

The Impact of Caring for People with Spinal Cord Injury (SCI) on Carer's Subjective Well-Being and Physical Health: A Realist Synthesis Review

Maz J*

Associate Director of Student Education/ Lecturer in Healthcare, University of Leeds,
United Kingdom

***Corresponding author:** Julia Maz, Associate Director of Student Education/
Lecturer in Healthcare, University of Leeds, United Kingdom, Tel: 0113 3431463; E-mail: J.Maz@leeds.ac.uk

Review Article

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Abstract

Objective: To identify and summarise studies of the psychological well-being of informal carers of people with spinal cord injury.

Design: The review included studies if they reported the carers perspective of care giving – studies that focused mostly on the person with spinal cord injury were included only if the carers perspective of the caregiver role could be extracted.

Data sources: Electronic searches of MEDLINE, CINAHL, Psych Info, Sociological Abstracts and The Cochrane Library were carried out between December 2013 and February 2015, with update searches undertaken in October 2016.

Review methods: A realist synthesis approach was adopted to evaluate studies according to their contribution and drew together evidence from a range of methodologies, including qualitative and quantitative studies.

Findings: 28 studies met the inclusion criteria. Nineteen studies focused only on the caregiver (quantitative studies = 13; qualitative studies = 5 and 1 mixed method approach) and four included caregivers and the person with a SCI (quantitative studies=2; qualitative=1 and 1 mixed method approach). Three papers used non care giving age matched comparative approaches. The majority of the studies were conducted in the USA (11), with three from the UK, 2 from Australia and 3 from Brazil. The remainder of studies were international and comprised 1 from China, 1 from Turkey, 1 from the Netherlands, 1 from Canada, 1 from Denmark, 1 from Fiji and 1 from Iran. The total number of SCI carers was 1772; the majority were female (ranging from 88 % to 100% of the samples included) with an age range average (where this has been calculable) of 43.6

Common methodological limitations of studies included in this review were a lack of non-carer age-matched comparison groups, focus on the experience of female caregivers, small sample sizes, and failure to follow up caregivers longitudinally. Several studies provided estimates of the prevalence of subjective well-being and physical health distress among caregivers but no conclusions could be drawn from the current evidence base. The review suggests that many factors are related to caregiver subjective well-being including caregiver attributes, the severity of the spinal cord injury, the relationship dynamics between the carer and the spinal injured individual and objective and subjective assessments of the burden of care. The perceived adequacy of support also emerges as an important aspect with perceived positive and potentially negative impacts on the carer.

Conclusion: Further studies are needed to clarify the prevalence of SCI caregivers' subjective well-being and situation specific factors that predict poorer carer health outcomes. This work will enable appropriate interventions to be developed and evaluated.

What is already known about this topic?

- Emphasis has been increasingly placed on the delivery of care to patients with SCI in the community and this approach places increased care responsibilities on informal carers.
- General carer literature indicates that providing care is associated with poorer psychological health outcomes.

What this paper adds

- Although from small studies with methodological limitations there is evidence to suggest that providing informal SCI care is stressful.
- A number of factors are associated with carer subjective well-being including lack of professional support.
- Rigorous, longitudinal studies using age-matched comparative controls are needed to develop and evaluate interventions for this population.

Keywords: Care giving; Spinal cord Injury; Realist synthesis

Introduction

Spinal Cord Injury (SCI) often results in physical limitations such that receiving assistance from others is critical to maintaining health and facilitating full societal integration. In the general population, almost 70% of people with SCI receive some form of assistance and support from family members. Similarly, the availability of family care giving is crucial to most individuals with SCI, but there is little research addressing this topic and no appropriate and available method to comprehensively assess the strengths of and burdens on family caregivers.

In recent years emphasis has been increasingly placed on delivery of care to patients with SCI in the community. With this approach increased care responsibilities are placed on the families who are required to carry greater care burdens for longer periods of time. Caregiver burden reflects the extent to which a carer perceives their emotional health, physical health, social life and financial status have been affected as a result of caring for a friend or relative [1-4]. The terminology used to define a 'carer' is ambiguous [5]. The term 'informal caregiver' is often used to refer to a person who is providing care but is not a health care professional and is unpaid, however, it has been argued that the provision of care by 'informal' carers is formal in everything but the receipt of pay [6]. In the UK, the term 'carer' has been adopted by the Department of Health (2006) [7] to demarcate the care provided by family or friends from the care provided by health and social professionals. Carers themselves, in particular spouses, do not refer to the notion of being a carer of a caregiver, often describing the experience as an extension

of their loving role and commitment to the person requiring support [8,9]. As such, this article uses the terms synonymously and 'carer', 'caregiver' are used interchangeably dependent upon how the original authors used the term.

Despite the growing numbers of SCI caregivers and potentially high burden, little is known about the effect the SCI has on the care givers psychological well-being. It has been estimated that between 40% and 70% of caregivers have clinically significant symptoms of depression [4]. A meta-analysis of 84 studies indicate that carers had significantly higher levels of depression and stress and lower levels of general subjective well-being than non-carers [10]. In that review, spousal care giving was particularly stressful, as there were large differences in the levels of depression and stress of carers who were spouses compared to non-carers. In addition, caregiver strain is associated with a mortality risk that is 63% higher than no care giving comparisons [11].

Previous reviews have focused on information needs and interventions designed to meet the needs of carers [12-14] and the general impact of providing care to a person with SCI [15,16] but there appears to be little evidence of the information and support needs specific to SCI caregivers, and only one study of interventions designed to meet these needs in the form of Brief Problem-Solving Training for family carers immediately post rehabilitation [17] was identified. However, prior to the development of interventions designed to help SCI carers in their care giving role, greater understanding of the psychological impact of the provision of informal care

is needed. The aim of this paper is to investigate, through a narrative review of international published literature, the psychological burden for SCI caregivers and their perception of the adequacy of care provided by health professionals.

Methods

The aim of this review was to identify and summarise studies of the subjective well-being of informal carers of people with SCI. Specifically, the objectives were to address the following questions: (i) What is the prevalence of psychological distress in carers of individuals with SCI, (ii) what factors are associated with carer distress; and (iii) How do caregivers perceive support from health care professionals. The literature was reviewed using a realist synthesis approach. Realist synthesis is a relatively new strategy for synthesising research. Developed by Pawson [18-20] (Table 1) this method of synthesis explores linkages between mechanisms (processes) and outcomes in interventions to better understand “inside workings” of the intervention and its impact on the outcomes. In this approach, interventions are understood to consist of a chain of steps (processes) that emerge in a non-linear fashion. Each stage involves negotiations and feedback, such that the intervention can work as expected, ‘misfire’, or be subjected to modification and change as stakeholders learn and come to understand the intervention and its required components. Realist synthesis can assist in better understanding the plurality of evidence by supporting each of the linkages that connect interventions.

Realist synthesis follows a heterogeneous and iterative process, which is less prescriptive than a traditional systematic review. The approach can accommodate multiple types of evidence [21]. This approach was adopted in order that a framework for reviewing and drawing together evidence from a range of methodologies could be provided [22]. This type of review is useful where the aggregation of data is difficult because diverse studies or fields are being analysed [23,24].

The steps in this realist review were adopted from Pawson and Boaz (2004) and are identified in Table 1:

Steps adopted (Adapted from Pawson& Boaz, 2004)
Step 1: Clarify Scope
· Identify the review question including the nature and content of the intervention and its use

· Refine the purpose of the review by mapping the territory
· Articulate key theories to be explored and formalise the model
Step 2: Search for evidence
· Exploratory search of the literature
· Progressive focusing to identify key area; refining inclusion criteria in light of emerging data
· Purposive sampling to test a defined subset of theories with additional snowball sampling to explore new hypotheses as they emerge
· Final search for additional studies when the review is near completion
Step 3: Appraise primary studies
· Use judgement to supplement formal critical appraisal checklist and consider relevance and rigour
Step 4: Data Extraction
· Develop data extraction forms and notation devices
· Extract different data from different studies to populate evaluative framework with evidence
Step 5: Synthesise evidence and draw conclusions
· Synthesise data to achieve refinement of theory
· Allow purpose of review to drive the synthesis process
· Use ‘contradictory’ evidence to generate insights about the influence of context
· Present conclusions as a series of contextualised points
Step 6: Disseminate, Implement and Evaluate
· Draft and test out recommendations and conclusions with key stakeholders

Table 1: The steps in this realist review were adopted from Pawson and Boaz (2004).

Inclusion Criteria

All study designs were included in the review including qualitative research studies, randomised controlled trials, quasi-experimental designs, observational and descriptive studies. Studies were included if they reported the carers perspective on care giving – studies that focused mainly on the person with SCI were included only if the carers perspective of the caregiver role could be extracted.

Studies were included in which participants were identified as the caregiver of a person with SCI and 18 years or older. Studies of all SCI severity levels alongside longevity of the caring relationship were included as were

those studies that included participants with different diagnoses providing details specific to the SCI group could be extracted.

Studies were excluded if they were not published in English. Further exclusions included papers that presented data collected from caregivers only relating to their views regarding the patient's condition and care experience and did not reflect the caregivers' views about providing care.

Search Methods

Search strategies were designed using broad-based terms and no year constraints. Search terms included: carer OR caregiver AND SCI (or tetraplegia, paraplegia). Electronic searches of MEDLINE, CINAHL, Psych info, Sociological Abstracts and the Cochrane Library were carried out between December 2015 and February 2016. A full text copy of an article was obtained if the study appeared to meet the following criteria:

- i. Individuals with SCI
- ii. Carers experiences as expressed by the carer
- iii. Primary research- including quantitative and qualitative designs

Electronic searches were supplemented by citation tracking of reference lists from papers meeting the study's inclusion criteria. Documents were excluded if they were theses or if their sole focus was patient or health care professionals' views of carer issues. Gray literature searches of conference proceedings, research reports, book chapters, dissertations and spinal injury organisations web sites were undertaken but yielded no further evidence regarding the research aim.

Search Outcome

Over 1230 papers were retrieved, with 220 being read in full, and 94 eliminated on second review. The total number of references retrieved by combining the search results was 126 and 28 studies met the final inclusion criteria (Figure 1).

