



REVIEW ARTICLE

WHAT IS THE EVIDENCE ABOUT THE NEEDS AND EXTENT OF PSYCHOLOGICAL ADJUSTMENT OF ADULT FAMILY CAREGIVERS OF INDIVIDUALS LIVING IN THE COMMUNITY WITH SPINAL CORD INJURY? A SYSTEMATIC REVIEW

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ABSTRACT

Spinal cord injury (SCI) is a dramatic event which has a significant impact on the individual and his/her family. The actual adjustment to SCI starts when an individual leaves the rehabilitation unit and is no longer under the care of the rehabilitation team. Family caregivers are vital community-based resource who provide care for SCI persons. The objective of this review is to identify and synthesize the best available evidence on the needs and extent of psychological adjustment of adult family caregivers of spinal cord injury persons living in the community. The review considered all empirical studies that explored the needs and psychological adjustment of adult family carers living in the community published in English language. An extensive search was conducted using the following databases; Web of knowledge, Web of science, CINAHL, Medline, Psyc INFO, EMBASE and JBI, as well as manual search of the bibliographies of retrieved articles. The Hawker *et al.* (2007) three-stage critical appraisal instruments were used to extract data and assess for quality of the papers. A narrative summary of findings was carried out for this review. The finding showed that a total of six papers were included in the review. Four papers used quantitative methods, one paper utilized quantitative method while the remaining one paper utilized mixed methods. Fifty-six papers were initially identified but fifty were excluded as they did not meet the inclusion criteria. Findings were extracted and summarised using the Hawker *et al.* three-stage critical appraisal method. Six themes emerged from the review: 1) family needs, 2) change in family dynamics, 3) uncertainty, 4) feeling of burden, 5) intimacy and 6) moving on. There is need for healthcare professionals to embark on positive perspective in training and supporting family caregivers of SCI persons living in the community. Family caregivers require continuous, consistent and comprehensive support from professionals, peer and extended family. This support and education help family caregivers develop the required future-oriented adjustment for community integration in SCI.

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INTRODUCTION

This dissertation presents a study which aims to critically review selected articles that report research addressing the needs and extent of psychological adjustment among adult family caregivers of persons with Spinal Cord Injury (SCI). Its main focus is on research about those who give the care in the domestic home. SCI has been considered a life-changing catastrophe (Alpert & Wisnia, 2008, Barone & Waters, 2012, Bracken & Shepard, 1980, Chevalier *et al.*, 2009). Although only one person will directly experience the injury, it significantly affects their entire family. Nurses have the responsibility of working with patients through difficult periods, hence the critically important role of nurses in the care of spinal cord injured persons.

Preparing families to effectively take up the vital role of providing care for their relatives with SCI following hospitalization is an important role of the rehabilitation nurse. In developing as well as developed countries, family caregivers are vital community-based resource who provide care for physically disabled persons (Cripps *et al.*, 2011, Lapham-Randlov, 1994, Nwadinigwe *et al.*, 2004b, Rahimi-Movaghar *et al.*, 2010). However, significant caregiving commitment is known to adversely affect caregiver health and thereby their ability to provide care over a long period as the case with SCI. Spinal Cord Injury (SCI) is a dramatic event which has a significant impact on the individual and his/her family. Its sudden occurrence often does not give opportunity for anyone to prepare to cope with its various consequences.

This review focuses on research relating to family caregivers of SCI persons. The inspiration to undertake the review stems from the high incidence of this condition in my country Nigeria, where I work as an orthopaedic nurse, the unavailability of resources to cater for their needs and the role being played by family caregivers in their care. According to Boschen *et al.* (2003) managing acute SCI, providing comprehensive rehabilitation, and securing acceptable supports to allow community reintegration are resource-intensive undertakings. There had been significant advances over the past five decades in lessening morbidity and mortality following SCI and improving quality of life and long-term health outcomes of persons affected by SCI in developed countries (Burns & O'Connell, 2012, Nwankwo & Uche, 2013, Cripps *et al.*, 2011). Unfortunately, these advances are yet to receive impact on the majority of SCI persons in resource-limited or developing countries like Nigeria. For persons who survive the acute period of SCI, long-term survival is gloomy. There exists little or no government support for SCI injured patients in Nigeria, where healthcare is poorly funded with no social policy to ameliorate the burden of this permanent disability. The rate of spinal cord injury continues to skyrocket in Nigeria as a result of bad road conditions and network, and gross non-compliance with traffic regulations.

The concept of spinal cord injury in developing countries has a significant difference from that of the developed world. Public buildings are usually not accessible to them and domestic accommodation is a source of serious concern. The environment is not equipped to meet their needs. In a study conducted in Nigeria by Nwadinigwe *et al.*, (2004), 97% of discharged SCI persons were lost to follow-up. These stems from the fact that caregivers are most times overwhelmed with their care and consequently may allow them to die at home without adequate care. Abandonment occurs when families, friends and significant others cease to identify with patients; during hospitalization, patients are sometimes left at the mercy of nursing and medical staff when the cost of care overwhelms the family. This is common in Nigeria where the cost of care poses a huge burden on patients' relatives (Elechi & Etawo, 1990, Nwadinigwe *et al.*, 2004b, Solagberu, 2002). It is more significant when the illness is prolonged with no prospect of full recovery. In resource poor countries, there are no standard spinal cord injury centres where comprehensive care could be given to SCI persons (Burns and O'Connell, 2012, Kurylo *et al.*, 2001, Rathore *et al.*, 2008). According to Nwadinigwe *et al.* (2004a), mortality and morbidity rates due to SCI are on the increase as a result of non-availability of follow-up care. SCI persons depend on others for personal hygiene, toileting, feeding and ambulation. The effect of this dependence is sometimes manifested in anxiety, depression, and feelings of guilt and grief (Elliott *et al.*, 1991, Kelly *et al.*, 2012). However, several authors have confirmed the need for family support following hospitalization as SCI places a lot of adaptation demand on both patients and family member (Elliott & Shewchuk, 1998, Burns & O'Connell, 2012, Kurylo *et al.*, 2001, Rathore *et al.*, 2008). Thus, conducting a systematic review to investigate the evidence on needs and extent of psychological adjustment of family caregivers of SCI persons especially after clinical rehabilitation may assist health care professionals provide adequate support for caregivers and as well help them address tasks and routines which are essential for optimum family functioning.

Gaps in current knowledge: Researches related to SCI have mainly focused on provision of care issues, interventions and outcome within acute care (Krause & Anson, 1997) and sometimes rehabilitation settings. Studies also have concentrated on the SCI person's needs and psychological adjustment to the injury (Gill, 1999, Krause *et al.*, 2004, Van Loo *et al.*, 2009). Very few studies have been done on responses and psychological adjustment of family members to SCI of a relative (Webster & Hindson, 2004) or the needs of caregivers after SCI (Elliott & Shewchuk, 1998, Rintala *et al.*, 1996). SCI may place great strain and dysfunction on roles and relationships within the family. Most contemporary literature does not capture specific knowledge that would frame and illuminate the complex aspects of the needs and psychological adjustment of family caregivers after rehabilitation. Even though there are few literature examining family needs and psychosocial outcomes in caregivers of individuals with SCI, most of the studies have focused on North American and Western-European caregivers. There is a lack of research in these areas in regards to SCI caregivers from other cultures; given inter-cultural differences in values and approaches to caregiving, it is reasonable to think that needs and outcomes may be different in caregivers from other regions (Guarnaccia, 1998). For instance, rehabilitation centres are limited in developing countries, as is day care for adults, support groups, and respite care.

Objectives of the study

The main objectives of the review are as follows;

- To understand the role of systematic review in evidence-based practice.
- To evaluate needs as perceived by family caregivers and the extent to which needs are being met.
- To identify the extent of psychological adjustment of family caregivers of SCI individuals.

Research questions

- The specific questions to be considered in this review are:
- What are the specific needs of family caregivers of SCI people?
- What is the extent of their psychological adjustment to this caring role?

