI data from other conditions (for example, traumatic brain injury).
- Studies featuring non-family carers.
- Non-peer-reviewed, published articles, case studies or conference presentations.

Assessment of methodological quality

Methodological quality was assessed using the Oxford Centre for Evidence-Based Medicine levels of evidence guidelines¹⁴ for the quantitative studies and using the recommendations described by Anderson¹⁵ for the qualitative studies.

RESULTS

The database searches yielded 1147 studies, which after screening of abstracts and application of inclusion/exclusion criteria resulted in 22 studies being included for this review (Figure 1). The most common reasons for exclusion were studies containing non-family carers, studies containing a combination of conditions (not exclusively SCI) and non-published studies. Three additional studies were identified from the reference lists of the initial search results, giving a total of

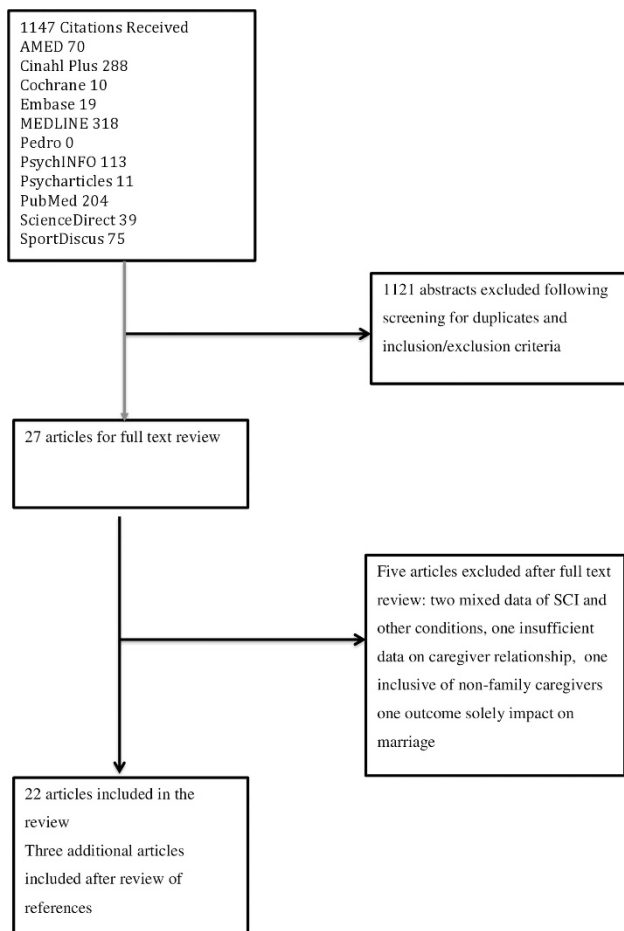


Figure 1 Flow chart of study selection procedure. A full color version of this figure is available at the *Spinal Cord* journal online.

25 studies reviewed, four of which were qualitative in nature (Table 1) and 21 of which contained quantitative data (Table 2).

Quality of studies

Under the Oxford Centre for Evidence-Based Medicine Levels of Evidence system, the majority of studies reviewed were considered level 3 studies consisting of cross-sectional studies (with inconsistently applied reference standard and blinding), often with non-randomized samples and small sample sizes. There were four level 2 studies reviewed—all of which were randomised controlled trials,^{16–19} but these studies had a number of inherent weaknesses including small study cohorts and inconsistent description of processes involved¹⁸ in addition to poor completion rate.¹⁷ All of the qualitative studies^{20–23} give explicit descriptors of the subjects involved, the recruitment process, and the methodology used to transcribe, synthesise and analyse data. All studies consistently use direct quotations from the subjects throughout the results and discussion sections to support themes identified and emphasise the importance of the results identified in the work. Three of the studies^{20,22,23} also highlight potential limitations to their research—specifically in recruitment of subjects^{20,22} and small sample sizes.^{21–23} Despite the potential biases, the qualitative studies ensure the results are relevant through detailed description of the processes involved, use of experienced investigators and thorough recording and analysis of the interviews and provide additional insight into the challenges the family caregiver faces that are not captured in the quantitative research. Details of study design, data collection methods, participants and main findings are presented in Tables 1 and 2. Further evaluation of the qualitative studies is presented in Table 3.

Interventions and outcome measures

Numerous interventions to support family caregivers are discussed in the reviewed studies. These include face-to-face problem-solving training,¹⁶ video problem-solving training,¹⁷ psycho-educational interventions,¹⁸ computer/telephone technology¹⁹ and support groups.²⁴ Frequency of interventions varied from monthly interventions^{16,17} to three times a week,²⁴ with the duration of each intervention lasting 60–90 min in most instances.^{18,19,24}

These studies suggest that education and standardised information are the most beneficial interventions in improving the health and outcomes of the caregiver, particularly when sessions also include the care recipient. These interventions are shown to improve caregiver general health, mental health, physical functioning and bodily pain outcomes. Group sessions are also reported to help with social integration, feelings of isolation and regaining a sense of identity through meeting other families in similar positions in addition to interacting with and learning from trained healthcare professionals. Support groups were also shown to positively impact upon caregiver QOL (Table 4)²⁴. A common theme in many of the studies was the need to include family members in the rehabilitation process post-SCI from the outset.^{2,5,16–19,24–26} Also, that there may be some potential for tele-health^{16,17} and community based support² to help assist caregivers on an ongoing basis.

A variety of outcome measures were used in the studies reviewed, with 28 different quantitative outcome measures employed to assess the broad range of issues that impact upon QOL. This may be reflective of both the breadth of defining a topic such as QOL and also the diverse geographical locations and languages of the participants for each of the studies. As discussed previously, QOL encompasses a broad range of domains including physical and mental health, and this is reflected in the diversity of outcome measures used by the studies in