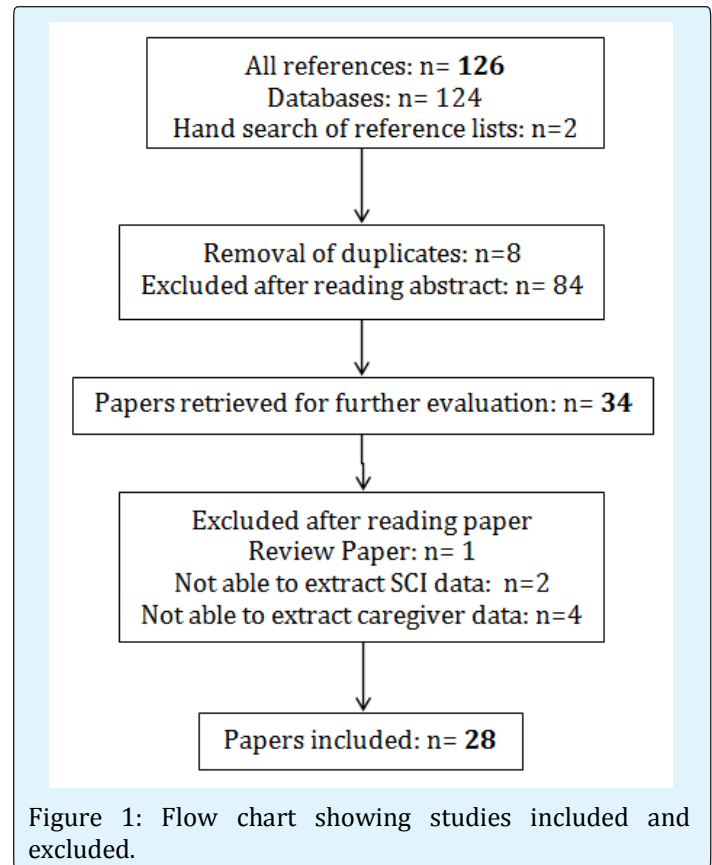


Figure 1: Flow chart showing studies included and excluded.

Quality assessment and appraisal: Evaluating the quality of the articles and quality appraisal to determine methodological rigour (e.g., sample size, statistical power, presence and strength of the comparison group, use of sound outcome measures, recruitment of the sample) was undertaken using Derish and Annesley's (2011) [25] criteria. Essentially this comprised critical evaluation of (i) key results, (ii) limitations, (iii) suitability of the methods used to test the initial hypothesis, (iv) quality of the results obtained, (v) interpretation of the results and (vi) impact of the conclusions. As such articles are not graded but thorough appraisal pertaining to the above constructs was adhered to. The Qualitative Research Quality Checklist [26] (Table 2) is a 25 point quality appraisal form designed to evaluate credibility, dependability, confirmability, transferability, authenticity, and relevance of qualitative studies. The QRQC is a guide which facilitates the interpretive curiosity and as such rating scales per se are not implemented. As such, qualitative studies were appraised in terms of their epistemological and theoretical frameworks, study setting, study design, sampling procedures, data collection, ethical issues, reflexivity of the researcher, data analysis, and reporting of the findings. Each item was

assigned two ratings: “applicable: and “addressed” each of which consisted of three possible elements (yes, no, unclear). Due to differences in epistemological and ontological stance, not all elements of the QRQC are “applicable” to qualitative studies. Therefore, the QRQC includes three columns for each element. The first column indicates whether the element is relevant to the particular study. Determination of applicability was based on (i) what the author stated they did, and (ii) their epistemological paradigm. For instance, if the author declared they were from a positivist paradigm, it was assumed a reflexive journal would not be part of their process. The appropriateness of the research design was also considered against the author’s epistemological

paradigm. The second column indicates whether there is sufficient information in the study for the reviewer to assess whether the specific element has been “addressed”. A third column as also available as a space for the reviewer to comment generally upon the study and/or the qualitative element being addressed. The quality appraisal was conducted on a case-by-case basis during the literature search, extraction, and synthesis process. No papers were excluded in respect of quality because of the dearth of literature meeting the inclusion/exclusion criteria. The quality of the review was maintained by maintaining quality measures in the research process the author adopted.

Question	Sub-question	Lucke et al., -2004 MM	De-Santo-Madeya - 2006	Chen & Boore -2009 MM	Beauregard& Noreau (2010)	Dickson et al. (2010)	Angel & Buus (2011)	Dickson et al. (2012)	Lucke et al. (2013)
Is the purpose and research question clearly stated?	R	Y	Y	Y	Y	Y	Y	Y	Y
	SI	Y	Y	Y	Y	Y	Y	Y	Y
	C	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative approach appropriate to answer the research question?	R	Y	Y	Y	U	Y	Y	Y	Y
	SI	Y	Y	Y	U	Y	Y	Y	Y
	C	Y	Y	Y	U	Y	Y	Y	Y
Is the setting of the study appropriate and specific for exploring the question?	R	Y	Y	Y	Y	Y	Y	Y	Y
	SI	Y	Y	Y	U	Y	Y	Y	Y
	C	Y	Y	Y	U	Y	Y	Y	Y
Is there prolonged engagement to render the inquirer open to multiple influences?	R	U	U	U	U	U	U	U	U
	SI	U	U	Y	U	U	U	U	U
	C	U	U	Y	U	U	U	U	U
Is there persistent observation in the setting to focus on the issues relevant to the question?	R	U	U	U	U	U	U	U	U
	SI	U	U	U	U	U	U	U	U
	C	U	U	U	U	U	U	U	U
Is there compatibility between research question, method chosen, and research design?	R	Y	Y	Y	U	Y	Y	Y	Y
	SI	Y	Y	Y	U	Y	Y	Y	Y
	C	Y	Y	Y	U	Y	Y	Y	Y
Is the process of sample selection adequately described and consistent with research design/question?	R	Y	Y	Y	Y	Y	Y	U	Y
	SI	Y	Y	U	Y	Y	Y	U	Y
	C	Y	Y	U	Y	Y	Y	U	Y
Is the sample size and composition justified and appropriate for the method/design/question?	R	U	Y	U	U	Y	U	U	U
	SI	U	Y	U	U	Y	U	U	U
	C	U	Y	U	U	Y	U	U	U
Are the methods for data collection consistent with the research question?	R	Y	Y	Y	Y	Y	Y	Y	Y
	SI	Y	Y	Y	Y	Y	Y	Y	Y
	C	Y	Y	Y	Y	Y	Y	Y	Y
Are the methods of data collection consistent with the methods/design/question?	R	Y	Y	Y	Y	Y	Y	Y	Y
	SI	Y	Y	Y	Y	Y	Y	Y	Y
	C	Y	Y	Y	Y	Y	Y	Y	Y
Is a range of methods used for triangulation?	R	Y	N	Y	N	N	N	N	Y
	SI	Y	N	Y	N	N	N	N	Y
	C	Y	N	Y	N	N	N	N	Y
Is there an articulation of who collected the data, when the data was collected, and who analysed the data?	R	U	Y	Y	U	Y	Y	Y	Y
	SI	U	Y	U	U	Y	Y	Y	Y
	C	U	Y	U	U	Y	Y	Y	Y
Is there an audit trail regarding data collection, including tapes,	R	U	U	U	U	Y	Y	Y	U
	SI	U	N	U	U	Y	Y	Y	U

memos, and note-taking of decisions made in the study?	C	U	U	U	U	Y	Y	Y	U
Is there adequate consideration of ethical issues?	R SI C	U U U	Y U U	Y U U	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y
Has the researcher identified potential and actual biases (researcher and research design?)	R SI C	U U U	U U U	N N N	N N N	U U U	N N N	N N N	N N N
Did the researcher(s) use a reflective journal in the analysis and interpretation?	R SI C	N N N	U U U	U U U	N N N	U U U	N N N	Y Y Y	N N N
Is the process of data analysis presented with sufficient detail and depth to provide insight into meanings and perceptions of the sample?	R SI C	Y Y Y	Y Y Y	Y Y Y	U U U	Y Y Y	Y Y Y	Y Y Y	Y Y Y
Are quotes used to match concepts and themes derived from the raw data	R SI C	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y
Do the findings emerge from the experience of the sample?	R SI C	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y	Y Y Y
Was member checking employed?	R SI C	N N N	U U U	N N N	N N N	U U U	N N N	N N N	Y Y Y
Did the researcher provide a "thick description" of the sample and results to appraise transferability?	R SI C	Y Y Y	Y Y Y	Y Y Y	N N N	Y Y Y	Y Y Y	N N N	Y Y Y

Table 2: The Qualitative Research Quality Checklist.

Types of Studies Included in the Review

28 studies met the inclusion criteria (Table 3). Nineteen studies focused only on the caregiver qualitative=1 and 1 mixed method approach). Three studies used a non-care giving age matched comparative group [1-3]. The majority of the studies were conducted in the USA (11), with three from the UK, 2 from Australia and 3 from Brazil. The remainder of studies were international and comprised 1 from China, 1 from Turkey,

(quantitative studies = 13; qualitative studies = 5 and 1 mixed method approach) and four included caregivers and the person with a SCI (quantitative studies=2;

1 from the Netherlands, 1 from Canada, 1 from Denmark, 1 from Fiji and 1 from Iran (Table 3). The total number of SCI carers was 1772; the majority were female (ranging from 88 % to 100% of the samples included) with an age range average (where this has been calculable) of 43.6.

Authors & Year	Sample	Test	Design	Results	Conclusions
Weitzenkamp, et al. 1997 UK	One hundred twenty-four spouses of a longitudinally followed sample of SCI survivors, all of whom had been injured 23 or more years when the study was conducted in 1993	CES-D; PSS, LSI-Z and responses to survey questions.	Survey, including demographics, health concerns questionnaire, alongside Administration of the Center for Epidemiologic Studies Depression Scale (CES-D), the Perceived Stress Scale (PSS), the Life Satisfaction	Spouses had more depressive affect ($p < .001$) than their partners with disabilities, as measured by the CES-D. On the PSS, they exhibited no significant differences. Compared with spouses who were not caregivers, the care giving spouses reported more physical stress ($p = .005$), emotional stress ($p = .011$), burnout ($p = .007$), fatigue ($p = .002$), and anger and resentment ($p = .029$). On the CES-D, they had more symptoms of depressive affect ($p = .004$) and somatic depression ($p = .005$).	Spouses of long-term SCI survivors who fulfill a care giving role report more symptoms of stress and depression than their partners with disabilities and other spouses who are not caregivers.

