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Experiences of providing care to people with long term conditions

Full Report

Project Director:

Dr. Jennifer Harris
Social Policy Research Unit
University of York
York YO10 5DD.

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Project Team:
Stephen Piper
Hannah Morgan

Expert Panel:
Alex McClimens
Sonali Shah
Hannah Reynolds
Sally Baldwin
Hilary Arksey
Hazel Qureshi

THE UNIVERSITY *of York*

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Background to the Project

The Department of Health commissioned a brief scoping study be carried out in order amass evidence concerning people with long term conditions' use of health and social care services. This report covers a related study that examined literature containing evidence on informal carer's experiences of providing care to people within the target groups. The service users in the target group were of working age only (18-65) and the target conditions were epilepsy, Multiple Sclerosis (MS), Motor Neurone Disease (MND), Parkinson's disease, brain injury, spinal cord injury, polio and cerebral palsy.

Aims and Objectives

The study aimed to provide an overview of the types of evidence that exist on carer's experience of caring for a person with a long term condition and negotiating with health and social care services as part of this role. The brief was to illuminate the experience of providing care to people in the target groups. The primary purpose of the study was to gather evidence on carer's experiences to underpin other review work being undertaken for the Department of Health. The main objective of the study was to identify the key studies on carers' experience of the provision of care for each of the target long-term conditions.

Methods

The study relied on a 'hub and spoke' method of reviewing and compiling evidence. The part time research co-ordinator was responsible for identifying key studies in this field. These studies were routed to a panel of expert readers for assessment. The latter used a standard proforma to record their assessments. In the final stages of the project the proformas formed the basis of the draft report.

The study replicated the methods that were used in the brief scoping study of user's experiences (Harris et al 2003) which relied upon searching electronic databases, primarily using the internet and accessing key literature from patient organisations (for example MNDA, SCOPE). The following databases were searched:

SIGLE
SSCI - Social Science Citations Index
Sociological Abstracts
University library sources (mainly York and Leeds)
HMIC
Medline

CINAHL
EMBASE
PREMEDLINE
AMED

Please see Appendix 3 for the search strings utilised in searching these databases.

Exclusions

Population Groups	All patients/clients outside the target groups
Interventions	All intervention studies
Experience Areas	All areas not directly related to Health and Social Service carer/patient interface
Publication Date	All studies published before 1993
Language	All studies published in languages other than English
Study Focus	Medical, pharmacological or biological research. Disease prevention research. Medical/ pharmacological intervention studies
Study Type	Reference works, book reviews, commentaries and PhD theses

Inclusions

Setting	All Health and Social Service carer/patient interface settings, both in hospital, out-patient services and community services.
Publication location	Primary focus: UK studies. Secondary focus: studies published in English from other locations.
Methodology	Qualitative, ethnographic studies, patient/client view surveys, grey literature, studies published through target groups' organisations, relevant quantitative studies.
Age Group	Patients/service users between the ages of 18 and 65 years
Study Focus:	Experiences of providing care to a person within the target group long terms conditions
Study Types:	Empirical and non-empirical studies, quantitative and qualitative. Grey literature, mainly web based literature.
Language	Only studies published in English.

Organisations Contacted

The following organisations were requested to send information concerning target group carer's views and experiences and in particular, to identify literature sources, references and booklists. The vast majority of these organisations responded positively. Many offered the use of their librarians and search capacities. The organisations contacted were:

Motor Neurone Disease Association
Multiple Sclerosis Society
Parkinson's Disease Society
Headway
SCOPE
ASPIRE
INSPIRE
Spinal Cord Injury UK
Spinal Injuries Association
The British Polio Fellowship
Long Term Medical Conditions Alliance

Ordering of Evidence

Expert Panel members categorised the studies using the following typology:

T1   Target Group Carer Experience
Studies/literature written or published by carers or through their organisations that are about care issues of people in the target groups – especially in relation to Health and Social Services.

T2   Target Group Academic/Professional
Studies/literature produced by academics/professions for publication in the mainstream academic/professional press about care of people in the target groups especially in relation to Health and Social Services

T3   Non-Target Group: Carer produced
Studies produced by carers or their organisations that explore general issues of care experience of Health and Social care services with patients/service users outside the target groups.

T4   Non-Target Group: Academic/professional produced
      Studies produced by academics/professionals that explore issues of carer
      experience of Health and Social care services with patients/clients outside the
      target groups

Confidence Rating

Expert Panel members were asked to rate the text 'high, medium or low' to express their confidence in the robustness of the study. In making this judgement they were asked to consider

a)   Whether the methodology could reliably be replicated (generalisability)

b)   The extent to which they considered the findings valid and

c)   Reliable.