Table 1 Qualitative studies focussing on SCI family caregivers' experiences

Reference and Country	Sample size and caregiver sex	Family member	Recruitment location	Data collection	Qualitative analysis	Findings
Charliffe <i>et al.</i> ²⁰ USA	73 (11 Male, 62 female)	39 Spouses/partners, 27 Parents, 7 Other relatives	Four SCI rehabilitation Facilities in USA	Semi-structured interview as a focus group at each of the facilities involved, lasting 90–120 min. Total of 16 focus groups completed	Groups recorded and transcribed verbatim, systematic qualitative analysis using NVivo Software. Constant comparative analysis used for each transcript, concepts identified using open and axial coding	Four main themes identified (positive/negative aspects of caregiving, health issues, life changes and sources of strength/coping strategies). Positive and negative issues involved in caregiving but 'positive aspects were disproportionately limited in comparison to negative themes'. Emotional/physical strain, loss of identity and fatigue/lack of sleep common issues. Lack of spontaneity and limited socialisation problematic. Feeling more and less appreciated by family members highlighted, friends/co-workers source of support, others find support from within
Chen and Boore ²¹ Taiwan	15 (2 Male, 13 female)	8 Parents, 5 spouses, 1 Child, 1 Sibling	Rehabilitation hospital in Taiwan	Semi-structured interview and group discussion	Line-by-line <i>in vivo</i> coding, categories and subcategories identified	3 Categories identified: (1) 'catastrophic life event' (worry, uncertainty, family role changes); (2) 'confronting challenges' (future planning, seeking education); and (3) 'family resilience' or 'family breakdown' (positive or negative support systems, communication)
Dickson <i>et al.</i> ²² UK	11 (1 Male, 10 female)	Spouses	GENSIUS and SIS	1 in GENSIUS, 10 in caregivers homes, interview, open-ended, non-directive question	Interpretative phenomenological analysis, master themes and sub-themes identified	3 Master themes: (1) 'emotional impact of SCI' (fear, grief, loss, anxiety, uncertainty); (2) 'post-SCI shift in relationship dynamics' (role reversal, maternal-role adoption); and (3) 'impact of caregiving on identity' (loss of identity)
Lucke <i>et al.</i> ²³ USA	9 (1 Male, 8 female)	5 Spouses, 4 Parents	Three SCI Centres in Southern Texas	Semi-structured interviews (11 in total), two face-to-face and seven via telephone due to difficulty travelling to SCI centre	Recorded and transcribed bilingually (English and Spanish), Spanish answers translated to English by the team involved. Grounded theory data analysis approach taken, constant comparative analysis used to identify the categories	Resolving to Go Forward was the core category identified in themes of 'learning to care for' the SCI survivor and 'getting through' the difficulties. Facing the future best for family in spite of physical/emotional tolls taken on caregiver. Caregivers neglecting their own health highlighted, negative perception of external paid home-care workers. Feeling isolated, alone, overwhelmed and sad. Sense of loss and loss of role in family.

Abbreviations: GENSIUS, Queen Elizabeth National Spinal Injuries Unit Scotland; SCI, Spinal Cord Injury; SIS, Spinal Injuries Scotland.

Table 2 Quantitative studies focussing on SCI family caregivers' experiences

Reference and country	Sample size and caregiver sex	Family member	Length of caregiving role (years/hours per week)	Study design recruitment	Outcome measure (s) used	Findings
Arango-Lasprilla <i>et al.</i> ² Colombia	37 (5 Male, 32 female)	18 Parents 11 Spouses 6 Siblings 2 Other family members	11.79 (±8.83) years 79.9 (±45.3) hours per week	Cross-sectional, recruited from local foundation for disabled rights (convenience sample)	CNQ, ZBI, PHQ-9, SWLS and ISEL-12	21 Caregivers report 'no depression, 16 report being dissatisfied with life abe 25 report some level of burden and being overwhelmed by role as caregiver. Younger caregivers scored better for physical abilities but less so for coping skills, older caregivers had better coping skills but more physical ailments.
Blanes <i>et al.</i> ³ Brazil	60 (11 Male, 49 female)	16 Wives 14 Sisters 11 Mothers 19 Other family members	5.2 (±4.9) years 79.1 (±58.03) hours per week	Cross-sectional, convenience sample recruited via outpatients departments at 'Sao Paulo Hospital and two rehabilitation centres'	Short form health survey (SF-36), CBS	Care recipients primarily male low scores on all domains of SF-36 and CBS, bodily pain and vitality scoring lowest. 23 Caregivers suffering from chronic illness; score significantly worse for pain, physical function, general health and mental health
Chan ²⁵ China	40 (5 Male, 35 female)	40 Spouses	≥2 years No information given on hours/week caregiving	Cross-sectional, purposive sample. Structured questionnaires and semi-structured interviews, recruited from local hospital and health centres	PSR, WOC, BDI, SWLS, CBI	Spouses with external locus of control, poor coping strategies and limited social support (<i>n</i> = 11) scored highly for depression and burden and low for satisfaction with life. Those in full-time employment suffered most with stress
Coleman <i>et al.</i> ⁵ Colombia	34 (3 Male, 31 female)	No details provided	≥6 Months No information given on hours/week caregiving	Cross-sectional, convenience sample recruited from local foundation for disabled rights	ZBI, SWLS, PHQ-9, RSES, STAI	Physical function, pain and general health significantly associated with caregiver burden, anxiety and satisfaction with life. Poor general health in SCI survivor linked to low caregiver satisfaction with life. Lower pain levels in SCI survivors associated with higher burden, anxiety, depression and lower self-esteem in caregivers. No statistically significant link between employment and satisfaction with life or depression
Decker <i>et al.</i> ⁴² USA	67 (8 Male, 59 female)	57 Spouses 10 Other family members	No information given on total years caregiving No information given on hours/week caregiving	Cross-sectional, recruited via family member with SCI who had previously participated in research by the author	LSIA-A, CES-D, non-standardised 'Likert-type' scales assessing 'health status', 'social support' and 'perceived control'	Better perceived health and social support associated with less depression and higher life satisfaction, Lower life satisfaction and increased depression associated with increased hours caregiving, needing increased assistance with ADLs and increased perceived burden. Caregivers not more at risk of depression than normal populace
Dreer <i>et al.</i> ²⁹ USA	121 (18 Male, 103 female)	46 Spouses 45 Parents 10 Sisters 9 Children 11 Other family members	< One year ≥42 hours per week	Cross-sectional, recruited during initial inpatient admission	IDD, SPSI-R	More severe injury for SCI survivor more likely to lead to caregiver depression. 19 caregivers meet criteria for major depressive disorder. Depressed caregivers more likely to report problems with pain and ill-health and to display dysfunctional problem-solving style.
Ebrahimzadeh <i>et al.</i> ³³ Iran	37 (0 Male, 37 female)	37 Spouses	Not stated clearly, but reported > 20 years No information given on hours/week caregiving	Cross-sectional, convenience sample recruited through local University	SF-36	Significantly lower mental health scores in wives than in their SCI surviving husbands. Lower general health and higher bodily pain scores in wives than husbands also noted. Better physical function scores in SCI husbands correlated with better mental health scores in wives 29 caregivers unemployed

Table 2 (Continued)