METHODOLOGY

This chapter discusses the generation of quality evidence for healthcare improvement through the conduct of a systematic review. It presents the systematic review (SR) of literature in several contexts. It also discusses the strengths and weaknesses of systematic reviews (SRs), the search strategies for this study, followed by the criteria for considering studies for this review. It concludes with the account of how study quality was assessed, the process of data extraction and data synthesis.

Rationale for this review: This current review focuses on generating evidence for the needs and extent of psychological adjustment of family caregivers of SCI persons living in the community. Generally, researches related to SCI have mainly focused on provision of care issues, interventions and outcome measures within the acute care and rehabilitation settings

(Krause *et al.*, 2004, Lucke *et al.*, 2004). Studies also have concentrated on the SCI persons' needs, quality of life (QoL) and psychological adjustment to the injury (Chen & Boore, 2008, Craig *et al.*, 1994, Dijkers, 2005, Hammell, 2006, Kennedy *et al.*, 2009, Kennedy *et al.*, 2006). In a related development, according to Webster and Hindson (2004), very few studies have been conducted on responses and psychological adjustment of family members to SCI of a relative. The needs of caregivers of SCI persons has not also been given due consideration in contemporary studies (Elliott & Berry, 2009, Rivera *et al.*, 2008, Robinson-Whelen & Rintala, 2003). SCI may place great strain and dysfunction on roles and relationship within the family. Most contemporary literature does not capture specific knowledge that would frame and illuminate the complex aspects of needs and adjustment of life for the family caregiver after the injury.

As a result of the impact of managed care and technological advancement in treatment and diagnoses, inpatient period for rehabilitation following SCI have been greatly reduced, or on the other hand, thereby minimizing the time for learning and adjustment by SCI persons and their family caregivers. Consequently, the SCI person and family caregivers often return home without adequate resources, accessibility to the environment, or sources of information for support (Lucke *et al.*, 2004). In a practice setting where there is no health insurance, especially in developing countries, there is huge economic loss to the victims and family (Solagberu, 2002). This makes SCI one of the greatest consumers of health fund in the Orthopaedic Hospitals (Cripps *et al.*, 2011, DeVivo *et al.*, 2011, French *et al.*, 2007, Kawu *et al.*, 2011, Kiekens *et al.*, 2011). Spinal units were established in the West as early as World War II. These units were dedicated to the treatment and rehabilitation of SCI patients in order to manage their needs in a comprehensive manner (Guttman, 1973). There are no such SCI centres established in Nigeria. The centres where SCI are being managed do not have all the members of a standard multidisciplinary rehabilitation team available (Cripps *et al.*, 2011, Olasode *et al.*, 2006). In resource limited regions where there are no structured pattern of follow-up care the family has a great deal of responsibility in maintaining medical regimen and ensuring adequate integration of the SCI person into the community following discharge from the hospital (Chan and Chan, 2005, Emejulu & Ekweogwu, 2009, Nwadinigwe *et al.*, 2004a, Nwankwo & Katchy, 2003, Riis & Verrier, 2007).

Protocol justification: Protocol is a pre-planned decision set aside to guide the process of a review (Cook 1995). It is the first stage of a review ensuring that bias and subjectivity are reduced if not eliminated Pearson *et al.*, (2007). Therefore, prior to this review, a protocol was developed (Appendix 1). The major issues raised in the protocol are further discussed.

Search strategy: The aim of SR is to collate as much evidence as possible and relate to the review questions (Holopainen *et al.*, 2008a, Ogilvie *et al.*, 2005, Stevens, 2001). The search strategy should be explicit, recognizable and reproducible in the individual database (Gough, 2012). The search stage of the SR is time consuming and sometimes challenging, requiring identification, location, expertise and skill in the subject are and the assistance of a knowledgeable librarian to carry out a thorough database search (Ogilvie *et al.*, 2005).

Searching electronic data bases: The search for this review was retrieved between February and July 2013. An initial search started in the Joanna Briggs Institute (JBI), the Campbell Collaboration and the NHS Centre for Research and Dissemination databases for systematic studies on the needs and psychological adjustment of family caregivers of SCI persons living in the community. There was no evidence that a SR review had been conducted on the reviewed topic. This was followed by search in the bibliographies of major electronic databases such as MEDLINE, CINAHL, PsycInfo, Web of knowledge and Web of science. The key words in synonyms were utilized to identify potential relevant studies (Appendix II). However, the inclusion of the word 'community' failed to yield results in the databases. This may be due to the assumption that family caregivers of SCI persons are expected to be community dwellers. Hence 'community' was excluded from the search terms in the long run.

Criteria for considering the inclusion and exclusion of studies for review: A PICO framework for both qualitative and quantitative studies was applied in searching for the review articles. All empirical studies are included. Additionally, the search terms and their synonyms were applied for this review to search for relevant studies (Appendix VII).

The criteria for considering inclusion of studies for review were:

- Empirical papers (qualitative and quantitative designs).
- Papers published in English language.
- Papers in which all the participants studied were family caregivers or caregivers of spinal cord injured (SCI) patients.
- Papers examining needs (physical, social, emotional, economic) and psychological adjustment/adaptation of SCI persons' caregivers.
- Papers conducted with participants who are community-dwellers.
- The criteria for exclusion from the study were:
- Non-empirical paper (e.g. 'grey' literature and secondary research)
- Papers not published in English language
- Papers in which caregivers are below eighteen years
- Paper examining needs and psychological adjustment during hospital rehabilitation.
- Papers that considered other conditions like traumatic brain injury or cancer.

Quality assessment: The usefulness of any systematic review is mainly dependent on the quality of studies included (Crowther & Cook, 2007, Stevens, 2001). Crowther & Cook (2007) opined that the quality of a SR evidence is dependent on the quality of primary studies included. Thus, (Egger *et al.*, 2008) suggest that studies should be critically examined for their methodological quality before inclusion into SRs. The process for the assessment of quality for this review was conducted using the Hawker *et al.* (2002) three-stage critical appraisal process which shall further be discussed. The three stages are;

Stage 1- Assessment of relevance.

Stage 2- Data extraction.

Stage 3- Scoring for methodological rigour.

Assessment forms were developed by Hawker et. al (2002) for each stage of the assessment, this was to enable the maintenance of an audit trail.

Stage 1- Assessment of relevance: This stage does not only assesses and records details, but also determines whether a paper should be 'accepted' or 'rejected' for the review. This decision for criteria according to Hawker *et al* (2002), was based on four basic sets of criteria; relevance to the research question, the context of the material, the source of the data and the type of study (Appendix III).

Stage 2- Data extraction: The data extraction for this review was conducted using the Assessment Form 2 (Appendix IV) developed by Hawker *et al*. Usually, at least two independent reviewers are required for data extraction in order to reduce reviewer subjectivity in the interpretation of findings and errors (Holly *et al.*, 2012, Khan *et al.*, 2001).

Stage 3- Scoring for methodological rigor: For the purpose of this review, the Hawker *et al* (2002) tool was used for assessment of methodological quality (Appendix V). Using this tool makes it possible to evaluate the methodological rigour of each study regardless of their design. This tool contains nine criteria on the methodology of the studies which guides the reviewer in making decision to exclude or include into study. However, clarifications were sought from my supervisor for independent opinion in the event of articles that posed challenges.

Data synthesis and summary of findings: The analysis and synthesis of qualitative studies is commonly called meta-synthesis (Evans & Pearson, 2007). Meta-analysis and synthesis are only properly applicable when summarized data are homogenous - when patients, treatments and end results are similar or at least comparable (Dixon-Woods *et al.*, 2005, Hawker *et al.*, 2002). Narrative discussion is the traditional approach of summarizing results from more than one study; describing located studies as well as highlighting those with similar or contradictory findings. A narrative summary of findings was carried out since meta-analysis was not possible for this review. This was because of the inclusion of studies from different paradigms and designs. Hawker *et al.*, (2002) identify the need to include evidence from a variety of perspectives and research methods into a SR. This has the intention of synthesizing large amount of disparate data as well as provide a database of reviewed articles, opinions and informed comment, thereby providing resource for other researchers in the area of review (Hawker *et al.*, 2002).