Studies that it was judged cover a-c attracted a 'high' rating. Studies that cover 2 criteria attracted 'medium'. Those that have only one criteria attracted a 'low' rating.

Findings Typology

The findings from the study are presented in impairment group order below within a basic typology. The typology used is as follows;

A)   'Carers of people with sudden onset long term conditions': incorporating Brain Injury and Spinal Cord Injury

B)   'Carers of people with intermittent/unpredictable long term conditions'; incorporating Epilepsy

C)   'Carers of people with progressive long term conditions'; incorporating Cerebral Palsy, Motor Neurone Disease, Multiple Sclerosis and Parkinson's Disease.

Notes:

The brief also covered carers of people with polio, although no studies were identified. It is hypothesised that this could be due to the similar problems identified in the users' study (Harris et al 2003) in that people who had polio as children may now mostly be older and therefore outside the age range set (18-65 years) and that new cases may be under the age range (in children). It also seems probable that any people with polio who require care in the former group will be treated as older

people for the purposes of social services and not distinguished from others on impairment grounds.

It was not possible to distinguish between the two forms of MS within the literature studied and it is recognised that some of the literature that appears in this heading in group C has implications for group B also.

Group A: Carers of People with sudden onset long term conditions: Brain Injury, Polio and Spinal Cord Injury

Brain Injury

UK studies

The search yielded only professional/academic studies (T2) as categorised by the expert panel. Only one T2 study attracted a high rating. This was Nickson (2003; CA0003: high) which is a report of findings of a survey of Social Services Departments. However, views of carers are not obviously present. The results were obtained from a self-completed survey of departments. Although all departments surveyed claimed to have respite facilities available for carers only a quarter could provide a contact name. The author recognises that many individuals who suffer traumatic brain injury (TBI) now survive although the nature of the disability has serious implications for their immediate family. The general thrust of the argument is that services for individuals are patchy and services for carers are patchier still. This leads to the conclusion that such services are aspirational rather than actual. The report suggests that on the evidence provided services for individuals with TBI and their families are not seen as a priority area. To address this it recommends that departments use an additional classification to accommodate the needs of TBI sufferers and their families.

In the medium confidence rating section, Gosling et al (1999,CA0742: medium) studied the effect on marriage of head injury, in particular the effects on spouse carers. Key findings were that:
- Marriages were reported to have severe problems
- Sexual satisfaction was rated as low and they were dissatisfied
- The partner with head injury was dependent
- They felt that their partner felt like a stranger and avoided sex
- The relationship was no longer equal, sharing or providing companionship
- They were concerned about the effect of their partner's injury on the children
- They spoke of sadness and recognition of their losses

The implications of this study were that spouse carers need help with practical and emotional aspects of coping with added responsibilities.

Connolly et al (2001; CA2621: medium) reported that care-givers are more likely to feel low self-esteem if they perceived the impact of the 'disabilities' as being out of

their control or being unchangeable. The results suggest that 'behavioural disabilities' (for example increased aggression, restlessness, swearing and so on by the brain injured person) was most associated with carer's increased stress levels.

The role of social support is taken up again in Ergh et al (2001; CA0133: medium) in which it was found that care-givers with adequate social support adjust better to their new role, and are less distressed than those with low social support, who become increasingly distressed as time since injury elapses and patient executive dysfunction worsens. It was also found that patient neurobehavioural disturbance increases care-giver distress regardless of social support level.

Tennant et al (1995; CA1183: medium) conducted interviews with carers on the subject of quality of life for the brain injured individual and revealed similarity with direct reports (from the patient) on issues such as memory loss, ability to concentrate, irritability and headaches. There was disagreement, however, on tiredness and decision-making. Caring for a brain injured individual who scored poorly usually meant that the carer was likely to suffer from social exclusion and to suffer from lack of sleep and accompanying fatigue. The authors conclude that early intervention in the form of counselling to brain injured individuals and their families could have long-term benefits.