Reference and country	Sample size and caregiver sex	Family member	Length of caregiving role (years/hours per week)	Study design recruitment	Outcome measure (s) used	Findings
Ebrahimzadeh et al. ³⁰ Iran	72 (0 Male, 72 female)	72 Spouses of SCI patients Control cohort of 74 spouses of non-SCI injured patients at local clinic	Not stated clearly, but reported >20 years No information given on hours/week caregiving	Cross-sectional, prospective study. Convenience sample recruited via local military organisation	HADS, WHOQOL-BREF	All outcomes worse for spouses of SCI survivors than control, with significantly higher depression also noted. Higher depression associated with youth, lower education and lower QOL. Lower QOL associated with higher probability of anxiety. 64 Caregivers unemployed
Ebrahimzadeh et al. ³¹ Iran	72 (0 Male, 72 female)	72 Spouses	<22 years for 48 caregivers, ≥22 years for 24 caregivers	Cross-sectional, convenience sample, recruitment method not explained	SF-36	All sub-scales of SF-36 significantly lower for spouses in this study than normative values for Iranian women. Older caregivers had reduced physical function and QOL. Better educated caregivers had better physical function and QOL. Being employed and longer duration of caregiving associated with lower physical functioning and QOL. 64 Caregivers unemployed
Elliott and Berry ¹⁶ USA	60 (11 Male, 49 female)	22 Spouses 26 Parents 7 Siblings 4 Children 1 Other family member	< one year No information given on hours/week caregiving	RCT. Controls: <i>n</i> = 30 Intervention: <i>n</i> = 30 Intervention: three face-to-face problem-solving technique sessions. Educational materials and telephone contact as requested	SF-36, IDD, SPSI-R	Outcomes measured at baseline, 6 months and 12 months. Individually tailored problem-solving technique and ongoing education lowered dysfunctional problem-solving (which is associated with increased depression and lower mental health). However no significant effect was noticed for the intervention reducing depression in family caregivers. No figures on employment status of groups
Elliott et al. ¹⁷ USA	61 (7 Male, 54 female)	24 Spouses 19 Parents 4 Grandparents 3 Siblings 5 Daughters 6 Other family members	2.67 (±5.7) years No information given on hours/week caregiving	RCT. Controls: <i>n</i> = 29, Intervention: <i>n</i> = 32 Intervention: monthly problem-solving training sessions via video-link. Recruited via inpatient rehabilitation facility and community	SF-36, IDD, SWLS	Outcomes measured at baseline, 6 and 12 months. At 6 month assessment, problem-solving technique appears to reduce depression but by 12 month assessment, no difference noted. 28 Caregivers discontinued study (<i>n</i> = 16 of control group, <i>n</i> = 12 of intervention) which authors state affected the outcome and thus cannot make conclusion about the impact of problem-solving technique via video-link. However, the suggested problem-solving technique may help social functioning of caregiver over time. No figures on employment status of groups.
Lucke et al. ²⁶ USA	10 (1 Male, 9 female)	4 Mothers 4 Spouses 2 Sisters	<6 Months No information given on hours/week caregiving	Mixed-method longitudinal design. Convenience sample recruited prior to discharge from inpatient facility, face-to-face in-depth interviews	SF-36, VAS for QOL	Outcomes measured at 1, 3 and 6 months post-inpatient rehabilitation. SCI survivors generally scored lower than caregivers in all domains except mental health and vitality. Caregiver QOL lower at 3 months but returns to initial level at 6 months (suspected due to physical improvements/independence in paraplegic patients and provision of paid carers for tetraplegics). No figures on employment status of groups

Table 2 (Continued)

Reference and country	Sample size and caregiver sex	Family member	Length of caregiving role (years/hours per week)	Study design recruitment	Outcome measure (s) used	Findings
Molazem <i>et al.</i> ¹⁸ Iran	62 (3 Male, 59 female)	24 Spouses 32 Parents 4 Sisters 2 Other family members	9.00 (±6.5) years No information given on hours/week caregiving	RCT, Controls: <i>n</i> = 36, Intervention: <i>n</i> = 26 Intervention: 4 × 90 min. educational sessions Recruited via referral to local welfare organisation	SF-36	Outcomes measured pre-intervention, 2 weeks and 6 weeks post-intervention. 13 caregivers discontinued study (<i>n</i> = 6 of intervention and <i>n</i> = 7 of control) due to insufficient participation/withdrawal. All participants showed low QOL, particularly in mental health sub-set. After intervention, non-significant improvements in caregivers' vitality, bodily pain, general health and mental health reported. No figures on employment status of groups
Nogueira <i>et al.</i> ⁴¹ Brazil	59 (6 Male, 53 female)	22 Spouses 14 Mothers 9 Sisters 14 Other family members	No information given on total years caregiving No information given on hours/week caregiving	Cross-sectional, observational study Recruited via Brazilian Unified Health System, Sao Paulo	SF-36, CBS	All aspects of SF-36 reduced, especially role physical and pain. This was worse for caregivers of tetraplegics. Reduced QOL reported for caregivers, especially if care recipient has complications. Hypertension and depression also reported.
Nogueira <i>et al.</i> ⁷³ Brazil	59 (6 Male, 53 female)	22 Wives 14 Mothers 9 Sisters 14 Other family members	No information given on total years caregiving Range of care hours 'from half an hour to the entire day', no further detail given	Cross-sectional Survey in institutions accredited by Unified Health System from 1998 to 2008 to identify appropriate families	SF-36 (Portuguese version 'culturally adapted to Brazil')	Lowest mean scores associated with role physical, bodily pain, vitality and role emotional. Age and hours spent on care daily negatively correlated with all domains of SF-36, weak positive correlation seen for increased length of time caregiving (in years). Female caregivers scored lower for role physical and role emotional, male caregivers scored lower for physical functioning, bodily pain, general health and social role
Paker <i>et al.</i> ⁶⁰ Turkey	31 (11 Male, 20 female)	14 Spouses 11 Siblings 2 Mothers 2 Children 2 Other relatives	No information given on total years caregiving No information given on hours/week caregiving	Cross-sectional Recruited during initial inpatient admission	HADS, Brief WOC	High anxiety and depression in early stages post-injury, both correlated negatively with SCI duration (i.e. the longer post-injury, the lower the anxiety and depression)
Raj <i>et al.</i> ²⁸ India	53 (27 Male, 26 female)	18 Parents 16 Spouses 9 Siblings 5 Children 5 Other family members	No information given on total years caregiving No information given on hours/week caregiving	Cross-sectional Recruitment method not clearly explained	LSS, Revised CIS-R	28 Caregivers score highly for psychiatric morbidity (most commonly depression or mixed anxiety depression) with female spouses at statistically significant higher risk. Similarly, female spouses scored significantly lower on LSS. No figures on employment status of groups
Schulz <i>et al.</i> ¹⁹ USA	173 (42 Male, 131 female)	120 Spouses 4 Parents 14 Children 34 Other family members	1–63 Years (median = 8 years) No information given on hours/week caregiving	RCT (dual intervention) Control group: <i>n</i> = 60 Intervention 1 (caregiver only): <i>n</i> = 56 Intervention 2 (dual-target caregiver/	CES-D, ZBI	Outcomes measured at baseline, 6 and 12 months post intervention. 26 Caregivers discontinued study (<i>n</i> = 20 of intervention and <i>n</i> = 6 of control) with main reasons refusal to continue, unable to contact, moving out of area, illness and death. Caregivers in dual-participant group (caregiver and recipient both involved in