RESULTS

This chapter presents the findings of the review. It sets out the results of the search strategy, assessment of methodological quality of included studies, characteristics of participants, description of studies and summary of studies. Figures and tables are used where necessary to give a pictorial representation of the findings.

Literature Search Results: Two types of search were undertaken, manual and via data bases. Further search to identify 'grey' literature were not carried out due to time limitation and resource constraints, which serves as one of the

limitations of this study. This review includes only published studies. All selected studies were both quantitative and qualitative studies. During the first stage of the search, all potential titles were carefully examined to identify non-relevant or duplicated studies. Fifty-six (56) studies were identified from the Web of knowledge, Web of science, CINAHL Medline, PsycINFO, EMBASE and JBI databases. The abstracts of the studies were retrieved when article titles included references to the needs or adjustments or both of family caregivers of SCI persons.

The study abstracts were read and re-read to ensure their qualification for inclusion or exclusion in this study. As a result, twenty (20) duplicated studies from the databases were removed from the list of studies. A further nineteen (19) studies which did not meet the inclusion criteria were eliminated. Seventeen (17) studies from the databases met the inclusion criteria that was set up in the review protocol. At this point, the full articles were retrieved and further assessed for eligibility. 11 more studies were excluded and only 5 studies met the credibility criteria from the databases search.

The studies were excluded for various reasons

- Two studies included conditions such as stroke and traumatic brain injury.
- Three studies did not address the needs and psychological adjustments of family caregivers.
- Five studies addressed only needs and adjustments of the SCI person.
- One study was conducted while the SCI persons and family caregivers were still in the rehabilitation centre.

Endnote Web Library was used to hold all the references retrieved from data bases. A manual search from the reference list of the studies was done and 1 further study was obtained. Thus the total number of studies obtained at this phase were 6, 5 from the databases and one from manual search. The 6 studies still qualified for this review after an assessment of methodological quality was done (Appendix 11), these were used for the review. Figure 1 shows the number of studies remaining at each stage of the search process.

Assessment of methodological quality of included studies:

There were six studies included in this review (Table 2). Two of the studies used a cross-sectional design (Arango-Lasprilla *et al.*, 2010b, DeSanto-Madeya, 2009). The remaining four studies (Beaugard & Noreau, 2010, Dickson *et al.*, 2010b, Lucke *et al.*, 2013b, DeSanto-Madeya, 2006) are qualitative studies. Quality assessment was carried out using Assessment Form devised by Hawker (Hawker *et al.*, 2002).

This tool contains nine assessment parameters which are: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, findings/results, transferability/ generalizability and implications and usefulness.

The scores were categorized into 'good' with 40 scores, 'fair' with 30 scores, 'poor' with 20 scores or 'very poor' with only 10 scores. Generally, the quality of the included studies was high, with scores ranging between 330 and 340 out of 360. Details of the evaluation is as specified in Table 2.

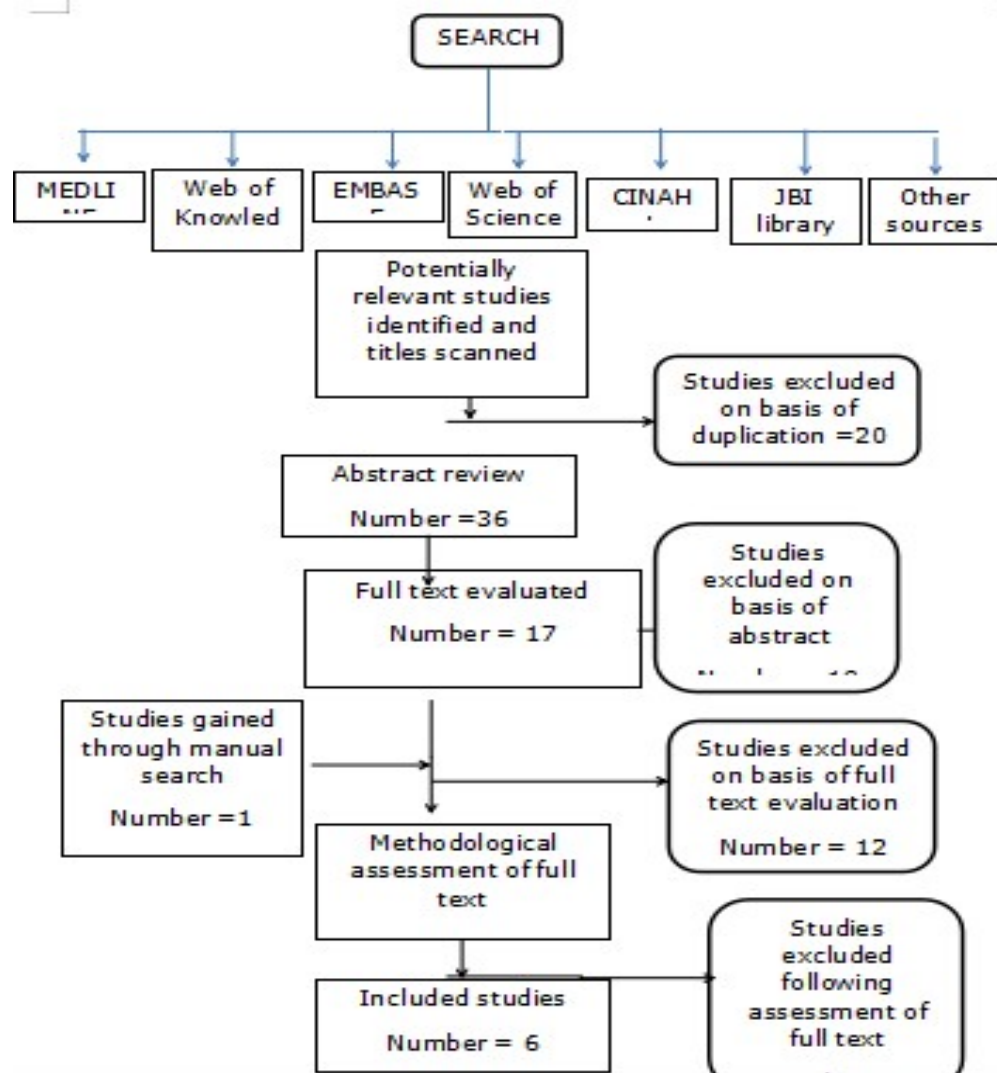


Figure 2. Flow chart depicting the search strategy

Description of Studies: Due to the words count and to avoid monotony, for the purpose of this narration, a numbering system put in brackets (), will be applied for each included study in this chapter to replace the name of authors. This numbering has been arranged in alphabetical order (Arango-Lasprilla *et al.*, 2010a, Beauregard and Noreau, 2010, DeSanto-Madeya, 2006, DeSanto-Madeya, 2009, Dickson *et al.*, 2010a, Lucke *et al.*, 2013a), and is referred to in the list of papers in Table 2 (see page 42). Six papers were identified as meeting the criteria for inclusion in the systematic review (1,2,3,4,5, and 6). All six papers reporting the studies are in English. Even though there was no geographical restrictions, none of the studies were from Middle Eastern or African countries. All of these papers examined the needs and psychological adjustments of family caregivers of SCI persons living in the community. All the studies included adult caregivers of SCI persons who were living in the community as participants. The majority of the studies were undertaken in the USA (3,4,6), one from Canada (2), one from Columbia (South America)(1), while the remaining one was undertaken in Scotland (5). The studies were conducted in the participants' home except for one participant who was interviewed in a hospital private room for convenience (5). Studies from both Canada (2) and Scotland (5) explored the experiences, impact and coping of spousal caregivers, while the rest of the studies (1,3,4 & 6) included other family members like sisters,

brothers, daughters, sons and parents who were performing caregiving roles. It was however noted that only studies 1 and 6 gave a clear description of the concept of family caregiving.