			Index (LSI-Z), and the Quality of Life and Individual Needs Questionnaire		
Elliott et al., 1999 USA	11 male and 55 female caregivers were matched with data from 38 men and 18 women with recent spinal cord injuries.	Acceptance of Disability Scale score and pressure sore diagnosis	Design: Correlational methods were used to test the hypothesis.	Caregiver tendencies to impulsively and carelessly solve problems were associated with lower acceptance of disability and were significantly predictive of pressure sore diagnosis among those returning for a medical evaluation 1 year later.	Caregiver characteristics are associated with the adjustment of persons with SCI and warrant consideration in terms of psychological interventions and health policy
Chan, 2000 China	Forty spouses of persons with SCI	Coping strategies, depression, care-giving burden, life satisfaction and marital adjustment. Levenson's Internality, Powerful Others, and Chance Scale (LIPC) Provision of Social Relationship (PSR) Ways of Coping Checklist (WOC) Beck Depression Inventory (BDI) Satisfaction with Life Situation (SWLS) Katz's Adjustment Scale - Relative Forms 2 and 3 (KASR) Caregiver Burden Inventory (CBI) Dyadic Adjustment Scale (DAS)	A cross-sectional correlation design. A set of structured questionnaires and semi-structured interviews were administered.	The most stressful situations concerned health issues of their injured partners, the family and marital interactions, and the care-giving burden imposed on them. Cluster analysis indicated a potential at-risk group, characterized by high scores in external locus of control, inadequate coping modes and limited social support. They were noted to manifest high levels of depression, care-giving burden, low levels of life satisfaction and marital adjustment.	The identification of the potential at-risk group indicates that spouses of persons with SCI suffer levels of stress comparable to those of their injured partners. Rehabilitation plans should include this potential at-risk group to help them release the stress and to prevent them from developing clinically significant mental disorders.
Unalan et al., 2001 Turkey	Fifty primary caregivers of spinal cord injured patients living in the community and 40 healthy age-matched population based-controls.	SF-36 (short form-36) questionnaire forms.	To compare the quality of life scores of primary caregivers of spinal cord injury survivors living in the community with healthy age-matched-population based controls and to determine the relationship between some severity parameters related with spinal cord injury and the quality of life scores of primary caregivers.	Quality of life scores measured by SF-36 were significantly low in the primary caregivers group compared to age-matched healthy population based controls. No significant relation was demonstrated between the quality of life scores of primary caregivers and parameters such as the duration of injury, lesion levels, ASIA scores, degree of spasticity, bladder and/or bowel incontinence and pressure sores respectively	Being a primary caregiver significantly interferes with quality of life; some severity parameters related to the injury however do not seem to have an additional impact on the primary caregiver's life quality.

Lucke et al., 2004 USA	A convenience sample of 12 SCI participants and their FCs	SF-36 and two horizontal visual analog scales, one for pain and one for QOL and a face-to-face in-depth interview at 1-, 3-, and 6-months following inpatient rehabilitation.	this mixed method, descriptive, longitudinal feasibility (pilot) study was to describe and compare QOL in 10 adult SCI individuals and their family caregivers (FCs) during the initial 6 months following rehabilitation.	SCI individuals reported low physical function, role physical (RP), and role emotional (RE) scores on the SF-36, while reporting high general health (GH), mental health and social functioning on the SF-36. FCs reported lower RP, GH and vitality scores, while reporting higher physical functioning and RE scores. On the visual analog scales, persons with SCI reported lower QOL while FCs reported more pain at 3 and 6 months.	suggests that more work is needed to identify interventions which could enhance QOL during the transition from rehabilitation to home for SCI individuals and their FCs.
Post et al., 2005 Netherlands	All members of the Dutch patients organisation DON (N¼1004) and their caregivers, if applicable, were invited. Responses were obtained from 461 persons with SCI. Of 265 couples, patient as well as partner data were available.	Physical disability of the person with SCI was measured using the Barthel Index (BI). A number of secondary conditions, other practical problems and psychosocial problems were recorded. Partner support was described using a list of ADL support, other practical support and emotional support.	Cross-sectional survey. Burden of support was measured by a six-item measure (Cronbach's alpha 0.92), Mean age of the partners was 49.4 years (SD 12.2) and 69.8% were women. Mean BI of the persons with SCI was 12.3 (SD 4.7) on a 0–20 scale and 60.4% were seriously disabled (BI<15).	Nonparametric descriptive statistics and correlations were used. Linear regression was used to identify predictors of caregiver burden. Most partners provided various kinds of support. ADL support and other practical support were given much more often by partners of persons with serious disability, but less difference was seen regarding emotional support. Professional (paid) support was obtained by 45.3% of all couples. Perceived burden of support was high in 24.8% of partners of persons with serious disabilities against 3.9% of partners of persons with minor disabilities. Significant predictors of caregiver burden were (in order of importance) the amount of ADL support given, psychological problems of the patient, partner age, partner gender, BI score and time after injury (total explained variance 47%).	A substantial proportion of partners of persons with SCI suffer from serious burden of support. Prevention of caregiver burnout should be part of the lifelong care for persons with SCI.
Foster et al., 2005 Australia	154 family caregivers nominated by SCI respondents and an additional 25 family caregivers	This comprised a one-page spinal cord injury questionnaire (SCIQ) designed to collect information from the individual with SCI, and a family caregiver questionnaire (FCGQ) for completion by his or her family caregiver. The FCGQ comprised four sections: socio-demographic information; description of family care giving, additional care provided by others; and services required	Descriptive survey conducted with The survey collected social and demographic information and details of the type of care provided by family caregivers	Family caregivers' perceptions of the types of services they require to assist them in their caring roles. Family care giving typically involved physical, practical, and emotional support, and in many cases this occupied in excess of three hours a day, with no additional source of care giving provided. The most frequently reported service types required by family caregivers included respite, personal support, information services, and health professional services.	Mapping caregiver needs in this area establishes a critical basis for service planning and more importantly provides a guide for the development of a range of services dedicated to maintaining the health and well-being of family caregivers of individuals with SCI.

Boschen et al. 2005 USA	Convenience sample; self-selected subsample in focus groups.	Productivity status, satisfaction with community integration, quality of life.	Quantitative phase (interview-completed questionnaire; n=100), followed by qualitative phase (8 focus groups; n=46).	Supporting a person with SCI brings significant life change. Greater support provision was related to lower productivity and community integration of the SPs. They felt underserved and unprepared emotionally and cognitively for their new, unanticipated role.	More attention, understanding, and service directed to SPs are required to reduce trial-and-error learning and emotional and physical burden. Enhanced injury resource materials, peer networks, and knowledge-building opportunities may ameliorate SP difficulties
DeSanto-Madeya, 2006 USA	20 spinal cord injured persons and their family members to examine the meaning of living with spinal cord injury 5 to 10 years after the initial injury.	Interviews	Phenomenological study	Seven themes emerged from the data. The themes are looking for understanding to a life that is unknown, stumbling along an unlit path, viewing self through a stained glass window, challenging the bonds of love, being chained to the injury, moving forward in a new way of life, and reaching normalcy. The uncovered meanings enhance our understanding and appreciation that living with spinal cord injury is a continuous learning experience.	The study findings may be useful in the development of self-care strategies and ongoing interventions that focus on maintaining physical and psychological health for both spinal cord injured persons and their family members throughout the course of living with the disability.
Blanes et al., 2007 Brazil.	60 primary caregivers of persons with paraplegia (T1 to S2) following traumatic spinal cord injury (SCI). Among 60 caregivers evaluated, 49 (81.7%) were female, with mean age of 35.8 (SD=12.91) years, 16 (26.6%) being wives and 14 (23.4%) sisters of persons with paraplegia	structured questionnaires and interviews The HRQoL was assessed by the Short Form-36 (SF-36) health survey questionnaire and caregiver burden was evaluated by the Caregiver Burden Scale (CBS).	A cross-sectional descriptive study	It was found that the caregivers spend an average of 11.3 h/day caring for individuals with paraplegia. Twenty-three caregivers (38.3%) had a chronic disease and 32 (53.3%) were sole caregivers taking upon themselves the full responsibility of caring for the persons with paraplegia. The subjects reported lower scores on bodily pain and vitality than the other dimensions of the SF-36. The mean global CBS score was 1.71 (SD=0.50) and mean scores for each dimension ranged from 1.39 (SD=0.64) for emotional involvement to 2.44 (SD=0.79) for environment dimension.	The primary caregivers of spinal cord-injured persons reported low scores on all of the SF-36 and CBS dimensions, bodily pain and vitality being the SF-36 dimensions that received the lowest scores.
Dreer et al., 2007 USA	Eighteen men and 103 women caregivers (mean age of caregivers = 45.66 years, SD = 12.88) of individuals with SCI.	Inventory to diagnose depression	Correlational and logistic regression analyses of data collected in a cross-sectional design.	Nineteen caregivers (15.7%) met criteria on the Inventory to Diagnose Depression for a major depressive disorder. A dysfunctional problem-solving style was significantly predictive of caregiver depression, regardless of the severity of physical impairment of the care recipient or the physical health of the caregiver and caregiver demographic variables.	The percentage of caregivers with probable depressive disorder may parallel that observed among persons with SCI, using a more conservative self-report measure designed to assess symptoms associated with a depressive syndrome. Family caregivers with a dysfunctional problem-solving style and assisting individuals with more severe injuries may have probable depression

Chen & Boore, 2009 Taiwan	Fifteen family carers	Data were collected through in-depth, tape-recorded, semi-structured interviews and observation of a group discussion and two religious activities Eight individual interviews and seven participating in the group discussion.	Qualitative study with a cross-sectional and descriptive-explorative design. Grounded theory was used to explore the psychosocial implications for family carer who has a relative with spinal cord injury.	The findings resulted in the core category 'living with a relative who has a spinal cord injury' and identified the experience of taking care of a relative who has a spinal cord injury. Three stages, including four categories: stage 1 'A catastrophic life event'; stage 2 'Confronting challenges'; and stage 3 'Family resilience' or 'Family breakdown'.	Family carers experience a catastrophic life event, they have to confront challenges and the positive consequence is family resilience, the negative consequence is family breakdown
Schulz et al., 2009 USA	One hundred seventy-three caregiver and care-recipient dyads	A multivariate outcome comprised of six indicators linked to the goals of the interventions was the primary outcome of the study. The multivariate outcome included measures of depressive symptoms, burden, social support and integration, self-care problems, and physical health symptoms.	A multisite, three-group, randomized controlled trial comparing two active intervention conditions with each other and to an information-only control group. One hundred seventy-three caregiver and care-recipient dyads were randomly assigned to one of three conditions: a caregiver-only treatment condition in which caregivers received a multicomponent intervention based on their risk profile; a dual-target condition in which the caregiver intervention was complemented by a treatment targeting the care recipient, designed to address both caregiver and care recipient risk factors; and an information-only control condition in	At 12 months, caregivers in the dual-target condition had improved quality of life as measured by our multivariate outcome when compared to the control condition. Using the dyad as the unit of analysis, the dual-target condition was superior to both the control condition and the caregiver-only condition in our multivariate outcomes analysis. Dyads enrolled in the dual-target condition had significantly fewer health symptoms than control condition and caregiver-only condition participants and were less depressed when compared to participants in the caregiver-only condition. In follow-up analyses we found that a higher proportion of caregivers in the dual-target condition had clinically significant improvements in depression, burden, and health symptoms when compared with the caregiver-only condition.	Caregivers are in need of and can benefit from interventions that help them manage the medical and functional limitations of the care recipient. Intervention strategies that target both the caregiver and care recipient are particularly promising strategies for improving the quality of life of caregivers.