Table 2 (Continued)

Reference and country	Sample size and caregiver sex	Family member	Length of caregiving role (years/hours per week)	Study design recruitment	Outcome measure (s) used	Findings
Shejia and Manigandan ²⁴ India	36 (2 Male, 34 female)	36 Spouses	No information given on total years caregiving No information given on hours/week caregiving	Quasi-experimental pretest/post-test design, thrice weekly. One hour group sessions for seven sessions (experimental) versus nointervention (control) Limited information on recruitment process	HADS, WHOQOL-BREF, GHQ-12	Reports of significant anxiety and depression in the group pre-intervention. Significant improvement in QOL and reduction in anxiety and depression in experimental group after intervention. Three subjects in paid employment, 33 housewives. 20 spouses report 'receiving help' with caregiving
Shewchuk <i>et al.</i> ³² USA	62 (8 Male, 54 female)	Not mentioned	No information given on total years caregiving No information given on hours/week caregiving	Longitudinal design, assessments carried out at 1, 6 and 12 months post discharge from in patient rehabilitation	CESD, STAI, PILL, PANAS	Considerable distress, anxiety and depression recorded among family caregivers, with higher anxiety recorded among caregivers of younger SCI survivors. Caregiver anxiety also linked to caregiver physical health. No figures on employment status of groups
Weitzenkamp <i>et al.</i> ²⁷ UK	124 (12 Male, 112 female)	124 Spouses, only 80 reported as being primary caregiver	Not mentioned, but SCI survivors reported to have had SCI for 'at least 23 years' No information given on hours/week caregiving	Population-based longitudinal study	CESD, PSS, LSI-Z, QOL and Individual Needs Questionnaire	Caregiving partners had more depression, physical and emotional stress, fatigue, anger and burnout than non caregiving spouses, with lower satisfaction with their lover and lower well-being. Spouses more depressed than their SCI surviving partner. No figures on employment status of groups. No figure on hours per week caregiving.
				care recipient): <i>n</i> = 57 Control group: standardized packet of written information on SCI and three 'check-in' telephone calls over 9 months intervention for both groups: seven 60–90 min individual sessions and five structured, telephone-based support group sessions over 6 months		intervention) had significantly less health problems and significantly lower depression than caregiver only intervention group and control group. 24 unemployed, 45 retired, 17 home-makers and 87 employed.

Abbreviations: ADLs, activities of daily living; BDI, Beck Depression Inventory; CBS, Carer Burden Scale; CBI, Caregiver Burden Inventory; CES-D, Centre for Epidemiologic Studies—Depression Scale; CNQ, Caregiver Needs Questionnaire; HADS, Hospital Anxiety Depression Scale; IDD, Inventory to Diagnose Depression; ISEL, Inter-personal Support Evaluation List; LSI/A-A, Life Satisfaction Index-A; PSR, Provision of Social Relationship; PHQ9, Patient Health Questionnaire; QOL, quality of life; RCT, randomised controlled trial; RSES, Rosenberg Self-Esteem Scale; SCI, spinal cord injury; ZBI, Zarit Burden Interview; SWLS, satisfaction with life scale; SPSHR, SF-36, Social Problem-Solving Inventory—Revised; STAI, State Trait Anxiety Inventory; WOC, ways of coping checklist; WHOQOL-BREF, World Health Organisation Quality of Life-BREF.

Table 3 Evaluating qualitative studies (Anderson¹⁵)

Reference	Clear research question?	Terminology explained and ethical approval process described?	Selection criteria clearly explained, recruitment method described and study sample/location described?	Method of recording and transcribing data and process of analysing and verifying described? Themes identified?	Sufficient data presented to allow reader to assess if interpretation is accurate?	Outlying negative or deviant cases highlighted?	Findings presented in relation to other research in the area?	Discussion of existing literature and how present research contributes to it?	Strengths, limitations and potential biases discussed?
Charliffe <i>et al.</i> ²⁰	Yes—clearly identified in the abstract for the study	Yes—terminology broadly described, abbreviations explained and approval from Institutional Review Boards acknowledged	Yes—including demographic data, location and method of recruitment and inclusion/exclusion criteria	Yes—recording and verbatim transcribing of groups, Nvivo 8 software used to assist systematic qualitative analysis, three researchers independently examined each transcript using constant comparative analysis using open and axial coding to identify themes, consensus used when differences on appropriate coding occurred	No—specific quotations used to back up themes identified but limited data given numbers involved	No	Yes	Yes	Yes—convenience sampling used, carers were predominantly of tetraplegic patients, no mention of complete or incomplete injuries
Chen and Boore ²¹	Yes—aims explained in abstract and introduction	Yes—terminology broadly described, abbreviations explained and approval from Institutional Review Boards and University Ethics Committee obtained	Yes—informed consent obtained by all participants. Demographic data, location and inclusion criteria recorded	Yes—Grounded theory approach used. Semi-structured, tape recorded interviews. <i>In vivo</i> coding identified categories and subcategories. Constant comparative analysis used with triangulation to help develop themes	No—specific quotations used to back up themes identified but limited data. Small numbers involved.	No	Yes	Yes	No—mention of triangulation used to help strengthen research but otherwise limited
Dickson <i>et al.</i> ²²	Yes—aim explained in abstract	Yes—ethical approval obtained from relevant NHS board and institution involved, limited explanation of terminology (e.g. interpretative phenomenological analysis)	Yes—recruitment location and process clearly explained, inclusion and exclusion criteria stated, limited information on subjects recorded	Yes—interviews recorded and transcribed verbatim, roles of each reviewer explicitly stated and process of developing themes reported (using interpretative phenomenological analysis)	No—specific quotations used to back up themes identified but limited data. Small numbers involved.	Yes—specific examples of contrasting and outstanding feedback highlighted	Yes	Yes	Yes—possible selection biases identified in recruitment process, three authors involved in conducting interviews and analysing data, use of triangulation to help with reducing bias, all involved had marriages that survived the SCI
Lucke <i>et al.</i> ²³	Yes—detailed description in abstract	Yes—terminology broadly explained and approval from Institutional Review Boards acknowledged	Yes—including demographic data, location and method of recruitment and inclusion/exclusion criteria	Yes—semi-structured interviews, grounded theory approach using constant comparative analysis, separately coded and then consensus used as needed	No—specific quotations used to back up themes identified but limited data. Small numbers involved.	No	Yes	Yes	Yes—small sample size, time and distance to travel highlighted as issues, researchers involved in translation of interviews from Spanish to English in some instances

Abbreviations: NHS, National Health Service; QOL, quality of life; SCI, spinal cord injury.