Two studies (3 and 5) were undertaken using Interpretive Phenomenological Analysis (IPA) with in-depth interviews. Two studies (1 and 4) used cross-sectional descriptive studies, using contentanalysis for data presentation. Study 6 employed the use of grounded theory with in-depth interview while study 2 employed semi-structured telephone interview. It is however worth mentioning that the cross-sectional descriptive study in study 4 used a tool, the Adaptive to Spinal cord Injury Interview Schedule (ASCIIS) which was developed from a secondary analysis of qualitative data from study (3) by the same author. Study (3) used a time frame of 5 to 10 years for living with SCI to assess psychological adjustment in SCI persons and their family and was conducted during a period of six months. All included studies had ethical approval from appropriate bodies. Summary of the included studies are as reflected in Table 3, pages 38 to 42.

Characteristics of participants: Most participants were recruited through the various Spinal Cord Injuries (SCI) centres within the study regions. A total of one hundred and two (102) people participated in the studies, these were described as either primary caregivers or spouses performing caregiving

Table 2. Quality score of included studies

S/N	Author	Abstract and title	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Findings/ results	Transferability/ generalizability	Implications/ Usefulness	Score	Comment
1	LarangoLasprilla et al. (2010)	G (40)	G (40)	F (30)	G (40)	G (40)	G (40)	F (30)	G (40)	F (30)	330	Good quality
2	Beauregard&Noreau (2010)	G (40)	G (40)	G (40)	F (30)	G (40)	F(30)	G (40)	F (30)	G (40)	330	Good quality
3	DeSanto-Menaya (2006)	G (40)	G (40)	F(30)	G (40)	G (40)	G (40)	F (30)	G (40)	G (40)	340	Good quality
4	DeSanto-Menaya (2009)	G (40)	G (40)	G (40)	F (30)	F (30)	G (40)	G (40)	F (30)	G(40)	340	Good quality
5	Dickson, A. et al (2010)	G (40)	G (40)	F (30)	G (40)	G (40)	G (40)	G (40)	F (30)	G (40)	340	Good quality
6	Lucke et al. (2013)	G (40)	G (40)	F (30)	F (30)	G (40)	G (40)	G(40)	F (30)	G (40)	330	Good quality

*Key: G=good (40), F= fair (30), P= poor (20) and VP= very poor (10).

Table 3. Summary of studies

S/N	Author	Year	Country	Aims of the study	Study Participants	Settings	Method	Main findings and conclusion
1	Arango-Lasprilla et al.	2010	Colombia	To identify the most frequent need of family carers of SCI persons, to describe caregivers' needs and as well examine the relationship between caregivers' needs and psychosocial functioning.	37 caregivers of SCI individuals in Neiva.	Participants' homes.	A cross-sectional study. Caregivers' needs questionnaires were administered to participants. PHQ- The Patient Health Questionnaire, Satisfaction with Life and the Interpersonal Support Evaluation tools were administered.	Some level of depression, burden or being dissatisfied with life was recorded in half of the participants. Psychosocial functioning was however related to various family needs.
2	Beauregard &Noreau	2010	Canada	To gain better understanding of the impact of SCI on spouses	24 spouse caregivers, Female- n=18, Male- n=6 Age- 25 – 77, Mean 48.1	Participants' homes via telephone	Semi-structure telephone interview	Spouses of SCI persons employ several strategies to overcome the challenges they face in caring for their loved ones. These techniques can be used by clinicians to assist them in achieving a healthy balance in life.
3	DeSanto-Menaya	2006	U. S. A.	The study was to gain understanding of the meaning of living with SCI from SCI persons and their family members' perspective in the years following the acute injury.	20 dyads of SCI person and a family member who had lived with the injury for 5 to 10 years. Ages 24 to 55 years	The first interview was conducted in the SCI persons' homes while the second interview took place 4-6 week later via interview.	Interpretive phenomenology using audio-taped recorded, semi-structured, in-depth interviews.	The study revealed that living with SCI is continuous learning experience. The findings were suggested to be useful in the development of self-care strategies and on-going interventions that focus on psychological and physical adjustments for the SCI individuals and their family members throughout the course of the disability.
4	DeSanto-Menaya	2009	U.S.A	To examine the physical, emotional, functional, social components of adaptation to SCI at one year and eight years post injury.	15 SCI person and their families. One dyad equals to one SCI person and a family member. 1 year n= 7 dyads, 3 years n=8dyads	Participants' homes through interviews in keeping with participants' request.	A cross-sectional descriptive design was used. Participants were interviewed for 45 to 90 minutes and audiotaped.	Adaptation to SCI during initial 3 years can be enhanced by providing social and educational support for SCI persons and their family members. Additional support from nurses and other health care professional were identified as being influential in the adaptation process.
5	Dickson, A. et al	2010	Scotland	The study is aimed at exploring the lived experience of primary caregivers' role on spouses of individuals with SCI.	11 spouses who are also caregivers of SCI individuals. Age 34- 36 years, who have performed the role for between 2- 12 years.	n=10 occurred in participants' homes. n=1 occurred in a private room at the hospital for convenience.	An interpretive phenomenological analysis, in-depth interviews were conducted between October 2007, to February, 2008.	Participants expressed sense of loss, emptiness and grief. It was also clear that SCI persons' caregivers do not receive necessary preparations for their care giving roles. There is need for caregivers to be more meaningfully integrated to the rehabilitation process.
6	Lucke et al.	2013	U. S.A.	The study is to describe the experiences and identify the decisional, informational, interpersonal and resource support needs of family caregivers of SCI Latino/Hispanic individuals.	10 Latino/Hispanic family caregivers of SCI persons. Ages 30- 60. Mean age= 48.	Participants' homes.	A qualitative grounded theory approach was used. In-depth interviews were conducted and recorded both in English and Spanish.	Family caregivers displayed and expressed profound sadness when describing their experiences of caring for their SCI members. They felt alone and abandoned while expressing barriers to services and resources because of language issues and economic status.

Table: Characteristics of Participants

S/N	Author	Year	Sample size	Gender	Age (years)	Ethnicity	Employment status of caregivers	Level of SCI of relative
1	Arango-Lasprilla <i>et al.</i>	2010	37 primary caregivers	Female- 32 Male- 5	Mean- 44.9	Columbia	Employed- 17 Unemployed- 20	Paraplegic n=19 Quadriplegic n=18
	Beauregard & Noreau	2010	24 spouses	Female- 18 Male- 6	25- 77 Mean age- 48.1	Canada	Not stated	Paraplegia n=13 Quadriplegia n=11
3	DeSanto-Menaya	2006	20 dyads	Female- n=18 Male- n=2	24-55 Mean n=31.1	White-n=17 Black- n=2 Hispanic n=1	Employed-n=18 Unemployed- n=2	Paraplegic- n=15 Quadriplegic- n=5
4	DeSanto-Menaya	2009	15 dyads	Female n=11 Male n=4	Mean= 41.4	White= 11 Black African American= 2 Latino= 2	Not stated	Paraplegic n=7 Quadriplegic n=8
5	Dickson, A. <i>et al</i>	2010	11 spouses	Female- n=10 Male n=1	34- 66 Mean age= 51.4	Scotland	Employed- n=8 Unemployed- n=3	Not stated
6	Lucke <i>et al.</i>	2013	10 family caregivers	Female- n=8 Male- n=1	30- 60 Mean age=48	English/Spanish- n=2 Spanish- n=7	Employed- n=1 Unemployed- n=9	Paraplegic- n=8 Quadriplegic- n=1

Table 5. Characteristics of included studies

S/N	Author	Year	Studydesign	Studysize	Setting	Country
1	Arango-Lasprilla <i>et al.</i>	2010	A cross-sectional study. Caregivers' needs questionnaires were administered to participants.	37	Participants' homes.	Colombia
2	Beauregard & Noreau	2010	Semi-structure telephone interview	24	Participants' homes via telephone	Canada
3	DeSanto-Menaya	2006	Interpretive phenomenology using audio-taped recorded, semi-structured, in-depth interviews	20	The first interview was conducted in the SCI persons' homes while the second interview took place 4-6 week later via interview.	U. S. A.
4	DeSanto-Menaya	2009	A cross-sectional descriptive design was used. Participants were interviewed for 45 to 90 minutes and audiotaped.	15	Participants' homes through interviews in keeping with participants' request.	U.S.A
5	Dickson, A. <i>et al</i>	2010	An interpretive phenomenological analysis, in-depth interviews were conducted between October 2007, to February, 2008.	11	N=10 occurred in participants' homes. N=1 occurred in a private room at the hospital for convenience	Scotland
6	Lucke <i>et al.</i>	2013	A qualitative grounded theory approach was used. In-depth interviews were conducted and recorded both in English and Spanish	10	Participants' homes.	U. S. A.