			which the caregiver received standard printed information about care giving, SCI, and aging.		
De-Santo-Madeya, 2009 USA	15 spinal cord injured individuals and their family members to examine the physical, emotional, functional, and social components of adaptation to spinal cord injury at 1 year (n = 7 dyads) and 3 years (n = 8 dyads) post-injury.	Interviews	Based on the Roy adaptation model, cross-sectional study	Findings indicate that spinal cord injured individuals and their family members, regardless of time since the initial injury, have a moderate level of adaptation and adjustment to spinal cord injury. s	The data suggested that adaptation to spinal cord injury during the first 3 years can be enhanced by providing ongoing social and educational support for not only the injured individuals, but also their family member
Elliott and Berry, 2009 USA	60 caregivers (49 women, 11 men). An intervention for new caregivers featuring brief PST, education, and contact may be associated with lower dysfunctional problem-solving styles over time	The Social Problem-Solving Inventory-Revised, the Inventory to Diagnose Depression, and the SF-36 were administered at baseline, 6 months and 12 months.	Family caregivers were randomly assigned to a usual care control group (N530) or an intervention group (N530) in which participants were to receive three face-to-face problem-solving training sessions (PST), educational materials, and telephone contacts as requested over the first year of care giving.	Caregivers in the intervention group reported a significant decrease in dysfunctional problem-solving styles scores over time; there were no observable effects for PST on caregiver depression.	There was also some indication that the intervention had beneficial effects on caregiver social and physical functioning.

Arango-Lasprilla et al., 2010 Colombia	37 caregivers	Care giver needs questionnaire composed of 27 questions (1–5 scale) and 9 subscales (emotional, information, economic, community, and household support, respite, physical health, sleep, and psychological health). The Patient Health Questionnaire (PHQ-9) was used to measure caregiver depression, the Zarit Burden Interview (ZBI) measured stress, the Interpersonal Support Evaluation List Short Version (ISEL-12) measured social support, and the Satisfaction With Life Scale (SWLS) was used to assess satisfaction with life	Cross-sectional.	Information, economic, emotional, community support, and respite needs were most frequently reported among this group of Colombian caregivers. Forty-three percent of the family caregivers reported some level of depression, 68% reported being overwhelmed by their caretaking responsibilities, and 43% reported dissatisfaction with their lives. Information, emotional, economic, physical, sleep, and psychological needs were positively correlated with depression and burden. Those with more household, physical, sleep, economic, and psychological needs had less satisfaction with life and social support. Caregivers with more community and respite needs had less social support, while those with more emotional needs had less satisfaction with life. Caregivers with more respite needs had more burden and those with more household needs had more depression.	Approximately half of the sample reports some level of burden, depression, or being dissatisfied with life. Psychosocial functioning was related to various family needs.
Beauregard & Noreau; 2010 Canada	Twenty-four spouses (eighteen women and six men) of persons with SCI	Individual interviews		The impact of SCI is focused primarily on three main areas: leisure, domestic tasks and family responsibilities, and sexuality. Spouses apply several strategies to overcome the difficulties they encounter, such as setting aside time for hobbies without the spouse, hiring staff to reduce the increased task load, reshuffling roles to coincide with the capabilities of the person with the spinal cord injury and maintaining open, honest communication with one's spouse on the topic of sexuality.	All these techniques, implemented and proven by experienced spouses, can be used as courses of action for clinical practitioners who work with spouses of people with disabilities in order to help them achieve a healthy balance in their life
Dickson et al., 2010 UK	11 participants who were both the spouse and primary caregiver of an individual with a SCI; of these, 10 were female and 1 was male. All interviews were transcribed verbatim and were subjected to Here we	Individual in-depth interviews	This study aimed to explore the lived experience of assuming the primary caregiver role in a group of spouses of individuals living with a traumatic spinal cord injury (SCI) (injuries ranged from paraplegia to quadriplegia). Interpretative	Three inter-related master themes: 'The emotional impact of SCI'; 'Post-injury shift in relationship dynamics' and 'Impact of care giving on identity'. Regarding the emotional impact of spinal injury, participants reported an almost instantaneous sense of loss, emptiness and grief during the injured person's rehabilitative period and feelings of anxiety were reported in anticipation of their return to the family home.	A distinct change in role from spouse and lover to care provider was reported and this ultimately contributed to relationship change and a loss of former identity.

			phenomenological analysis (IPA).		
Angel & Buus; 2011 Denmark	seven partners' narratives 1 and 2 years after their partner's injury.	Interview	Qualitative interview study focuses on the personal experiences of partners to a spinal cord injured person, using a Ricoeurian phenomenological-hermeneutic approach.	The study revealed how the injury was experienced from the partners' perspective through the aftermath. In the acute phase after the injury, partners also felt harmed, and support was needed in relation to their own daily activities, eating, resting, and managing distress. During the institutionalized rehabilitation, partners felt torn between supporting the injured partner and the demanding tasks of everyday life outside the institution. After discharge, partners struggled for the injured partner to regain a well-functioning everyday life and for reestablishing life as a couple.	The partner struggled to manage the overwhelming amount of everyday tasks. Some sought to reestablish their usual functions outside the family, whereas others focused on establishing a new life together. The partners experienced much distress and appreciated the support they got, but felt that they were mainly left to manage the difficult process on their own.
Gajraj-Singh, 2011 Fiji	30 primary caregivers of persons with SCI. The majority of the participants (n=20) were women, who had an ethnic Fijian background (n=18) and were married (n=18), and were spouses (n=13). Mean BI of the persons with SCI was 7.1 (s.d.=5.23) on a 0–20 scale, with 90% (n=27) suffering from moderate-to-very severe disability (BI<15). The mean duration of care giving was 6.1 years (s.d.=4.23). On average, the caregivers provided 6.1 h (s.d.=2.19) of care giving per day.	The Index of Psychological Well-Being (IPWB) was used to assess the psychological impact of care giving, and Caregiver Burden Inventory (CBI) was used to evaluate the burden associated with care giving for persons with SCI. Barthel Index (BI) scale was used to measure the functional abilities of the care recipients.	Cross-sectional	The experiences of care giving adversely affected the caregiver psychological well-being. Participants demonstrated high levels of time-dependent and development burden. Care giving was significantly related to the number of hours spent providing care ($r_s=0.35$, $P<0.05$), and the older caregiver age ($r_s=0.46$, $P<0.01$).	Being a primary caregiver of a SCI person contributes to caregiver burden and psychological distress. The findings indicate that the contributions of these people should be recognized and interventions should be tailored not only toward the needs of the care recipients but also to the needs of the caregivers.
Dickson et al., 2012 UK	11 spousal caregivers to people with a traumatic spinal cord injury. The findings are discussed in relation to the wider literature and recommendations for future caregiver support are highlighted.	Semi-structured interviews	Interpretative phenomenological analysis (IPA).	Two inter-related master themes: (1) coping with the spousal caregiver role; and (2) putting the pieces back together again. Adjustment was reportedly hindered by the introduction of paid caregivers as this represented a loss of privacy and power for the participants.	Within these, the analysis describes how regular venting of emotion, social support and focusing on the positive aspects of the situation all promoted coping.

<p>Nogueira et al., 2012 Brazil</p>	<p>59 individuals with SCI and their respective caregivers. Most patients with SCIs were male, aged 35.4 years old on average, with a predominance of thoracic injuries followed by cervical injuries. Most caregivers were female aged 44.8 years old on average.</p>	<p>The scale Short Form 36 (SF-36) was used to assess HRQOL and the Caregiver Burden Scale (CBScale) for care burden.</p>	<p>Cross-sectional observational study carried out by reviewing medical records and applying questionnaires.</p>	<p>Tetraplegia and secondary complications stand out among the clinical characteristics that contributed to greater care burden and worse HRQOL. Association between care burden with HRQOL revealed that the greater the burden the worse the HRQOL.</p>	<p>Preventing care burden through strategies that prepare patients for hospital discharge, integrating the support network, and enabling access to health care services are interventions that could minimize the effects arising from care burden and contribute to improving HRQOL.</p>
<p>Rodakowski et al., 2013 USA</p>	<p>Caregivers of community-dwelling adults aging with SCI (n=173) were interviewed as part of a multisite randomized controlled trial. The mean age \pm SD of caregivers was 53\pm15 years and of care-recipients, 55\pm13 years.</p>	<p>Abridged Version of the Zarit Burden Interview</p>	<p>Secondary analyses of cross-sectional data from a large cohort of adults aging with SCI and their primary caregivers. A hierarchical multiple regression analysis examined the effects of social supports (social integration, received social support, and negative social interactions) on burden in caregivers of adults aging with SCI while controlling for demographic characteristics and care giving characteristics.</p>	<p>After controlling for demographic characteristics and care giving characteristics, social integration ($\beta=-.16, P<.05$), received social support ($\beta=-.15, P<.05$), and negative social interactions ($\beta=.21, P<.01$) were significant independent predictors of caregiver burden.</p>	<p>Findings demonstrate that social support is an important factor associated with burden in caregivers of adults aging with SCI. Social support should be considered for assessments and interventions designed to identify and reduce caregiver burden.</p>