Table 4 Types of intervention and outcomes achieved

Reference and country	Type of intervention	Frequency of assessment	Outcome measure (s) used	Outcomes
Elliott and Berry ¹⁶ USA	Problem-solving training Intervention a combination of three face-to-face PST sessions (baseline, 6 months and 12 months) with educational materials and telephone contact as requested vs control of 'usual care' consisting of usual access to outpatient staff and information from rehabilitation centre regarding SCI management PST was explained in the steps as per Elliott <i>et al.</i> ¹⁷	Outcomes measured at baseline, 6 months and 12 months post-participation	SF-36, IDD, SPSI-R	Post-intervention outcomes show a decrease in dysfunctional problem-solving over time for caregivers who received PST and an increase among caregivers in the control condition. Both groups had declining physical functioning over time but the rate of decline was much steeper for caregivers assigned to the control group. Social functioning increased over time in the intervention group but neither of these changes were significant.
Elliott <i>et al.</i> ¹⁷ USA	Video PST Intervention a combination of initial face-to-face introduction/training of technology followed by 12, monthly video PST sessions and telephone contact as requested vs control of standard education materials with opportunity to discuss same at monthly video-conferencing interaction. PST was explained in five basic steps: (a) problem definition; (b) optimism and positive orientation toward problem-solving; (c) creativity and generating alternatives; (d) understanding and decision-making; and (e) solving the problem with implementation and evaluation of a solution	Outcomes measured at baseline, 6 months and 12 months post-participation	SF-36, IDD, SWLS, SPSI-R	28 Caregivers discontinued the study and their follow-up data were unavailable at the final assessment. Post-intervention results show older caregivers were more likely than younger caregivers to remain in the study. Intent-to-treat analyses projected a significant decrease in depression among caregivers receiving PST; efficacy analyses indicated this effect was pronounced at the 6th month assessment
Molazem <i>et al.</i> ¹⁸ Iran	Group educational sessions Intervention of 90 min sessions once a week for 4 weeks vs control of education booklet only Intervention a combination of lecture, questions and answers, and discussion. Specifics of intervention broadly described as 'strategies of coping with stress and depression, relaxation techniques, crisis confrontation strategies, principles of correct relationship within the family, and strategies for providing the SCI patients with correct physical care, preventing backache, and accurately transferring the patients from the bed to the wheelchair and vice-versa'	Outcomes Measured pre-intervention, 2 weeks and 6 weeks post-intervention	SF-36	All the study participants had a low QOL and the lowest score was related to mental health in both groups. Post-intervention results showed all dimensions of the intervention group caregivers' life quality had improved while no significant difference was observed in the control group. A statistically significant difference was found between the two groups regarding all the dimensions of life quality
Schulz <i>et al.</i> ¹⁹ USA	Individual education sessions and telephone support group Dual intervention groups of caregiver only intervention and caregiver/care-reipient dyad vs control of three 'check-in' telephone calls and standard written information on SCI, aging, community resources and caregiving Intervention delivered over 6 months consisting of seven 60–90 min individual sessions and five structured telephone support groups, and standard written information as per control group above. Intervention targetted five areas: lack of caregiving knowledge, social support/integration, emotional well-being, communication and self-care/physical health	Outcomes measured at baseline, 6 months and 12 months post-participation	CES-D, ZBI	26 Caregivers discontinued study (20 from intervention groups and 6 from control group) with main reasons refusal to continue, unable to contact, moving out of area, illness and death. Caregivers in dual-participant group (caregiver and recipient both involved in intervention) had significantly less health problems and significantly lower depression than caregiver only intervention group and control group, and improved QOL compared with the control group

Table 4 (Continued)

Reference and country	Type of intervention	Frequency of assessment	Outcome measure (s) used	Outcomes
Shejia and Manigandant ²⁴ India	Support groups Intervention of 1 h sessions thrice weekly, totalling seven sessions over 2 weeks vs control of no intervention Intervention based on 'RISEUP' programme with each session discussing a 'core topic' which were: introduction, group interaction, stresses in life, problems faced and strategies employed, coping strategies, return to community and revision and summary Layout of sessions consist of 'warm-up', 'discussion of previous sessions' home task', 'discussion on specific core topic', 'assignment of home task' and 'wind down'	Outcomes measured preassessment and at end of intervention period (2 weeks)	HADS, WHOQOL-BREF, GHQ-12	Pre-intervention, both groups had significant depression and anxiety with no significant difference in their levels of depression, anxiety and quality of life before intervention Post-intervention results showed significant improvement in all domains of QOL in the experimental group as compared to the control group, with significant reduction in anxiety and depression also noted in the intervention group

Abbreviations: CES-D, Centre for Epidemiologic Studies—Depression Scale; IDD, Inventory to Diagnose Depression; PST, problem-solving training; SCI, spinal cord injury; SF-36, Short Form 36; SPSI-IR, Social Problem-Solving Inventory; SWLS, Satisfaction With Life Scale; QOL, Quality of Life; ZBI, Zant Burden Interview.

the current review. Table 5 provides further detail on the construct or area measured by each outcome measure, as well as the associated psychometric properties of each. Due to the heterogeneity of outcome measures used in this review, it was not possible to perform a meta-analysis on the data.

Caregiver characteristics

The mean age for caregivers (where available) was between 40 and 45 years of age. Caregiver ages varied geographically with older mean ages noted in the USA^{16,17} and the UK²⁷ and younger mean ages in India²⁸ and Brazil.³ Similarly, the period of time devoted to caregiving (when reported) varied from between 42 and 79 hours a week.^{2,3,29} Interestingly, the two studies with the highest number of hours spent caregiving^{2,3} also reporting close to 50% of caregivers being in employment outside of the home. Additional caregiver characteristics, including gender and relationship to care recipient, are presented in Tables 1 and 2.

Quality of life of caregivers

The qualitative studies reviewed^{20–23} highlighted several common issues for SCI caregivers. These included fear, uncertainty and familial role changes that occur following SCI, as well as the impact these changes have on the care recipients, caregivers and the wider family dynamic. Loss of identity was also reported to occur in line with role changes, specifically with the perceived change from partner and lover to carer.