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1	Arango-Lasprilla <i>et al.</i>	2010	A cross-sectional study. Caregivers' needs questionnaires were administered to participants.	37	Participants' homes.	Colombia
2	Beauregard&Noreau	2010	Semi-structure telephone interview	24	Participants' homes via telephone	Canada
3	DeSanto-Menaya	2006	Interpretive phenomenology using audio-taped recorded, semi-structured, in-depth interviews	20	The first interview was conducted in the SCI persons' homes while the second interview took place 4-6 week later via interview.	U. S. A.
4	DeSanto-Menaya	2009	A cross-sectional descriptive design was used. Participants were interviewed for 45 to 90 minutes and audiotaped.	15	Participants' homes through interviews in keeping with participants' request.	U.S.A
5	Dickson, A. <i>et al</i>	2010	An interpretive phenomenological analysis, in-depth interviews were conducted between October 2007, to February, 2008.	11	N=10 occurred in participants' homes. N=1 occurred in a private room at the hospital for convenience	Scotland
6	Lucke <i>et al.</i>	2013	A qualitative grounded theory approach was used. In-depth interviews were conducted and recorded both in English and Spanish	10	Participants' homes.	U. S. A.

Table 6. Tabulation of key findings

Intimacy Loss of sexual relationship (2, 5, 6) Lack of reciprocity (2,4) Loss of intimacy (2,4) Spending more time with family (3,4,6) Source of motivation (2) Deprivation from social activities (2)	Change in family dynamics Role shift (3,5, 6) Loss of identity (2,6) Constant alertness (5) Difficulty balancing roles (3) Added responsibility (2,3,4,5,6)
Burden feeling Bored and frustrated Getting no sleep (4) Depression (3) Emotional and physical exhaustion Burnout (1,2, 4) Emptiness (5) Trapped by caregiver's duty (6) Helplessness, hopelessness (5) Sacrifice (1, 5) Grief (5)	Family needs Need changing jobs (3,4,6) Need love (1, 2) Social support (3) Support from others (4,6) Access to transportation (4) Need to discuss feelings (1,2 ,3 6) Ability to care for oneself (1, 6) More time to sleep (1) Information needs (1,6) Training needs (6,3)
Uncertainty Setting a balance (3) Worry about the future (3,5) Facing the future (3,6) Ability to provide care in the future (3,6)	Moving forward Accepting change (4) Success achievement (5) Life goes on (3) Faith in God (1,6) Focus on the future (1,3,6) Helping others (6) Relentlessness (5)

Table 7: Most frequent family needs

Family needs	Mean (SD)
"I need help from community organizations"	Mean = 4.29
"I need specialized information about organizations, associations, and/or support groups that help or support individuals with SCI and their families"	Mean = 4.18
"I need to receive complete information on the patient's physical, cognitive, and emotional problems, including their evolution, prognosis, and treatment"	Mean= 3.94
"I need to receive complete information on the patient's physical, cognitive, and emotional problems, including their evolution, prognosis, and treatment"	Mean= 3.94
"I need money to meet my present needs"	Mean = 3.72

Table 8

Number	Author	Family needs	Change in family dynamics	Uncertainty	Feeling of burden	Intimacy	Moving forward
1	Arango-Lasprilla et al. (2010)	√	×	×	√	×	√
2	Beauregard&Noreau (2010)	√	√	×	√	√	×
3	DeSanto-Menaya (2006)	√	√	√	√	√	√
4	DeSanto-Menaya (2009)	√	√	×	√	√	√
5	Dickson, A. et al (2010)	×	√	√	√	√	√
6	Lucke et al. (2013)	√	√	√	√	√	√

Key:√= Present,×=Absent

roles. A total of fifteen (15) were males while eighty-seven (87) were females. All participants were adults with age range of twenty-four to seventy-seven (24- 77) years. Details of the participants' ethnic group were only given in two studies (1 and 6) who are natives of Naïve in Columbia and Latino/Hispanic in North America respectively. Majority of participants were unemployed, although studies 2 and 4 did not state their employment status. A total of forty-four (44) caregivers were into full employment while thirty-four (34) caregivers were unemployed. Two studies (3and 4) were undertaken in pairs of a SCI person and a family caregiver which was described as a dyad. Studies 2 and 5 are mainly spousal caregivers of SCI persons. The review indicate that a total of fifty-two (52) SCI persons are paraplegic while 43 are quadriplegic. Study 5 did not state the level of injury of the SCI persons. Table 4 highlights the characteristics of participants while table 6 presents the key findings.

Results from study (1): Study (1) was undertaken using the Caregiver Needs Questionnaire (CNQ), the Zarit Burden Interview (ZBI), the Patient Health Questionnaire (PHQ9), the Satisfaction With Life Scale (SWLS) and the Interpersonal Support Evaluation List (ISEL). The results are of family needs are as indicated in Table 7 below:

Caregiver psychosocial functioning: According to (1), 32% of caregivers reported little to no burden, 51.4% mild to moderate burden, 13.5% moderate to severe burden while 2.7% reported severe burden. A large percentage (56.8%) of caregivers did not report any symptoms of depression, 18.9% reported mild symptoms of depression, 18.9% had moderate symptoms of depression, and 5.4% experienced moderate to severe symptoms of depression.

Relationship between family needs and psychosocial functioning: More economic, information, sleep, psychological, emotional, and physical needs were positively correlated with depression (rs ranged from 0.35 to 0.56, $p < 0.01$) and burden (rs ranged from 0.42 to 0.56, $p < 0.01$), while greater economic, household, physical, sleep and psychological needs were negatively correlated with satisfaction with life (rs ranged from -0.35 to -0.41 , $p < 0.01$) and social support (rs ranged from -0.39 to -0.59 , $p < 0.01$).

Themes from the data

Family needs: Most of the studies (1,2,3 &5) identified the need for caregivers to be given information. According to (3), many family members pointed out that SCI person cannot be stereotyped as each has his /her own unique needs. They spoke of how health care professionals belief that one situation applies to all. "I need to receive complete information on the patient's physical, cognitive, and emotional problems, including their evolution, prognosis, and treatment" (1, pg. 88) Family caregivers spoke of their frustration with the healthcare system as they lacked information on what it is expected of them in their caregiving role. In Columbia the following remark was typical: "I need to discuss my feelings about the patient with someone who has gone through the same experience" (1, pg. 88)). This is as a result of the value they place on community support. They expressed the need to be able to take care of their health. Information, emotional, community support, economic and respite needs were most frequently reported by family caregivers (1,3,5). Greater emotional, economic, physical, sleep and psychological needs

were positively correlated with depression. "I need to be able to take care of my health, which has gotten worse since beginning to provide care for the person with SCI" (1, pg. 88) Several family caregivers had to quit their jobs in order to fulfil their caregiving obligation, this not only reduced the family income but also took away a source of interpersonal support for the caregiver (6).

Change in family dynamics: The period of adjustment commences on return from hospital, when the family has to develop a routine around the needs of the SCI person.