Rodakowski et al., 2012b USA	Community-dwelling caregivers of aging adults with spinal cord injuries ($N = 173$) interviewed	The Center for Epidemiological Studies Depression Scale measured caregiver depression symptom levels.	Cross-sectional secondary data analyses as part of a multisite randomized controlled trial. A hierarchical multiple regression analysis examined the effect of social support (social integration, received social support, and negative social interactions) on depressive symptom levels for the caregivers of adults aging with spinal cord injuries, controlling for demographic characteristics, and care giving characteristics	Caregivers were, on average, 53 years old ($SD = 15$) and care-recipients were 55 years old ($SD = 13$). Average Center for Epidemiological Studies Depression Scale scores indicated that 69 (40%) of caregivers had significant depressive symptoms (mean 8.69, $SD = 5.5$). Negative social interactions ($\beta = 0.27, P < 0.01$) and social integration ($\beta = -0.25, P < 0.01$) were significant independent predictors of depressive symptom levels in caregivers of adults aging with spinal cord injuries.	Findings demonstrate that negative social interactions and social integration are associated with the burden in caregivers of adults aging with spinal cord injuries. Negative social interactions and social integration should be investigated in assessments and interventions intended to target caregiver depressive symptom levels.
Ebrahimzadeh et al., 2013 Iran	72 wives of 72 veterans who were categorized as spinal cord injured patients based on the American Spinal Injury Association (ASIA) classification.	Health related quality of life was assessed by the Short Form (SF-36) Health Survey.	Pearson's correlation was carried out to find any correlation between demographic variables with SF-36 dimensions. To find the effect of the factors like age, employment status, duration of care giving, education, presence or absence of knee osteoarthritis, and mechanical back pain on different domains of the SF-36 health survey, Multivariate analysis of variance (MANOVA) was used.	The mean age of the participants was 44.7 years. According to the ASIA classification 88.9% and 11.1% of the veterans were paraplegic and tetraplegic respectively. Fifty percent of them had a complete injury (ASIA A) and 85% of the spouses were exclusive care givers. All of the SF-36 scores of the spouses were significantly lower than the normal population. Pearson's correlation demonstrated a negative significant correlation between both age and duration of caring with the PF domain. The number of children had a negative correlation with RE and VT.	The burden of care giving can impact the QOL of caregivers and cause health problems. These problems can cause limitations for caregiver spouses and it can lead to a decrease in the quality of given care

Graca et al., 2013 Brazil	Fourteen women (seven caregivers and seven controls)	Medical Outcomes Study 36 - Item Short-Form Health Survey (SF-36) and the Caregiver Burden Scale (CBS) Questionnaires.	The data from both questionnaires were compared using the Mann-Whitney U testing procedure for differences between caregivers and controls ($p < 0.05$).	The results from SF-36 were not statistically significant between groups, however, for the CBS data, there were significant differences between groups ($p > 0.05$), characterized by the percentage difference of 62%, 66.7%, 55%, 50%, 57% and 63% for tension, isolation, disappointment, emotional involvement, environment and overall score, respectively.	The CBS questionnaire was more adequate for verifying quality of life of caregivers of SCI patients, and care giving may have a negative impact on their quality of life.
Lucke et al., 2013 USA	Family caregivers of Latino/Hispanic individuals with spinal cord injury (SCI) during the early years of recovery. 10 self-reported Latino family caregivers from whom informed consent was obtained from two Participants included 2 English/Spanish-speaking, and 7 Spanish speaking family caregivers who were interviewed within 2 years after their respective family member's injury. Five caregivers were wives, 3 were mothers, and 1 was a father. Ages ranged from the 30s to the 60s, with a mean age of 48 years. Educational levels ranged from some grade school to some college. Only 1 of the caregivers was working full time outside the home; one family had a paid caregiver around the clock for their son.	Semistructured interviews with 9 family caregivers of Latino SCI survivors injured within the previous two years. Two interviews were conducted face to-face face, and seven interviews were conducted by telephone at the request of family members because of distance of the families from the researchers. A total of eleven interviews were conducted: nine in-depth interviews and two follow-up interviews. Interview questions were developed from the literature and previous studies.	Grounded Theory	"Resolving to go forward" was the core category that emerged from two simultaneous processes of "learning to care for" and "getting through" during the initial years as the primary informal caregiver. Most caregivers felt alone and abandoned after the injured person returned home, and experienced barriers to services and resources primarily because of language issues and economic status.	We recommend that researchers develop and evaluate culturally appropriate, informal care giving models to improve outcomes for both Latino individuals with SCI and their family caregivers.

<p>Middleton et al. (2014) Australia.</p>	<p>(NZ44; spouses, parents, others) nominated as a primary caregiver by the person with SCI.</p>	<p>General Health Questionnaire-28 (GHQ-28), Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), and Caregiver Strain Index (CSI) assessed the extent of psychological distress, HR-QOL, and burden, respectively, among caregivers. Functional status and community participation/care needs of the persons with SCI were assessed by the FIM and Craig Handicap Assessment and Reporting Technique, respectively.</p>	<p>Prospective longitudinal cohort study with measurements at 4 time points (6wk prior to discharge from subacute inpatient rehabilitation and 6wk, 1y, and 2y post discharge to community).</p>	<p>Multilevel piecewise models showed that psychological distress (GHQ-28 score) decreased significantly after discharge (slope estimate Z₋₀₃, P<.008). At the pre discharge time point, the caregivers' mental component summary score on the SF-36 was significantly lower than Australian national norms. The scores improved from pre discharge to 6 weeks post discharge (slope estimate Z_{.39}, P<.001), but they did not change significantly across the following 2 time points (slope estimate Z_{.02}, PZ_{.250}). At all 3 post discharge time points, the mental component summary scores were not significantly different to national norms. In contrast, the physical component summary score of the SF-36 did not significantly change across the pre discharge and 6-week post discharge time points (slope estimate Z_{.14}, PZ_{.121}) and the 3 post discharge time points (slope estimate <.01, PZ_{.947}). Scores at all 4 time points were not significantly different to the national norms. Caregiver burden showed no significant change over the study period (pre discharge to 6wk post discharge slope estimate Z_{.02}, PZ_{.426}; 3 post discharge time point slope estimates <_.01, PZ_{.334}). Reflecting this, 42% of caregivers met CSI criterion at the first time point, and 46% met the criterion at the fourth (2y) time point. Higher burden was significantly correlated with increased hours of care being provided by the caregiver and lower FIM scores and lower community participation (for the person with SCI) at each time point. Psychological distress correlated with caregiver burden at 6 weeks and 1 year post discharge but not at 2 years post discharge.</p>	<p>The trajectory of scores for psychological distress and HR-QOL was consistent with caregiver adaptation to the challenge of providing support to a person with SCI in the early post discharge period. Caregiver burden did not display similar reductions but did not worsen over the study period.</p>
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Table 3: Included Studies.

Data Extraction

A data extraction form was developed and uploaded electronically into a reference management file. Data extraction of the available data (e.g., statistical power, sampling strategies, and strength of the comparison groups and methods of evaluation, internal and external validity) was undertaken. The author assessed the level of statistical power on reported differences between treatment and comparison groups and the sample size available for the analyses. To assess the rigour of the age matched comparators designs, the author assessed the

presence of, or appropriateness and comparability of the comparison groups as well as the recruitment strategies to determine whether relevant sources of bias could have potentially been introduced. To address the quality of evidence available, the author considered whether the studies presented sufficient descriptions of the components and their mechanisms according to quality appraisal techniques. The verification of emergent findings may be deemed credible with regards to the decision making implicit within this article.

Synthesis

According to Popay et al. (2006) [27], a realist synthesis review tells a trustworthy story. Thematic analysis invoking a constant comparative approach [28] was applied to the data to synthesise the findings, relationships and general robustness [27] of the research articles.

Findings

Prevalence of Caregiver Psychological Distress in Carers of Individuals with SCI

17 studies provided estimates of the prevalence of psychological distress among SCI caregivers. Estimates included measures of depression [2,17,29-34], stress and mood [35], mental health measure as part of a generic quality of life tool [1-17,32-42]. Four questionnaire based studies [31-34] used the Centre for Epidemiological Studies Depression Scale (CES-D) (REF). The CES-D is a self-report instrument consisting of 20-items, each scored 1-4, and individuals scoring 16 or more are generally considered to be at risk for clinical depression. In a cross-sectional study, Dreer, et al. (2007) [30] found 15.7% (n=121) met the criteria on the Inventory to Diagnose Depression (IDD) for a major depressive disorder. Rodakowski, et al. (2013) [32] using a sample of 173 subjects further demonstrated that caregiver perceived health status significantly predicted caregiver depression. Schulz, et al. (2009) [33] using a randomised controlled trial design (n=44) demonstrated depression scores as high with mean scores above the risk threshold for clinical depression (8 on the 10-item CESD). Weitzenkamp, et al. (1997) [34] reported that carers were at risk of increased depression that other spouses who were not carers and indeed scored lower quality of life scores compared with their partners who had the SCI.

Caregiver stress was measured in 8 studies [3,29-41] using predominantly the Caregiver Burden Inventory (CBI). The CBI is a multi-dimensional instrument developed by Novak and Guest (1989) [43] that measures the impact of burden on the caregivers. CBI consists of five subscales: (i) Time-Dependence Burden (burden because of restriction on the caregiver's time); (ii) Development burden (feeling of being left behind in their development in respect to their peers); (iii) Physical Burden (feelings of chronic fatigue and damage to physical health); (iv) Social Burden (feelings of role conflict, resulting in arguments and time limitation) and (v) Emotional Burden (negative feelings towards the care recipient). Each subscale consists of five items except for

the Physical Burden Scale, which contains only four items. Each item is scored on a Likert Scale from 1 (strongly disagree) to 4 (strongly agree). Scores from each subscale (with a maximum score of 20) are added to give a total score ranging from 0 to 100. The higher the scores in each subscale, the more severe the burden imposed on the caregivers. CBI has shown good internal reliability (0.73-0.85) and inter-correlations of subscales, and high-factor loadings [43].

The Medical Outcomes Study 36 - Item Short-Form Health Survey [2-17,37-45] was administered to a total of 312 SCI caregivers. The majority of carers were female (85.3%) and married to the patient (61%). According to the SF-36 mental component summary, caregiver scores were below the standardised normal values, and the lowest scores were observed for bodily pain and vitality [37]. However, because this study did not use a control group, it is not possible to quantify differences in percentage terms, which makes inferences about the larger impact of the act of providing assistance in the lives of caregivers difficult.

However, the SF-36 often cannot measure with depth the effects and consequences that caring can have on the life of family caregivers of people with SCI. Lucke, et al. (2004) [40] determined family carers reported lower physical role, general health and vitality scores and reporting higher physical functioning and emotional role scores. Further, Nogueira, et al. (2012) [41] found statistically significant correlations in all domains of the SF-36 including general strain, isolation, disappointment, emotional involvement, environment and overall burden. Unalan, et al. (2001) [2] determined caring for a SCI individual significantly interferes with QoL using the Turkish version interview mode of administration SF-36. Graca, et al. (2013) [3] determined no statistical difference on the SF-36 though the Caregiver Burden Scale (CBS) revealed statistically significant negative impact on quality of life with an overall score of 63%.

Factors Related to Psychological Distress

Several predictors of SCI caregiver psychological distress were tested in cross-sectional quantitative studies [3,29-47]. Other studies explored potential sources for caregiver distress in interviews [40,48-54]. Results reported in these studies are categorised in to the following themes: caregiver attributes (including gender, age and ethnicity), severity of the SCI and its management, quality of the relationship between the

caregiver and the patient; and caregiver perceived burden.