The quantitative studies reviewed reported on a broad range of issues that affect caregiver QOL with higher than normal levels of depression,^{19,24,27,28,30–32} anxiety,^{24,28,30,32} stress,^{25,27} distress,^{28,32} and lower overall satisfaction with life^{5,28} reported. Mental health of caregivers was found to be worse than that of care recipients in several studies,^{27,33} with feelings of being overwhelmed by their role reported by 68% of caregivers in one study.² Specific factors such as poor general health of care recipient³³ and dysfunctional problem-solving skills^{16,29} were linked to negative outcomes for carers.

DISCUSSION

This literature review is the first of its kind to investigate the significant issues affecting the QOL of primary family caregivers of people with SCI. The review has identified a range of physical and psychological stressors and pathologies that are suffered by primary caregivers when a loved one is affected by SCI. These include depression, anxiety, poor general health, relationship and financial pressures, stress and a lower overall satisfaction with life. A number of interventions have been suggested as potentially useful in supporting primary caregivers, with early intervention by support services being particularly important.

The negative impact of caregiving on the QOL of the family members involved in caring for loved ones with long-term pathology has been documented for a variety of conditions including stroke,³⁴ cancer,³⁵ multiple sclerosis¹⁰ and other chronic illnesses³⁶ and consequently it is unsurprising that similar issues are identified in SCI. There is a notable reduction in mental health with depression,^{29,30} anxiety,^{24,28} sleep disturbances³⁷ and isolation² identified as common themes reported for family caregivers of people with SCI. In addition, SCI caregivers also frequently report pain^{3,5} and poor physical health.^{3,27,33} This is likely due to the regular, often physical nature of caregiving for people with SCI, with tasks such as assisting with cleaning, dressing and toileting the SCI survivor along with performing rehabilitation exercises daily highlighted as being particularly stressful and tiring.²⁰ Performing intimate care (bladder and bowel

Table 5 Outcome measures used ADDIN EN.REFLIST ADDIN

<i>Outcome measure</i>	<i>Construct measured</i>	<i>Psychometric properties</i>	<i>Description</i>
BDI ²⁵	Depression	High reliability, very good concurrent, content, and structural validity ⁵⁹	21-Question scale, scored 0-3, total score 0-63, higher scores indicate increased severity of depression
Brief Ways of Coping Questionnaire ⁶⁰	Coping	Nil reported	30 Items, assessing five factors (self-confidence, optimistic, submissive, helplessness, seeking social support strategies). Higher scores in each factor demonstrate increased use of those coping strategies
CBI ²⁵	Caregiver burden	Internal consistency reliability of each factor 0.85, 0.85, 0.86, 0.73 and 0.77, respectively ⁶¹	24-Item questionnaire, 5 sub-scales (time dependence, developmental, behaviour, physical burden, social burden), scored 0-4, total score 0-48. Higher scores in each factor demonstrate increased use of those coping strategies
CBS ^{3,41}	Caregiver burden	Internal consistency of 0.87, correlation with depressive symptoms CES-D of 0.38 ⁶²	22 Items grouped in five dimensions (general strain, isolation, disappointment, emotional involvement and environment), scored 0-4. Higher scores indicate increased burden experienced
CNQ ²	Caregiver needs	Nil reported	Created for this study, 27 items in 9 categories (need for emotional support, psychological support, economic support, rest, information, improving physical health, support from the community, sleep, maintaining the household) answered on 1-5 scale. Higher scores indicate higher caregiver needs
CES-D ^{19,27,32,42}	Depression	Adequate to excellent test-retest and inter-rater/intra-rater reliability ⁶³	20-Item scale, four sub-scales (depressive affect, well-being, somatic affect, inter-personal affect), total score 0-60. Higher scores indicate greater depressive symptoms
GHQ-12 ²⁴	Distress and mental health issues	Cronbach alpha coefficient is a range of 0.82-0.86 ⁶⁴	12-Item scale, scored 0-3. Higher scores indicate poorer general health
HADS ^{24,30,60}	Anxiety and depression	Adequate to excellent test-retest reliability, internal consistency and construct validity ⁶⁵	14-Item scale, 7 for depression, 7 for anxiety, scored 0-3, total score 0-21 for both categories. Higher scores indicate increased depression/anxiety
ISEL-12 ²	Social support	Internal consistency and test-retest reliabilities range from 0.70 to 0.80, with moderate inter-correlation ²	12 Statements concerning perceived availability of potential social resources, scored 1-4. Higher scores indicate perception that social support easily available
IDD ^{16,17,29}	Depression	Acceptable test-retest reliabilities (0.98) and internal consistency (0.92) coefficients have been reported ¹⁶	22 Item measure of depressive symptoms, scored 0-4, total score 0-88. Higher scores indicate increased depression
LSS ²⁸	Satisfaction with life	Alpha reliability of 0.93 ⁶⁶	6 Items (psychological, educational, social, relaxational, physiological, aesthetic), scored 0-4. Higher scores indicate higher levels of leisure satisfaction
LSI-A ⁴²	Satisfaction with life	Reliability analysis resulted in a Cronbach's alpha of 0.84 ⁴²	20-Item scale measuring life satisfaction, scored 0-1, total score 0-20. Higher scores indicate increased life satisfaction.
LSI-Z ²⁷	Satisfaction with life	Internal consistency ranges from 0.79 to 0.90. Good test retest reliability ⁶⁷	13-Item scale of morale or life satisfaction, scored 0-2, total score 0-26. Higher scores indicate increased life satisfaction
PHQ-9 ^{2,5}	Depression	Reliable and valid in recognising major depression and sub-threshold depressive disorders in the general population ⁶⁸	9 ITEMS that reflect typical symptoms of depression, scored 0-3, total score 0-27. Higher scores indicate increased depression
PILL ³²	Physical Symptoms	Cronbach alphas range from 0.88 to 0.91 and 2-month retest reliability ranges from 0.79 to 0.83 ⁶⁹	54-Item scale of physical symptoms, scored 0-4. Higher scores indicate increased perception of physical symptoms
PSS ²⁷	Stress	PSS is an easy-to-use questionnaire with established acceptable psychometric properties ⁷⁰	14-Item measure of perceived stressfulness of life situations, scored 0-4, total score 0-56. Higher scores indicate increased stress

Table 5 (Continued)