They have to develop a routine of all the activities required in caregiving, as well as that of the entire family members. From the caregivers' perspective, there is a report of a shift in role, whereby caregivers, especially spouses take over the role of the injured person. Participants reported a complete role reversal in a relationship where formerly the spouse was considered to be 'superior' or 'dependable before the injury, and the wives now becoming the 'provider'. "I have to work because J. (husband) is unable to work." "It's hard on both of us, M.(husband) was always the one to provide for our family" (2, pg. 1951) Some difficulties in adjusting to the new caregiver role is evident in most of the studies. Role change takes place within the family, where the SCI person and their family have to leave paid employment. Thus, family caregivers fear disturbance in caregiving due to limited financial resources. There were reports of caregivers having to abandon some leisure activities as a result of limitations imposed by the disability. However, many people have devised strategies to counter this situation and discussed the possibilities of enjoying leisure activities as a couple by choosing assessable sites and making cautious plans.

Uncertainty: A number of participants expressed feelings of anxieties and uncertainties according to (2,5). Some participants appear doubtful of their new caregiving roles without a definite idea of when it will end or the impact it will have, they seemed unsettled and to a great extent mourning for the familiarity of their old lives (4). For many, the anxiety was related to a lack of preparation for their new role as family caregivers and for others, it was related to how their lives would change or the extent to which they might adjust to such changes. "Well, I want my husband back thank you, the way he were, but you can't have that, you know, that's not going to happen, so yes, that's the bereavement part of it, that you know that life is never coming back to you, you won't get it the way you had before" Wife of paraplegic (5, pg. 1107).

The totality and unfairness of the situation to some, gives the notion that as a result of their new caregiver role, nothing in their lives, neither their sense of self nor their relationship could ever remain the same again. The family caregivers and the SCI persons spoke of their concerns about the future of living with SCI. SCI can be frightening and overwhelming for the injured person and their family. While family members expressed their fears about their ability to care for the SCI persons, the SCI persons voiced their concerns and fears about having to be dependent and requiring care in the future.

Feeling of burden: The majority of the house work was carried out by the spouse of the SCI person; these extra tasks lead to feelings of burden (1,2,3,4,5,6). Difficulties were greatest when it came to caring for children, especially when children were young because tasks like giving baths and changing nappies were obviously more demanding for the partner of the person with a SCI (2,5). Lack of preparation

towards the caregiving role was identified as hindering the process of adjustment (5). To avoid the burden and exhaustion associated with housekeeping and personal care, one of the most frequent strategies was the idea of hiring a personal attendant or a house help to handle these responsibilities. "After a few years [of care-giving], I decided to ask for help because it was seven days a week without a let up. I found it to be a lot of work. I have received assistance for the last couple of years: someone comes in four mornings a week (Woman, tetraplegic partner). (2, pg. 1951)" In consideration of such situation, some people decided to move into another residence that is less demanding in terms of upkeep, such as a flat. In spite of the disabilities, sharing responsibilities between spouses was considered possible when the capabilities of the SCI person is taken into consideration. For example, one partner with SCI could assume responsibilities for children upbringing by assisting with homework. Paper (5) reported that many participants expressed feeling the brunt of SCI of their spouse. A sense of grief was evident in some participants. There was the expression of fears of entrapment and restrictions the caregiver role enforces on their lives. Participants expressed the feeling that caring for their spouses will mean sacrificing their independence and their sense of freedom. As for many, assuming the caregiver role was associated with a complete loss of control over their own lives. Difficulties in adjusting to the new caregivers role were evident in some people; they emphasize the relentless nature of their caregiving role and the idea that they are always alert and constantly set for every eventuality. Once their loved one was discharged, the realization that this was not a temporary situation began to develop, and quite often became overwhelming for the family caregiver.

Intimacy: While some participants reported a loss of intimacy in their relationship with the SCI person, many reported a high level of intimacy; that the bond between them actually became much stronger. In (3), mothers often acknowledged the fact that most of their attention is focused on their injured child because they considered them needing the attention. On the other hand, the injured person sometimes felt overprotected which sometimes initiated guilt feelings of receiving 'undeserved' attention. "It actually made us closer in a sense that wouldn't have happened under different circumstances (.) so in a sense it did make us closer because we're caring for each other (wife of a paraplegic) (5, pg. 1111) In overcoming the challenges of SCI, the most frequently reported challenge among couples was that of sexual intimacy. The difficulties of coming to terms with an incontinent partner; having to clean, change and dress them, hinders intimate sexual relationship. The lack of reciprocity in care provision was reported as giving caregivers feeling of being unloved and abandoned. They demonstrate their love on daily basis by accepting their caregiving roles and responsibilities and yet, receive little or no display of emotion in return. That's where it makes me feel more like his mother because there's no loving relationship anymore" (wife of a quadriplegic) (5, pg. 1109) A bond exists between people related by marriage or blood. This bond can be affected when a family member suffers from SCI. the injury in some cases brings about intimacy and further bonding (4), while in other instances, stains the relationship, placing stress and added responsibility on the family caregivers in their everyday life.

Moving on: Realizing the implications of their roles, family caregivers garner the determination to move forward and face

the challenges ahead of them. Family caregivers report tremendous personal satisfaction being of help to those who have given to them. Other caregivers are grateful for a deeper, more meaningful relationship that develops over the course of caregiving. Participants felt they did not have to 'run away' or 'turn their backs' on their marital commitment. "I mean you love them, you marry them and it's for better or worse and it's all for these things, so I think you just get on with it I think" (wife of a SCI person) (5, pg. 1111) Family caregivers of SCI persons expressed the need to see life differently and come to terms with the situation. In the attempt to move forward, they discussed ways of not allowing the 'negative and little things' to interfere with their daily activities. This direct and positive approach to living with SCI help the SCI person and family caregivers to move forward in everyday life. Their determination was formed from a blend of love for their family member, fear of what lies ahead of them, sadness over what had been lost, a felt obligation to care for their loved one and faith that God will see them through. "Sometimes one is not content with what happens to us, but when God wants things to be a certain way, one has to resign oneself to that. So it is, yes, well, I need to give thanks to God."(6, pg. 224)

Discussion: Six relevant studies (Arango-Lasprilla *et al.*, 2010a, Beauregard and Noreau, 2010, DeSanto-Madeya, 2006, DeSanto-Madeya, 2009, Dickson *et al.*, 2010b, Lucke *et al.*, 2013b) were included in this review and six themes were identified as key findings from the review; the themes are then discussed in relation to other research findings.

Family needs
Change in family dynamics
Uncertainty
Feeling of burden
Intimacy
Moving on

Family needs: Various methods have been used to explore the needs and psychological adjustments of family caregivers of SCI persons living in the community. Despite the variation in methodologies, the results of this review are consistent with past studies. Information, emotional, respite, economic as well as community support were most frequently reported among family caregivers. Similar studies ((Meade *et al.*, 2004b, Van Loo *et al.*, 2009) also suggest that many family caregivers have unmet needs relating to health information, financial and emotional support and help with family responsibilities. Family caregivers wanted to understand their role as caregivers and how caring will affect family relationships. According to Van Loo *et al.* (2009) they also need complete and honest information to better understand complications that may arise from the injury. In several studies, caregivers of SCI persons desire to have adequate training in caregiving (Post *et al.*, 2005a, Lim & Zebrack, 2004, Charlifue and Gerhart, 2004, Dasch *et al.*, 2011, Kurylo *et al.*, 2001). Family caregivers also indicated the need to information on how to assess supplies while at home. For example, after hospital rehabilitation, family caregivers of the Latino SCI persons (Lucke *et al.*, 2013a) realized they did not have equipment or supplies needed to provide safe and adequate care for their SCI family member in a way that will not jeopardize their own health. This is quite true of studies in developing countries where consumables are limited or not available for care at home (Burns & O'Connell, 2012, Solagberu, 2002). Considering that the SCI person needs wheelchair, special adaptations are

required at home, which also affect the finances of the family significantly. In developing countries, there is reduced access to public transportation and buildings, lack of sidewalks and ramps for wheelchairs, movement becomes a problem that affects both the SCI person and the family caregiver. This was corroborated in a study conducted by Nwadinigwe *et al.* (2004a), where 97% of discharged wheelchair-dependent SCI cases were lost to follow-up due to reduced transportation.