Caregiver Attributes: In this section caregiver attributes and their relationship with psychological distress are explored. No quantitative studies included in this review investigated a relationship between caregiver gender and psychological well-being, other than Blanes, et al. (2007) [37]. Conducted in Brazil, they showed that demographic characteristics of caregivers of individuals with SCI (older age, female gender, and compromised health status) and care giving characteristics (co-residing with care-recipient and recent spinal cord injury) are strongly associated with compromised psychological well-being. Women interviewed during qualitative studies suggested that being female was a positive caregiver attribute [49-54]. The wives caring for husbands with SCI, in particular, describe a nurturing feeling and sense of duty; they believed that being a woman helped them to manage in their care giving role [48].

In a quantitative study, Gajraj-Singh (2011) [39] examined the possible effect of caregiver age and perceived burden of 30 family caregivers of patients with SCI. They were found to be significantly more burdened than the younger caregivers, a finding which has previously been reported by Post, et al. (2005) [35]. They determined an adverse effect on the caregiver's psychological well-being with high levels of their time projected towards caring for the SCI individual with care giving significantly related to the number of hours spent providing care and the older caregiver age. The burden of support as perceived by partners (n=365) was measured using a self-developed questionnaire consisting of six items: no burden (1), minor burden (2), moderate burden (3) and serious burden (4). The total score is the mean of the item scores and ranges from 1 up to four. Cronbach's alpha of this measure was excellent (0.92). Further, Dreer, et al. (2007) [30] noted that social support is of special interest to care-givers with regards to the potential source isolation and decreased social support available. Rodakowski's (2012) [42] findings further suggest that social support may be an important target of interventions for reducing caregiver depressive symptoms.

Severity of Spinal Cord Injury: Paraplegic/Tetraplegic Studies have reported that demographics, level and severity of injury, and functional status were associated with caregiver poorer quality of life [30-35]. Dreer, et al. (2007) [30] linked injury severity to caregiver probable depression status. Several investigators have speculated

that severe injuries may be associated with greater caregiver distress [35,42]. For example, greater injury severity may require more demanding roles by caregivers, and this may in turn require caregivers to provide a higher level of assistance in activities of daily living and time spent assisting the person with SCI. Thus, the demands associated with these caregiver activities may increase the likelihood for caregiver distress. Associations between caregivers' perceptions of level of injury (tetraplegia or paraplegia) and caregiver stress were identified by Post, et al. (2005) [35] within a cross sectional survey. There was a strong correlation between severity of injury and caregiver burden. However, Elliott, et al. (2001) [31] data failed to support this notion. Demographic characteristics (age, gender and race), spinal cord injury level and severity, and functional status (basic and instrumental activities of daily living) were not correlated with depressive symptom levels in caregivers within this sample. The coding scheme for injury severity used in Post, et al. (2005) [35] study may have contributed in part to these results, but, in general, other research using prospective designs are required to examine this matter. Further Unalan, et al. (2001) [2] using ASIA scores identified some severity parameters related to the injury impacting upon quality of life of caregivers' but no more so than on those caregivers who are "well".

In qualitative reports, caregivers vividly describe the distress [48] associated with the caring role. Chen & Boore (2008) [50] talk of the initial stages as being a "catastrophic life event" with DeSanto Madeya (2006) [51] talking about an "unknown world filled with unfamiliar words, equipment and complications" culminating in a lack of freedom and sense of loss for the carer's themselves. Depending on the severity of the lesion Bearegard & Noreau (2010) [49] found that mainly individuals with tetraplegia needed assistance with all aspects of personal care which inevitably led to feelings of burden; supported by Post, et al. (2005) [35] and Weitzenkamp, et al. (1997) [34] using quantitative designs. All of these consequences of living with SCI took a toll on carers and transpired into carer distress and feelings of helplessness and guilt.

Gajraj-Singh (2011) [39] in their study conducted in Fiji corroborated the findings of Dreer, et al. (2007) [30] and Unalan, et al. (2001) [2] in Western countries in that no significant relationship between the level of injury and caregiver burden was demonstrated. This could be because Paraplegics are expected to be independent in self-care and mobility. In comparison, it is only possible to

discern from Dreer, et al. (2007) [30] study that 23 were complete cervical injuries and 42 were incomplete tetraplegic cervical injuries.

Relationship Dynamics between the Carer and the SCI Individual: In regard to the socio-demographic and clinical characteristics of caregivers, many studies present similar results, this serves to highlight the predominance of female caregivers who are married, aged 45 to 50 years old on average and with a low educational level [37,41]. In a study conducted in Colombia, Arango-Lasprilla, et al. (2010) [36] in a cross sectional design using the Zarit Burden Interview (ZBI) assessed the most frequent needs of 37 family caregivers of individuals with SCI and reported that 68% of carers felt overwhelmed by caretaking responsibilities. The results revealed that physical health, emotional and socio-economic needs were the subscales that most positively correlated with depression and burden.

However, there is an implicit obligation for the family, to provide the required level of care for their family members. That said a few caregivers considered leaving the situation *“I thought of leaving him and leaving all of it, you understand, because it was a heavy load. Then I thought about that, but it’s not right either, to leave him. But at the same time, I thought he needed me right now, and maybe I would need him in the future”* [54].

A number of research studies using qualitative methods provide descriptions of care giving from which the impact of SCI on carer-patient relationships could be extracted. Caregivers in Angel & Buus’ (2011) [48] study relate how they themselves felt “harmed” in the acute phase post injury and support was needed to help them manage their own daily activities, eating, resting and managing distress. Post discharge, partners struggled to regain a well-functioning everyday life in which re-establishment of life as a couple could take hold: *“I have resigned myself to looking after him for the rest of my life”* [52]. Beauregard & Noreau (2010) [49] introduced sexuality as a theme *“I believe that we develop something else – possibly less physical, more sentimental...the bond uniting us is as strong as it ever was”* (Woman, tetraplegic partner, pre-injury relationship). Dickson et al. (2010) [52] *“I just feel as if I have to do everything for him. And again, our relationship has changed from lovers, if you like to mother and son (...). But I think now I’m his mother, because there’s no sex life or anything...there’s no loving relationship any more”* [Erin].

The spiral of worsening SCI related conditions was found by Nogueira, et al. (2012) [41] to lead to expressions of increased emotional burden and strain on the relationship between carer and patient. Concern was expressed about keeping the patient “stable” and having to learn to care for activities of daily living often taken by able bodied people as for granted. Rodakowski, et al. (2013) [32] using the CES-D Scale found the chronicity of the situation was correlated with depression in the carer. Further, when a spouse is engaged in care-giving, symptoms such as physical and emotional stress, burnout, fatigue, anger, depression and resentment can be more exacerbated than for those who are not performing such tasks [34,35].

The time of marriage (pre-injury versus post-injury) appears to be critical in assessing the impact for the spouses. A comparison between the scores of spouses in pre-injury marriages with those in post-injury marriages reveals that the latter had significantly lower time-dependent caring scores for the burden and seem to manifest a better marital adjustment [29]. Weakening of the marital relationship and tensions were described by wives of men with SCI, though despite this they were determined to stay with their husbands and care for them [48,52]. Interestingly, Dickson et al. (2010) [52] proposed better relationship success in relationships where injury has been present from the beginning of the relationship.

Many caregivers expressed a desire for honest communication but felt restricted because of their own physical and mental health status [36,47-50].

Burden of Care - Objective and Subjective Assessments: Eight studies reported estimates of caregiver burden [3,29-42]. The Caregiver Burden Scale was used in six of these studies to produce statistically significant scores within all dimensions (General strain, Isolation, Disappointment, Emotional Involvement; Environment and Overall burden alongside the ZBI being used in the other two in which the ZBI was found to be predictive of caregiver depression [36,42].

Dreer, et al. (2007) [30] and Elliott & Berry (2009) [17] used regression analysis for predictors of caregiver burden, using the Inventory to Diagnose Depression (IDD) and the Social Problem Solving Inventory-Revised (SPSIR) with the three main variables being social problem solving abilities, caregiver health and negative problem orientation. A cross-sectional study [1] examined the relationship between caregivers’ problem-solving ability, patient adjustment in spinal cord injured participants and

the presence of pressure sores at 1 year post discharge from rehabilitation. Patient depressive behaviour on admission and caregiver tendencies to solve problems impulsively and carelessly were significant negative predictors of SCI acceptance of disability at discharge from rehabilitation. Additionally, completeness of the lesion and caregivers' impulsive-careless problem solving approach significantly predicted one or more pressure sores at 1 year post discharge.

Unalan, et al. (2001) [2] compared QoL scores of primary caregivers of SCI survivors living in the community with those of healthy age-matched controls. Although there were no differences between the groups in age, education, and income levels, the primary caregivers of SCI survivors reported significantly lower scores on all subscales of the SF-36 except for bodily pain. Differences could not be attributed to time since injury, level or severity of injury.

Arango-Lasprilla, et al. (2010) [36] included a number of objective measures of caregiver burden including information, emotional, economical, physical, sleep and psychological needs in attending their family member with SCI. These were positively correlated with burden of care. Chan (2000) [29] administered the Katz Adjustment Scale for Relatives (KASR) to 40 spouses and reported that relatives under care give burden as the main source of their stress. Gajraj-Singh (2011) [39] reported similar caregiver burden in a Fijian population.

On the CBI scale, caregivers scored much higher on the time-dependent and the development burden subscales compared with other subscales [39]. These findings are similar to that reported in a Chinese population with the scores in the previous study being slightly higher. Time dependent burden reflects the limitations imposed on the caregiver because of the amount of time spent providing care for the SCI person. Development burden is a feeling of being left behind in terms of development with respect to peers. A significant relationship was found in Gajraj-Singh et al.'s study between these two variables and the number of hours of care giving per day, indicating that burden increased with increasing time spent assisting the care recipients on a daily basis. These findings are consistent with the other studies which have identified levels of assistance provided in ADL and the number of hours spent providing support for the SCI person as strong contributors of caregiver burden [33,35].

Qualitative research revealed the reality of caring for a person with SCI which often meant putting one's own

health second as highlighted by the following quote: *"I began to have anxiety attacks. I started to worry about everything. After taking care of him every day for one year, my health began to show from the wear and tear. I had to have surgery on my knee. Now I have to have surgery on my wrist"* [54].

In contrast, care giving is also viewed as a positive experience in which being flexible and adjusting their lives to incorporate the caregiver role was important [55]. Several qualitative studies included caregiver reflections upon the multiple roles, including housewives, nurses and doctors, they adopted when providing care to the person with SCI [51]. Further, emphasis on the role of the caregiver within society is demonstrated in the following quote: *"There was a nurse or a nurse's aide who came to the house every day. But they did not help him get up. I learned how to do that myself"*. [54].