<i>Outcome measure</i>	<i>Construct measured</i>	<i>Psychometric properties</i>	<i>Description</i>
PANAS ³²	Positive and negative affect	Reliability and validity moderately good; strong reported validity with depression and state anxiety ⁷¹	20-Item scale (10 positive, 10 negative), scored 1–5. Higher scores on each subset indicate higher levels of positive or negative affect accordingly
PSR ²⁵	Social support	Nil reported	15-Item instrument, 2 dimensions (family support, friend support). Higher scores indicate better social support
QOL and Individual Needs Questionnaire ²⁷	QOL	Nil reported	15 Categories, each scored on 5 point scale. Higher scores indicate increased QOL
CIS-R ²⁸	Mental health issues	The CIS-R has been shown to have high inter-rater reliability ²⁸	14 Sub-sections (somatic symptoms, fatigue, concentration, sleep problems, irritability, worry about physical health, depression, depressive ideas, worry, anxiety, phobia, panic, obsessions and compulsions), scored 0–4. Higher scores indicate higher levels of mental health issues
RSES ⁵	Self-Esteem	High ratings in reliability areas; internal consistency was 0.77, minimum Coefficient of Reproducibility was at least 0.90 ⁷²	10-Item scale (5 positive, 5 negative), scored 0–3. Higher scores indicate higher levels of self-esteem
SWLS ^{2,5,17,25}	Satisfaction with Life	Psychometric studies of the SWLS have evidenced internal consistency (0.87) and reliability (2-month test–retest coefficient 0.82) ¹⁷	5 Items of life satisfaction, scored 1–7 for each item, total score 5–35. Higher scores indicate higher levels of life satisfaction
SF-36 ^{3,16–18,26,29,31,33,41,73}	QOL	Substantial evidence supports the basic psychometric properties; internal consistency reliabilities have ranged from 0.62 to 0.96; test–retest coefficients have ranged from 0.43 to 0.90 ¹⁶	35 Items grouped into eight dimensions (physical function, role function, bodily pain, vitality, general health, social function, emotional role, mental health), scored 0–100 with lower score equating to higher disability
SPSI-R ^{16,17,29}	Problem-Solving	SPSI has high reliability ranging from 0.72 to 0.85 ²⁸	52-Item scale to assess social problem-solving abilities, scored 0–4. Higher scores indicate greater problem-solving skills
STAI ^{5,32}	Anxiety	Test–retest reliability coefficients ranged from 0.31 to 0.86, internal consistency alpha coefficients ranged from 0.86 to 0.95 ⁷⁴	40 Items, divided into two sub-scales (state anxiety and trait anxiety), scored 0–3. Higher scores indicate greater anxiety
VAS for QOL ²⁶	QOL	Reliability and validity has been established for measuring subjective sensations, feelings, attitudes and opinions ²⁶	Straight line with opposing scores at either end
WOC ²⁵	Coping	Nil reported	59-Item scale divided into two sub-scales (positive and dysfunctional skills), scored 0–3. Higher scores in each subscale indicate greater levels of positive/dysfunctional coping accordingly
WHOQOL-BREF ^{24,30}	QOL	WHOQOL-BREF has good to excellent psychometric properties of reliability and performs well in preliminary tests of validity ⁷⁵	26 Questions forming 4 sub-domains (physical health, psychological health, social relationship and environmental health), scored 1–5. Higher scores indicate higher QOL
ZBI ^{2,5,19}	Caregiver Burden	Excellent internal consistency, adequate criterion validity ⁷⁶	22 Items asking about current situation, scored 0–4, total score 0–88. Higher scores indicate increased levels of burden

Abbreviations: BDI, Beck Depression Inventory; CBS, Carer Burden Scale; CBI, Caregiver Burden Inventory; CIS-R, Revised Clinical Interview Schedule; CES-D, Centre for Epidemiologic Studies—Depression Scale; CNQ, Caregiver Needs Questionnaire; GHQ, General Health Questionnaire; HADS, Hospital Anxiety Depression Scale; IDD, Inventory to Diagnose Depression; ISEL, Interpersonal Support Evaluation List; LSI-A, Life Satisfaction Index; LSS, Leisure Satisfaction Scale; PILL, Pennebaker Inventory of Limbic Languidness; PANAS, Positive and Negative Affect Schedule; PHQ-9, Patient Health Questionnaire; PSR, Provision of Social Relationship Scale; PSS, Perceived Stress Scale; QOL, Quality of Life; RSES, Rosenberg Self-Esteem Scale; SF-36, Short Form 36; SPSI-R, Social Problem-Solving Inventory; STAI, State Trait Anxiety Inventory; SWLS, Satisfaction With Life Scale; VAS, Visual Analogue Scale; WOC, Ways of Coping Checklist; WHOQOL-BREF, World Health Organisation Quality of Life-BREF; ZBI, Zarit Caregiver Burden Interview.

management) for a loved one is also highlighted as being difficult for both parties.²³

In SCI, the average age of caregivers is younger than that of caregivers with other conditions³⁷ despite the wide age ranges reported in most studies regarding caregiving. Average age for SCI caregivers is 53 years old³⁷ with average age of 60 years old for cancer caregivers,³⁸ 61.4 years for stroke,³⁹ 55.7 years for Parkinson's disease⁴⁰ and 57.1–63.5 years for dementia caregivers.¹² Younger people display poorer strategies for dealing with mental health issues² with higher depression reported in younger caregivers.³⁰ Given that the average age of SCI caregivers is lower than that of other conditions, depression and poor coping strategies are particularly problematic for SCI caregivers. In addition, it has been reported that there is an increased risk of hypertension, obesity and cardiovascular disease in SCI caregivers compared to other neurological conditions.^{37,41} One study⁵ stated that lower pain levels in SCI survivors resulted in increased burden, anxiety and depression for caregivers. The authors qualified this seemingly counter-intuitive outcome by stating that those survivors with SCI who had low levels of pain were more likely to be outgoing, active and therefore demanding of their caregivers. However, the majority of studies addressing severity of injury highlight this issue as a factor that may negatively impact upon caregiver QOL with greater depression noted in caregivers of more severely injured.²⁸ Lower satisfaction with life was reported for caregivers with increased hours caregiving and assistance needed for activities of daily living (ADLs).⁴² Caregivers of tetraplegics are identified as particularly at risk, scoring lower on all domains of SF36 in one study.¹⁸ Conversely, better physical functioning and general health in SCI survivors related to better mental health³³ and QOL in the caregiver.⁵ This highlights an additional level of complexity in the SCI survivor-caregiver relationship within the family.