A significant proportion of participants studied by Widerström-Noga *et al.* (1999) also reported that mobility impairment was very hard to deal with following hospitalization.

Change in family dynamics: According to some studies, (Ebrahimzadeh *et al.*, 2013, Lapham-Randlov, 1994b, McGowan & Roth, 1987, Pryor, 1999, Rintala *et al.*, 1996, Van Loo *et al.*, 2009, Weitzenkamp *et al.*, 1997b), SCI causes dramatic change in families and has great impact on the family dynamics; this is also consistent with this review. From this evidence, family appraisal, family capacity or resilience, and the process of family adjustment seem not to have been considered major health care issues (Arango-Lasprilla *et al.*, 2010a, DeSanto-Madeya, 2009, Dickson *et al.*, 2010b, Lucke *et al.*, 2013a). Consistent with other studies (Webster & Hindson, 2004, Post *et al.*, 2005b, Gibson, 2003) most of the family caregivers were dealing with complete disruption of their daily activities as a result of their family member's injury and consequent requirements. In SCI, family life is changed, often in major ways. The disability can consume a disproportionate part of a family's resources of time, energy, and money, so that other individual and family needs go unmet. The family's lifestyle and leisure activities are altered; dreams and plans for the future may be given up. According to Chandler *et al.* (2007) care-giving roles may lead to changed or abandoned career plans. Devivo and Fine (1985) argue that female family members are more likely to take on caregiving roles and thus give up or modify their work roles, this is quite the case in this review as there are more female than male family caregivers. Several studies suggest that when the added financial burden of disability is considered, it is better for families to divide role responsibilities (Bucklelew *et al.*, 1990, Kennedy *et al.*, 2012, Song and Nam, 2010, McGowan and Roth, 1987, Blanes *et al.*, 2007a). For example, male partners with SCI can make a major contribution to their children's upbringing or help with homework, thereby reducing caregiver stress (Chan *et al.*, 2000). Difficulties adjusting to the family caregiver role may be lessened by improved access to, and greater establishment of community resources and services.

Intimacy: This review identified that the shift in relationship dynamics causes a great deal of conflict in the family; the family caregiver (spouse) sometimes assume the dual role of lover and caregiver. There were reports of loss of intimacy between the SCI person and the spousal caregiver. For example, spousal caregivers found that providing personal care like bowel and bladder management eradicated feelings of romance. Despite this role conflict, DeVivo *et al.* (1995) argues that SCI persons still enjoy some intimacy with family caregivers. They claim that the disabilities of the partner with SCI do not always affect feelings of love or the quality of the relationship. A strong, caring and loving relationship has been considered requisite to overcoming the challenges of adapting to the new situation (Pearcey *et al.*, 2007). Nevertheless, Elliott and Shewchuk (1998) argue that relationships that provide a sense of attachment and intimacy are positively associated with more satisfying leisure activities among SCI persons and their

family caregivers. The extended family system and the collectivist spirit typical of many African-American families has been identified as a major factor in their capability to cope better with a disabling injury than their European-American counterparts (Pickett *et al.*, 1993, Stueve *et al.*, 1997). This factor may be positively reinforced when dealing with family caregivers of African origin.

Feeling of burden: This review affirms the finding of studies that have noted an increased level of burden feeling among family caregivers of SCI persons (Alpert and Wisnia, 2008, Boschen *et al.*, 2005a, Elliott and Shewchuk, 2003, Murray *et al.*, 1991). Arango-Lasprilla *et al.* (2010a)'s identification of mild to severe burden in caregivers in Columbia also coincides with that of (Post *et al.*, 2005b) in which more than half of caregivers sample in Netherlands reported moderate to severe burden. Apart from the physical limitations imposed by SCI, the family caregiver also experience multiple psychological, emotional, economic and environmental stressors (Decker *et al.*, 1989, Lapham-Randlov, 1994b, McGowan and Roth, 1987). This, according to this review requires a lot of adjustment. Family caregivers often have to make tremendous adjustment to accommodate the daily activities of caregiving into their routine. Data from this study reveals dissatisfaction with life among family caregivers, especially at the initial period of the assumption of the care giving role. Regarding the emotional impact of SCI, family caregivers reported 'an almost instantaneous sense of loss' (DeSanto-Madeya, 2006), grief and emptiness right from the onset of the injured person rehabilitation period and further feelings of anxiety in anticipation of the challenges of care giving role. Feelings of isolation were also expressed among caregivers of SCI persons; many felt socially isolated from friends as a result of the care giving experience. They perceived that friends visited less frequently and were left alone to handle the emotional fallout from their relations reactions to their SCI. In some studies, family caregivers also experienced sadness and denied depression (Gibson, 2003, Dasch *et al.*, 2011, Pinquart and Sörensen, 2007, Decker *et al.*, 1989, Elliott *et al.*, 2001b, Rintala *et al.*, 1996, Blanes *et al.*, 2007a, Lapham-Randlov, 1994a, Schulz *et al.*, 1990, Gajraj-Singh, 2011, Ebrahimzadeh *et al.*, 2013, Unalan *et al.*, 2001, Yim *et al.*, 1998, Elliott and Shewchuk, 2003, Alfano *et al.*, 1994, Weitzenkamp *et al.*, 1997a, Chan, 2000b). Factors that contributed to depressive feelings include feelings of role captivity, health status, physical symptoms and loss of self-identity. However, this study confirms better psychological adjustment in caregivers with higher level of met needs, such as availability of communal and social support. There is therefore need for health care professionals to explore various ways of preparing family caregivers to handle the complex emotional aspect of care giving in SCI. For example Barone and Waters (2012) opine that open communication is one of the strategies employed by couples to help in coping with difficulties. This was identified as fostering intimacy in the relationship. Nurses can foster channel of communication between spouses early in the rehabilitation process.

Uncertainty: From the review, families affirm that they are usually not well prepared for the role of care giving. When patients are discharged following SCI rehabilitation, families are usually confronted with lots of concerns while facing the challenges of care giving. According to (Elliott and Berry, 2009), they not only need information but education and counseling. (Elliott and Shewchuk, 2003) identify that care

giving adjustment is multifaceted; whereby one problem could lead to another. For example, it has been opined that caregiver anxiety is significantly predictive of the development of other physical symptoms during the first year of care giving for the SCI person (Shewchuk *et al.*, 1998). The development of depressive behaviour and anxiety has also been discovered to be significantly related to the support available to the caregiver. Supporting the findings of this review, (Boschen *et al.*, 2005a, Lapham-Randlov, 1994b, Robinson-Whelen and Rintala, 2003, Schulz *et al.*, 2009, Starkweather, 2011, Weitzenkamp *et al.*, 1997b) theorized that family members who assume care giving roles commence an 'unexpected career' which is illustrated by the tasks they perform and their relationship with the injured person. It could be argued that family caregivers enter this role without adequate preparation or specialized training. There is a need for the development of screening tools to identify family caregivers at risk of adjustment difficulties, so as to provide adequate psychological interventions.

Moving on: This theme indicates the resolve of family caregivers to examine their capabilities and the need to adjust to a new way of living. Similar studies (Lui *et al.*, 2005, McAllister *et al.*, 2012) found a similar theme (moving forward) in their study of caregivers of injured persons and people living with stroke respectively. Moving on implies the capacity of a family to manage challenging life situations successfully at any point in time. Starkweather (2011) suggests that it involves family caregivers defining pathways through harsh conditions, fitting their situations, their cultural orientation, their personal strengths and resources to achieve stability for the family structure. In this review, after careful exploration of available options, family caregivers decided the best option was to keep going, to prepare themselves to forge ahead and assist their injured family member in attaining optimal level of functioning. SCI according to Steinglass *et al.* (1982) is a family crisis and often a turning point for the family. Thus family must be supported to build resilience through the provision of social support. Moreover, local support groups may promote adjustment required for adequate community integration of the SCI person and the family caregiver.