Carers often spoke of the significant burden of carers who tried to remain vigilant and on the alert [42]. A quote provided by Family Carer 7 in Chen and Boore's (2008) [50] work offers: *"I never think about our future. I don't know how to solve this problem. Day in day out, our life is walinginto darkness"* reflects the demands of providing care. These studies all indicate the effect of the role of the family caregiver on the health and quality of life of caregivers themselves as well as that of the person with SCI.

Perceived Adequacy of Professional Support

This section relates to the literature pertaining to carers perceptions of professional support to assist them in their care giving role. Central to this theme was the need for information pertaining to SCI, its trajectory and symptom management of secondary complications of the resulting disability. Some carers expressed frustration and a lack of understanding by healthcare professionals [51] and felt they were left to manage the process on their own. Chan (2000) [29] reported that rehabilitation professionals were perceived to limit their attentions to the SCI person. Lucke, et al. (2013) [54], with a Latino-Hispanic population found that even though families had home care services for a period of time following discharge, the perception of the caregivers was that assistants did not help or even left early, before the care was completed: *"We had home health for an hour a day to bathe him and get him up, but they never stayed their time. I ended up doing everything anyway"*.

Specifically, carers expressed a need for support to better manage the complex and challenging sequelae a SCI had wrought upon them [51]. DeSanto-Madeya (2009) [46] reported that depressed carers want support from other family members, each other and friends alongside access to a support from nurses and other healthcare professional services. Indeed, Dreer, et al. (2007) [30] state that the percentage of caregivers with probable depressive disorder may parallel that observed among persons with SCI. Beauregard & Noreau (2010) [49] presented qualitative data to suggest that the greatest help came in the form of hiring staff to reduce the increased task load the carer perceives, and in the form of respite care [47]. In reality, access and utilisation of support mechanisms can be problematic, with many carers stating that they lack knowledge of and access to professional services [17,54]

Dickson, et al. (2010) [52] outline a number of key issues with regard to paid care potentially impeding to some extent the maintenance of a sense of personal control and self-efficacy: *"I have real difficulty with home carers coming in and out of the house because I ... your life's not your own, nothing is private any more. Somebody comes in every morning and every night for the rest of our lives"* (Erin). However, this is counterbalanced by Amy *"I can't do it [caring] full time so we have to use the facilities that we are offered and the funding that we are given to have somebody in to do it"*

There was also a tendency for carers to actively seek professional support during the initial acute rehabilitation episodes only [41-52]. Upon discharge, there appears to be a lack of support available other than a caregivers own resourcefulness, resilience and optimism. This is an understandable source of frustration for carers with some relaying stories of trying to survive with what is available to them and desperate to avoid placing their loved one in a residential home: *"[We can't put him in a nursing home; what we have here is meagre, it is clean. He would not do well there. This is what God wants. [We] can't put him in a home; [We] have to deal with it"* [54].

A trend of reluctance to bother health care professionals is evident and contributes to the unmet needs of caregivers in this situation [48], despite the evidence that time and interest in the family would have clear positive benefits [17,33,51]. There was an expectation by some carers that professional services should be readily available and should not require the carer to seek services [39,54]. The positive benefits to

utilisation of respite and support were most evident when carers described care that was provided by someone who understands the condition [54]. However, in these studies conducted in what can be construed as developing countries the absence of paid support and the presence of other family members in the care of SCI persons are apparent. Extended family structure is a common feature of such cultures. Caregivers acknowledged the support of family members who provided assistance with ADL, helped with respite care, accompanied SCI individuals on outdoor activities and provided financial support. Assistance of other family members is also reported in minority ethnic groups and other cultures [1,29,37,56]. Although paid support is a common feature in Western countries [35] it appears to be almost non-existent in developing countries. In these instances, the gap in the continuation of care is most likely filled by others present around these individuals.

Discussion

The primary objective was to determine the prevalence of psychological distress and risk factors of distress for informal caregivers of people with SCI. It is important to develop a greater understanding of care giving and psychological distress to identify caregivers whom may require more intensive assessment and support mechanisms. This review was limited by the sparse amount of studies that have assessed the prevalence of psychological distress, in particular depression, in this population. Common methodological limitations of studies included in this review were a lack of non-caregiver age-matched comparison groups, focus on the experience of female carers, small sample sizes, and failure to follow caregivers longitudinally.

In this review only six studies [29,31-36] used a psychometrically validated measure of depression with scores suggestive of depression ranging from 40% to 59%. The largest study that measured depression in SCI carers (N=173) [32] reported the strongest prediction of depression levels, coinciding with the work of Blanes, et al. (2007) [37]. In comparison, estimates show that between 40% and 70% of the caregiver population have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression [4]. Other studies indicate that the mean CES-D scores for the studies by Weitzenkamp, et al. (1997) [34] and Arango-Lasprilla, et al. (2010) [36] are higher than a meta-analysis of CES-D score across a range of chronic conditions [10]. In particular, isolation and lack of support

are likely to be a high burden and result in distress or mental health problems, which have been identified as being 20% higher in carers than non-carers [57]. The conflicting reports of psychological distress identified in this review of SCI caregivers are likely to be related to the small number of studies and small sample sizes included in the review that may have been subjected to sampling bias. In summary, no reliable estimates of the prevalence of depression for SCI caregivers can be made at this present time.

Psychological distress in caregivers results from a complex interplay of factors that included characteristics of the SCI individual and caregiver [3,29-47]. Limited research has focused on potential caregiver risk factors, such as age, gender, SCI severity and characteristics, for caregiver psychological distress. Only two studies [2,3] compared the presence of psychological distress of female SCI caregivers with an age-matched control group. Although these studies have the advantage of an age-matched comparator group, they are limited by small non-random samples, cross-sectional designs and the inclusion of wives only. No studies focused exclusively on males. No meta-analyses were located in reviewing the literature.

It is apparent that caregivers' subjective perception of SCI severity and the ability to alleviate distressing sequelae following SCI, reflects carers self-reported levels of psychological distress [3,29-47]. In support of this, qualitative research uncovered aspects of care issues specific to SCI that are particularly distressing for caregivers. Nurses are ideally placed to provide education and management strategies to assist caregivers to cope with living a meaningful life with SCI. Involving the caregiver in SCI rehabilitation sessions and other patient focused interactions for the promotion of self-management, are likely to be of benefit to both patient and caregiver [33]. However, this needs to be viewed within the context that many caregivers are reluctant to initiate engagement with healthcare professionals for non-emergency situations [29,47,49].

There has been increasing recognition in recent years of the importance of providing support for carers in their caring role. In the UK, this has been evident, for example, in the 2006 Health and Social Care White Paper [7], and the inclusion of carers; support in social services' performance ratings [58]. Despite these important advances, this review indicates that SCI carers are generally not aware of or receive formal services to assist with the care giving role [54].

Caregiver perceived burden was most frequently measured using the ZBI. This is a well validated and widely used tool to assess burden in the general caregiver literature. Perceived burden was associated with caregiver depression and other measures of psychological distress. Interestingly, objective measures of caregiver burden, such as time spent attending to the patient, were not significantly related to poorer psychological outcomes [36,42]. However, it cannot be assumed that objective measures of care giving, such as time spent attending to a patient with SCI, provide reliable indicators of caregiver perceived burden and psychological distress. This highlights the importance of healthcare professionals to address carers' needs, including the emotional impact of care giving.

Research exploring the impact of SCI in relationship dynamics between the patients and carer has consistently found that communication often suffered placing an increasing amount of strain on the relationship [3,48,55]. This finding is significant because poorer relationship quality was significantly associated with increased carer psychological distress [1,29-54]. Despite the adversity of providing care for loved ones, self determination and commitment to the person with SCI was apparent. In particular, wives of men with SCI disclosed a determination to continue providing care to their partners for as long as possible [34-40]. This determination is likely to be at great emotional cost to the caregiver and highlights the importance of the provision of carer support services.

Review Limitations and Future Research

Achieving the aim of the review was limited by the complexity of the phenomenon under investigation, the volume of 'evidence' available and the disparate settings and cultures from whence it emerged. Future research would benefit from real-world collaborative research reviewing the effects of caring for family members with spinal injuries in the non-sterile, complex and dynamic environments in which they live. First, psychological wellbeing of carers should be studied in context and with cognisance of the longitudinal effects. Secondly, the one-dimensional nature of many of the studies reported here needs to be addressed. There is a need for triangulation in improving the utility of research into such interactions and effects, and the dearth of mixed method approaches should be remedied. It may therefore be useful for researchers in an area dominated by psychology to undertake interdisciplinary work involving people who can use their respective skills, knowledge and research

methodologies to inform a topic that so clearly permeates and transcends boundaries and disciplines. Further longitudinal research is needed to determine whether caregivers with more needs report worse psychosocial functioning or if those with worse psychosocial functioning report more needs.

Conclusion

This paper has provided a review and analysis of studies that have explicitly investigated the subjective well-being of informal caregivers of patients with SCI and the attendant physical ramifications of doing so. The totality of the current evidence-base suggests that many factors are related to caregiver distress but it is not possible to gauge the prevalence of this at present. To date, research into the psychological impact of SCI care giving has largely been confined to small, local investigations with a potential for selection bias. Despite these methodological shortcomings, the messages arising from these international studies are clear - SCI care giving is associated with psychological distress, and is influenced by lack of practical interventions and support mechanisms. Sub-optimal carer support is likely to lead to greater reliance on the health system.

Whilst it is acknowledged that providing informal care provide a valuable service to society and can be rewarding to the caregiver, there is growing international concern about increased psychological distress and overall health deterioration experienced by family carers [57]. International policies focusing on future provision of long term care recommend a number of strategies to counteract the negative consequences of providing informal care – including payments for unpaid care, promoting flexible working conditions to enable carers to remain in the workforce, improved support service, such as respite [57]. Whilst such initiatives require significant upfront financial and social support family carers represent the key to long term care; the implementation of strategies to reduce the burden of providing care are essential. Further studies are needed to clarify the prevalence of SCI caregivers' psychological comorbidities and specific factors that predict poorer carer health outcomes, so that appropriate interventions can be initiated, developed, and evaluated with a view to enhancing quality of life.