Another feature of SCI caregiving that is shared with other conditions including stroke⁴³ and chronic illness³⁶ is that the vast majority of SCI caregivers are females and either spouses or parents. The duration of caregiving for SCI has been reported as being up to five decades⁴⁴ which is uncommon with many other conditions and highlights the ongoing, long-term demands placed on caregivers. Longer duration of caregiving is associated with poorer QOL for MS caregivers,⁴⁵ which is also reported to be an issue for SCI caregivers,³¹ again highlighting the similarities in issues faced by long-term caregivers as a whole, regardless of the condition of the care-receiver.

The qualitative studies reviewed provide important insights into several implications of assuming the caregiver role. All studies emphasise the significant amount of negative features associated with the role including the loss of identity felt by the caregiver^{20,22,23} coupled with profound role changes between the SCI survivor and caregiver.^{21,22} The caregiver's life outside of the caregiving relationship was also adversely affected with social isolation, loneliness and a lack of spontaneity all common themes.^{20–23} An overwhelming sadness is also commonly reported in the included studies due to the irreversible change in their life circumstances.²³ Although faith/religious beliefs were often mentioned as a source of strength, in one instance the subject believed that his family member's disability was related to sins committed in a previous life, and this belief was the source of distress.²¹ An additional theme commonly mentioned was frustration with paid caregivers,^{20,23} and the difficulty involved with performing intimate care tasks including bathing and toileting.^{20,22}

This review captures data from diverse geographical locations, and this is worthy of further discussion. Cultural differences significantly impact upon QOL outcomes for caregivers. Research from Latin America^{2,3,5} highlights the important role family support has with

assisting the caregiver in their task of taking care of the SCI survivor, with some of the lowest depression scores possibly indicating better QOL in these communities. In spite of this family support and reports of better QOL, one Colombian study reviewed reported that 68% of caregivers felt overwhelmed by their caregiver role.² This contrasts with reports from China and Taiwan^{25,21} which state that traditional roles in Chinese/Taiwanese culture can play a significant part in caregiver QOL, with additional pressures from caregiving not perceived to impact on their normal social role within the family, with potential discrimination from family members at perceptions of carers not fulfilling their duties. Studies in Asia show high levels of unemployment/retirement among family caregivers,^{18,25,30,31,33} while studies in the USA²⁶ report families employing paid care in addition to family caregiving, which may facilitate the higher rates of employment noted in USA¹⁹ and less risk of physical health issues for the family caregivers. However, concern has been raised in the literature, regarding the perceived poor level of care offered by paid caregivers compared with the attention and care provided by family members,²³ with formal caregivers considered less likely to go 'above and beyond' the contracted duties of their employment.⁴⁶

Due to the high level of spousal caregiving with SCI, changes in role identity are reported with loss of intimacy and sexual relations a commonly reported theme.^{21,22} A more maternal role develops for a female spouse caring for her male partner.²² Further role change is reported with a high incidence of caregivers being unemployed/retired and those who remain in employment often appear to be working reduced hours, likely due to the demands placed upon them as caregivers. Often caregivers are forced to leave paid employment due to their new role as caregivers,²¹ frequently resulting in financial difficulties for the family involved. Financial difficulties are a common issue in the literature, with caregivers for people with dementia,⁴⁷ Alzheimer's disease,⁴⁸ cancer,⁴⁹ motor neurone disease⁵⁰ and Parkinson's disease⁵¹ all reporting financial concerns as a cause of distress, highlighting an additional factor that negatively impacts on caregiver mental health.

Need for support is a common issue highlighted in caregiver research and it comes as no surprise that this is also the case for SCI. Support groups have been reported to be beneficial for caregiver mental health in a variety of conditions including SCI,^{18,19} Parkinson's Disease⁵² and the frail elderly.⁵³ Similarly, in the last decade the use of technology (for example, telephone support, online support, websites) has been explored across a significant range of conditions with varying success reported. A systematic review of the impact of telehealth on supporting caregivers over an extremely broad range of impairments reported positively on the impact telehealth can have on caregiver education and support.⁵⁴ However, contrasting reports on the benefits of telehealth exist; it has been shown to reduce anxiety and depression in caregivers of the frail elderly⁵³ but the benefits on caregiver depression and life satisfaction in stroke caregivers has been reported as unclear.⁵⁵ Inconclusive findings have also been reported with SCI caregivers, although this was perhaps due to methodological weakness (loss of participants to follow-up) in the study.¹⁷ Another support structure explored in the literature is problem-solving training, which has been assessed for caregiver support for SCI,¹⁶ stroke^{56,57} and chronic pain in youths⁵⁸ and has mixed reports of benefit, with the greatest success reported for parents of youths with chronic pain. An additional concept explored for SCI is joint education sessions with the SCI caregiver and recipient which show significant benefits to both parties¹⁹ and could be an option for further research across a variety of conditions.

Limitations of this review

The main limitation of this study is the quality of the available studies, which were largely mainly level 3 cross-sectional trials. The randomised controlled trials included suffered from high levels of attritional bias due to loss of contact with subjects at follow-up date. In spite of these issues, the number of studies worldwide reporting the difficulties faced by SCI caregivers emphasise the significance of this area of research and the limitations mentioned serve to highlight the need for high-quality research to be carried out on this important, international topic. In addition, QOL is a broad term encompassing a large variety of physical, mental and societal issues. As such, it is difficult to quantify, and drawing clear comparisons between findings is challenging, especially given the wide variety of outcome measures used across the literature. Finally, studies not specifically addressing QOL or satisfaction with life (for example, studies focusing on caregiver burden, coping, resilience and marital relationships) were omitted but may prove an additionally useful source of information regarding the impact of SCI on family caregivers.

CONCLUSION

This literature review is the first to examine the impact of SCI on family members who become primary caregivers. The research highlights the considerable impact that SCI has on the family unit with many carers enduring a broad range of physical and mental health issues. Typically, carers assume their roles in early-middle age and may persist as primary carers for several decades. This review has found the caregiver role to precipitate significant negative consequences including physical pain, depression, anxiety and sorrow. In addition, psychosocial issues including increased social isolation, loss of identity and role changes may also occur when the caregiving role commences. The studies reviewed highlight that these findings are reproduced internationally, notwithstanding elements of cultural diversity. The need for greater family involvement and support in the management of SCI from the onset is crucial, with the evidence advocating for educational interventions and support groups as the most effective intervention strategies, particularly when emphasis is placed on education for both the SCI survivor and caregiver. However, there is a lack of clarity regarding the optimum mix of elements composing such educational programmes. This review recommends that further, high-quality research is needed to contribute to this clinical area in order to develop successful interventions and strategies to support both the SCI survivor and their family. Specific focus on the use of appropriate, psychometrically tested outcome measures would add to the available evidence. Given the global nature of this issue, multi-centred randomised controlled trials may provide meaningful information as to how to best address this issue.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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