Clinical implications: The challenges associated with care giving in SCI require a multidisciplinary approach. Adaptation and adjustment of the SCI person and family caregiver to the injury could be enhanced by the provision of on-going support and education about prevention of complications. Support from nurses and other health care professionals has been noted as playing a significant part in the adjustment of the SCI person and family caregiver (Boschen *et al.*, 2003, Hammell, 2006, Chan, 2000a, Chen and Boore, 2008). Health education in the clinical setting is considered to be a fundamental of nursing care which has a tremendous role in assisting patients and significant others in regaining independence (Dally *et al.*, 2002). In SCI, it is crucial that families have an understanding of their relations' condition and are taught the management of associated health problems. Health education is vital for long-term conditions where patients and family caregivers are empowered to manage their lives after hospital rehabilitation. Education programmes according to (Elliott *et al.*, 2008, Kurylo *et al.*, 2001, Lucke *et al.*, 2013a), should incorporate variety of techniques to promote active learning, and to consider how it can be integrated into routine care over a long term. Such sessions according to Elliott and Berry (2009), if conducted in the local hospital or community will create better

understanding and proper societal integration. For example, long term follow up of SCI persons is a big problem in many of the developing countries including Nigeria, this is as a result of poorly developed transport and communication set-up as well as inadequate access to centres necessary for follow up. Conversely, considerations in providing educational programmes for family caregivers of SCI persons cannot be generated from a particular region due to cultural, socio-economic and geographical considerations (Loevinsohn, 1990). This was astutely affirmed in this review where care giving roles were considered as obligations in particular communities (Lucke *et al.*, 2013a). Schulz *et al.* (2009) theorized that education programme delivered to the family caregiver and the SCI person is more beneficial than that provided to only the caregiver. To a large extent, a huge modification of delivering education for family caregivers based on the result of this review may be required with adequate consideration to cultural, educational and socio-economic diversity, especially from resource-limited regions where there are no established SCI centres. Rehabilitation nurses can assume active role in research and development of effective interventions that address the physical, emotional, social, and economic issues confronted by the family caregiver in SCI. This serves to provide a solid foundation for enhancing long-term outcome for the SCI person and the family caregiver.

Limitations of the review: As mentioned earlier in the methodology, there are pros and cons around the results of a systematic review as the best resource in health care policy, hence few limitations concerning this review has been recognized. Firstly, as a novice reviewer, the approach on identification, critique and bringing together a wide range of literature may not have been as thorough as that of a more experienced reviewer; summarizing evidence from different study design proved a daunting task. The current study was the first experience of performing a systematic review. More also, the time constraint poses to be another limiting factor, which may create room for search bias. However, a thorough investigation over a longer period might have discovered more databases that could make this review more valid and credible. Another limitation is that articles from this study are limited to those published in English. As a result, this is likely to have contributed to the exclusion of some eligible studies. Additionally, it cannot be assumed that the findings of this review which was conducted mostly among family caregivers of people with SCI in the developed world have much relevance to caregivers in the developing world for whom interdependence, harmonious living and belonging, for example, may be exceedingly valued than independence, autonomy and personal achievement (Lin *et al.*, 2007, Rathore, 2012, Whiteneck *et al.*, 2004). Moreover, this review was conducted with studies where there are well established SCI centres; these are not available in most developing and resource-limited countries like Nigeria. Therefore, this review cannot be assumed to have passed the generalizability test. Also, this review managed to answer the review questions but then it was impossible to identify the extent of psychological adjustment of family caregivers of SCI persons separately since some of the studies combined other variables like impact, experience and psychosocial adjustment.

Recommendations for future research: Five out of the six papers in this review were conducted in the developed countries (UK, USA and Canada). Hence, the results might appear insufficient to outweigh the potential presence of

cultural bias. Moreover, none of the studies was conducted in resource limited regions or developing world. As a result, further studies may be required to elicit cultural and economic factors that affect needs and psychological adjustment of family caregivers of SCI persons. Family caregivers who have undergone inpatient rehabilitation following a SCI and those individuals who fulfil a caregiver/support provider role are critical resources and should be included in all aspects of training and education. Future studies need to continue on areas of support needs for family caregivers of SCI persons. Significant caregiving commitment is known to adversely affect caregiver health and thereby their capacity to provide ongoing care (Kurylo *et al.*, 2001). In resource-limited countries family caregivers are an important community-based resource who provide care for SCI persons. In developing countries like Nigeria, without healthy caregivers SCI persons would not receive care because there is no structured follow-up programmes. There is an urgent need for further investment in community-based research to develop effective interventions aimed to promote caregiver health and help them sustain their role. There is also need for further studies to understand the factors that contribute to the best economic and culturally appropriate caregiving model to improve care outcomes and quality of life of SCI persons and their family caregivers in developing countries.

CONCLUSION

The main aim of doing this research leading to a dissertation was to generate evidence on the needs and extent of psychological adjustment of adult family caregivers of SCI persons living in the community. This stimulated a critical review of the concept of evidence-based practice (EBP) and a rigorous systematic review process. A rigorous search process was carried out and identification of studies that met the inclusion criteria on the needs and psychological adjustments of adult family care givers of SCI persons was conducted and summarized in this review. Although the search strategy of this review identified many potential studies, only six were included in this review. The findings of the review revealed six themes: 1) family needs, 2) change in family dynamics, 3) uncertainty, 4) feeling of burden, 5) intimacy and 6) moving on – all of which have been discussed in the previous chapter. The review indicates the need to support family caregivers through education and training, improved access to, and greater establishment of community resources and services. The Hawker *et al.*, (2002) framework was utilized in the study, this enabled me synthesize studies that used different approaches, unlike the Cochrane and Joanna Briggs Institute (JBI) frameworks that can only summarize evidences from the same methodology.

The concept of EBP has increasingly been adopted in response to the demand for quality health care delivery. This concept demands that quality research be applied, in addition to clinicians' expertise and patients' preferences, in making valid and reliable clinical decisions (Brown, 2012a). As there is a growing awareness on the role of the family caregiver in SCI, nurses and other health care professionals are expected to make use of the most current evidence in clinical decision-making on ways of supporting family caregivers so as to attain optimum level of care in SCI. Implications for Advancing Nursing Practice, Health Policy Management Manley (1997), describes four sub-roles for the advanced nurse practitioner: expert

practitioner, educator, researcher and consultant roles. In my opinion, advancing practice means that nurses can identify areas of care that require modification, through reflection, and take necessary actions, including research and collaboration with other colleagues. National Orthopaedic Hospital, Kano, Nigeria, where I work as a nurse (head of department) is one of the three specialists orthopaedic hospitals in Nigeria. It serves as a referral centre for trauma and orthopaedic cases (including SCI) to nineteen northern states. Since Nigeria is a resource-poor country and the establishment of a standard Spinal Injury Centre may not be feasible for the time being, it is therefore supposed that family caregivers should be supported and empowered in providing care for SCI persons after discharge from the hospital. With new government policies and public awareness, there are ever-more pressures on health institutions in Nigeria to meet targets and deadlines and deliver quality health care, contributing to a rapidly changing environment. The results are expected to lead to the implementation of strategies to reduce the impact caused by SCI in family caregiver's life and health and consequently improve the care outcome of SCI persons living in the community under my leadership. Such strategies may include individualized or group advice for family caregivers, caregivers training and education, and coaching and consultation for family caregivers. According to (Salanova *et al.*, 2011, Tappen, 2001, Thompson, 2012), nursing leaders have the responsibilities of maintaining quality of care in all situations and circumstances. This calls attention to the critical importance of advancing nursing practice in Nigeria at this point in time. Moreover, due to shortage of medical staff, nurses have huge responsibility of delivering adequate care to SCI clients throughout hospitalization. Above all when patients' re-admissions to the hospital are reduced after rehabilitation due to effective family caregiving, the organization shall be seen as delivering quality care. Achieving the mission of my hospital for provision of qualitative care, research and training of relevant health personnel, is of high consideration in this programme.

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