Social and support networks, access to rehabilitation centres and health services with professionals cognisant of contemporary knowledge concerning individuals with SCI and caregivers are all extremely important towards a

goal of minimising care burden. Corroborated by what occurred in mental health decades ago, a decrease in length of rehabilitation stay had forced the responsibility of Caring for people with SCI onto family members and caregivers. Although the goal of formal and informal caregivers is to prevent complications and enhance quality of life, without adequate resources these costs are transferred to physical and psychological sequelae for family caregivers. If properly supported in the transition to caring for a spinal cord injured individual with a focus on daily functioning and support, new ways of engaging in desired and necessary activities can be fostered.

References

1. Elliott TR, Shewchuk RM, Richards JS (1999) Caregiver social problem-solving abilities and family member adjustment in recent onset physical disability. *Rehabilitation Psychology* 44(1): 104-123.
2. Unalan H, Gencosmanoglu B, Akgun K, Karamehemetoglu S, Tuna H, et al. (2001) Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire. *Spinal Cord* 39(6): 318-322.
3. Graca A, Amarante do Nascimento M, Lavado EL, Garanhani MR (2013) Quality of life of primary caregivers of spinal cord injury survivors. *Rev Bras Enfermagem* 66(1): 79-83.
4. Zarit S (2006) Assessment of family caregivers: a research perspective. In: *Family Caregiver Alliance (Edn) Caregiver Assessment: Voices and Views from the Field. Report from a National Consensus Development Conference (vol II) San Francisco*, pp: 120.
5. Spence A, Hasson, F, Waldron M, Kernohan G, McLaughlin D, et al. (2008) Active carers: living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing* 14 (8): 368-372.
6. Beesley L (2006) *Informal Care in England. The King's Fund, London, UK*, pp: 43.
7. Department of Health (2006) *Our Health, Our Care, Our Say. A New Direction for Community Services. NHS, London, UK*, pp: 236.

8. Bergs D (2002) "The Hidden Client" – women caring for husbands with COPD: their experience of quality of life. *Journal of Clinical Nursing* 11(5): 613-621.
9. Seamark DA, Blake SD, Seamark CJ, Halpin DMG (2004) Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliative Medicine* 18(7): 619-625.
10. Pinquart M, Sorensen S (2003) Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychological Aging* 18(2): 250-267.
11. Schulz R, Beach SR (1999) Care giving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 282(23): 2215-2219.
12. Lim JW, Zebrack B (2004) Caring for family members with chronic physical illness: a critical review of caregiver literature 2: 50
13. Toseland RW, Rossiter CM, Labrecque MS (1989) The effectiveness of peer-led groups to support family caregivers. *The Gerontologist* 29(4): 465-471.
14. Vrabec NJ (1997) Literature review of social support and caregiver burden 1980-1995. *Image: Journal of Nursing Scholarship* 29(4): 383-388.
15. Donelan K, Hill CA, Hoffman C, Scoles K, Feldman PH (2002) Challenged to care: Informal Caregivers in a changing health system. *Health Affairs* 21(4): 222-231.
16. Vitaliano PP, Zhang J, Scanlan JM (2003) Is care giving hazardous to one's health. A meta-analysis. *Psychological Bulletin* 129(6): 946-972.
17. Elliott TR, Berry JW (2009) Brief problem-solving training for family caregivers of persons with recent-onset spinal cord injuries: A randomized controlled trial. *Journal of Clinical Psychology* 65(4): 406-422.
18. Pawson R (2006) *Evidence-based policy: A realist perspective*, Sage, London, pp: 208.
19. Pawson R, Boaz A (2004) *Evidence-based policy, theory-based synthesis, user-led review: An ESRC Research Methods Programme Project*, London: ESRC UK Centre for Evidence Based Policy and Practice.
20. Pawson RT, Greenhalg, Harvey G, Walshe K (2004) *Realist synthesis: an introduction*. ESRC Research Methods Programme Working Paper Series.
21. Pope C, Mays N, Popay J (2008) *Synthesising Qualitative and Quantitative Health Evidence: A Guide To Methods*, *Sociology of Health Illness* 30(2): 330-331.
22. Dixon Woods M, Fitzpatrick R (2001) Qualitative research in systematic reviews: opportunities and problems. *BMJ* 323(7316): 765-766.
23. Slavin RE (1995) Best evidence synthesis: an intelligent alternative to meta-analysis. *Journal of clinical Epidemiology* 48(1): 9-18.
24. Baumeister R, Leary MR (1997) Writing narrative literature reviews. *Review of General Psychology* 1(3): 311-320.
25. Derish PA, Annesley TM (2011) How to write a rave review. *Clinical Chemistry* 57(3): 388-391.
26. Saini M (2011) *Qualitative research quality checklist*, University of Toronto.
27. Popay J, Roberts H, Sowden A, Arai A, Rodgers H (2006) *Guidance on the Conduct of Narrative synthesis in systematic Reviews*. ESR: 1.
28. Glaser BG, Strauss AL (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Hawthorne NY Aldine de Gruyter, Chicago.
29. Chan RC (2000) Stress and coping in spouses of persons with spinal cord injuries. *Clinical Rehabilitation*, 14(2): 137-144.
30. Dreer L, Elliott TR, Shewchuk R, Berry JW, Rivera P, et al. (2007) Family caregivers of persons with spinal cord injury: Predicting caregivers at risk for probable depression. *Rehabilitation Psychology* 52(3): 351-357.
31. Elliott TR, Shewchuk RM, Richards JS (2001) Family caregiver social problem-solving abilities and adjustment during the initial year of the care giving role. *Journal of Counselling Psychology* 48(2): 223-232.
32. Rodakowski J, Skidmore ER, Rogers JC, Schulz R (2013) Does social support impact depression in

- caregivers of adults ageing with spinal cord injuries. *Clinical Rehabilitation* 27(6): 565-575.
33. Schulz R, Czaja SJ, Lustig A, Zdaniuk B, Martire LM, et al. (2009) Improving the quality of life of caregivers of persons with spinal cord injury. *Rehabilitation Psychology* 54(1): 1-15.
 34. Weitzenkamp DA, Gerhart KA, Charlifue SW, Whiteneck GG, Savic G (1997) Spouses of spinal cord injury survivors: The added impact of care giving. *Archives of Physical Medicine and Rehabilitation* 78(8): 822-827.
 35. Post MW, Bloemen J, De Witte LP (2005) Burden of support for partners of persons with spinal cord injuries. *Spinal Cord* 43(5): 311-319.
 36. Arango Lasprilla JC, Plaza SL, Drew A, Romero JL, Pizarro JA, et al. (2010) Family needs and psychosocial functioning of caregivers of individuals with spinal cord injury from Colombia, South America. *Neurological Rehabilitation* 27(1): 83-93.
 37. Blanes L, Carmagnani MI, Ferreira LM (2007) Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord* 45(6): 399-403.
 38. Ebrahimzadeh MH, Shojaei BS, Golhasani Keshtan F, Soltani Moghaddas SH, Fattahi AS, et al. (2013) Quality of life and the related factors in spouses of veterans with chronic spinal cord injury. *Health and Quality of Life Outcomes* 11: 48.
 39. Gajraj Singh P (2011) Psychological impact and the burden of care giving for persons with spinal cord injury (SCI) living in the community in Fiji. *Spinal Cord* 49(8): 928-934.
 40. Lucke KT, Coccia H, Goode JS, Lucke JF (2004) Quality of life in spinal cord injured individuals and their caregivers during the initial 6 months following rehabilitation. *Qual Life Res* 13(1): 97-110.
 41. Nogueira PC, Rabeh SA, Caliri MH, Dantas RA, Haas VJ (2012) Burden of care and its impact on health-related quality of life of caregivers of individuals with spinal cord injury. *Rev Latino Am Enfermagem* 20(6): 1048-1056.
 42. Rodakowski J, Skidmore ER, Rogers JC, Schulz R (2012) Role of social support in predicting caregiver burden. *Archives of Physical Medicine and Rehabilitation* 93(12): 2229-2236.
 43. Novak M, Guest C (1989) Application of a multidimensional caregiver burden inventory. *The Gerontologist* 29(6): 798-803.
 44. Ware JF, Kosinski M, Weller SD (1994) *The SF-36 Physical and Mental Health Summary Scales: A User's Guide*. The Health Institute. New England Medical Centre, Boston.
 45. Middleton JW, Simpson GK, De Wolf A, Quirk R, Descallar J, et al. (2014) Psychological distress, quality of life, and burden in caregivers during community reintegration after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 95(7): 1312-1319.
 46. DeSantoMadeya S (2009) Adaptation to spinal cord injury for families post-injury. *Nursing Science Quarterly* 22(1): 57-66.
 47. Foster M, Amsters D, Carlson G (2005) Spinal cord injury and family caregivers: A description of care and perception of service need. *Australian Journal of Primary Health* 11(1): 91-101.
 48. Angel S, Buus N (2011) The experience of being a partner to a spinal cord injured person: A phenomenological-hermeneutic study. *International Journal of Qualitative Studies in Health and Well-Being* 6(4).
 49. Bearegard L, Noreau L (2010) Spouses of persons with spinal cord injury: Impact and coping. *British Journal of Social Work* 40(6): 1945-1959.
 50. Chen HY, Boore JRP (2008) Living with a relative who has a spinal cord injury: a grounded theory approach. *Journal of Clinical Nursing* 18(2): 174-182.
 51. De Santo Madeya (2006) The meaning of living with spinal cord injury 5 to 10 years after the injury. *Western Journal of Nursing Research* 28(3): 265-289.
 52. Dickson A, O'Brien G, Ward R, Allan D, O'Carroll R (2010) The impact of assuming the primary caregiver role following traumatic spinal cord injury: An interpretive phenomenological analysis of the spouses's experience. *Psychology and Health* 25(9): 1101-1120.

53. Dickson A, O'Brien G, Ward R, Flowers P, Allan D (2011) Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: an interpretative phenomenological analysis. *Journal of Health Psychology* 17(2): 247-257.
54. Lucke KT, Martinez H, Mendez TB, Arévalo-Flechas LC (2013) Resolving to Go Forward: The Experience of Latino/Hispanic Family Caregivers, *Qualitative Health Research* 23(2): 218-230.
55. Dickson A, O'Brien G, Ward R, Flowers P, Allan D (2012) Adjustment and coping in spousal caregivers following a traumatic spinal cord injury: an interpretative phenomenological analysis, *J Health Psychol* 7(2): 247-257.
56. Pinguart M, Sorensen S (2005) Ethnic differences in stressors, resources, and psychological outcomes of family care giving: A meta-analysis. *The Gerontologist* 45(1): 90-106.
57. Organisation for Economic Co-operation and Development (2011) Help wanted? Providing and Paying for Long-Term Care.
58. Commission for Social Care Inspection (2005) Performance Ratings for Social Services in England, CSCO, London, UK.