Hubert (1995; CA0014: medium) studied 20 young people and their families and reported that specialist social workers or psychologists, if allocated, were found helpful by parents as a consistent information point. There were some reports of conflict between parents and partners about who had 'rights' to the patient. The transition from intensive care to general wards where the patient got less attention and treatment was experienced by carers as 'abandonment' or being put 'on the back burner'. Moves to inappropriate wards with staff inexperienced in head injuries caused anxieties particularly when staff reacted negatively to violent struggles or outbursts. Parents would have appreciated counselling, or other parents who had been through the same experience to talk to – both for emotional support and information. Families had positive experiences of specialist rehabilitation wards in terms of restoration of functioning, though one or two felt this should be possible in a more homely environment rather than an institutional setting. Once at home with the family, the personality changes, and cognitive disability were found harder to deal with than physical impairments. Parents experienced grief for their 'lost' child. These are the least 'visible' effects of brain injury but the hardest to deal with and the ones which local services tended to offer least help with (in the view of families). There were also disagreements about levels of autonomy; problems of trying not to upset

the person 'walking on eggshells'; abuse and ill temper, anger, and frustration of the person with brain injury. There were difficulties in accessing support to deal with this, and in knowing what 'should' be done. (For example should the person drink (alcohol), and might arguments and emotional stress cause fits). Professionals (for example care manager, consultants) with experience/knowledge of head injury and after-effects were viewed as most valuable. Those who had less experience were perceived as less valuable. Headway was also valued. Disruptions of household and renegotiations of relationships affect siblings. The author suggests some of the above difficulties might be eased through provision of more information about what to expect and 'training' for families on how to deal with changes. Also required is much more on-going support for longer periods. The families experienced variable levels of on-going support depending on where they lived. Many feel 'forgotten' as time goes on. The implications of this study were that in hospital there should be trained staff on general wards to assist with continuity after transfer from intensive care or specialist units and the patient should have access to their own counselling. At home, rehabilitation should continue as long as needed in the individual case and the importance of daytime occupation should be recognised. Regular professional contact should continue. As soon as possible the patient should be able to access assistance to take up paid employment, and to leave home if desired.

McPherson et al (2000; CA0148: medium) studied perceived health and reported strain felt by 70 primary carers of individuals with a severe brain injury. Despite awareness that carers need support they continue to complain of being failed by services in terms of understanding needs, responding to crises and providing information. There is a correlation between the severity of the brain injury and the perceived health of the carer. Carers in this study scored lower than the general population particularly in physical and emotional health. In terms of relationships between carers and patients, spouses scored worse than parents in the health domain, especially in reporting bodily pain, vitality and emotional distress. Carers generally have an increased incidence of anxiety and depression. They are more prone to negative feelings of guilt and anger and they experience difficulty in adapting to new roles within the family.

Sinnakaruppan et al (2001; CA0140: medium) is a review article which identified seven papers ranging from behavioural to cognitive interventions to help carers adjust to particular problem behaviours in the brain injured person. Only one study used standard assessment tools. The remainder used a variety of methods including self-report measures and interviews. All interventions were reported as beneficial to carers. Overall the studies reviewed were found to be limited by biased sampling,

non-standardised outcome measures, using subjective methodologies and a lack of control samples. Most studies did not reveal pertinent information regarding the degree or type of head injury or rehabilitation history. The authors conclude that there is an outstanding requirement for large randomised controlled studies using standardised methodologies to identify efficacious carer programmes.

Finally, in a cross-cultural comparison between Scotland and New Zealand, McPherson et al (2000; CA0074: medium) claim that patients and carers need information about a range of items on discharge.

In terms of UK studies rated with a low confidence rating by the panel, the first item, Sinnakaruppan et al (2001;CA0134:low) is a literature review on the needs of family carers of people with head injury and reviews 13 articles. It is noted that when caring for a person with head injury, carers need a clear and regular explanation of their relative's condition and realistic prognosis and also need to feel there is hope and know what the future holds. They need to feel that healthcare professionals care and to receive honest responses to questions. They need time to themselves outside the house and also require information on the effects of head injury, community resources and financial assistance. Assurance that the person with head injury will be cared for in event of the carer's death is also required along with assistance with care in the home, (respite and financial). Over two years after injury needs change from medical/professional ones to include those around community, carer and family support, financial and health information. These needs are not always met leaving carers misunderstood and isolated. Unmet needs were linked with lower quality of life and greater psychiatric morbidity in carers. The article concludes that carers' needs should be explored further to ensure service provision can be effectively targeted over time but this should be sensitively targeted at individual family needs.

Tyerman et al (2001 CA0138: low) reviewed a community service provided to manage the disruption and distress of the families' experience of caring. The authors noted the need for information and explanation when coping with stress and loss. Carers feel a sense of obligation and duty to the person with TBI but also experience social isolation. They need time and empathy, help to solve problems, opportunities to reflect on their situation and express honest feelings and thoughts, commitment from services for ongoing support and help to adapt in the long term. Issues raised by spouses around TBI and marital issues are 'is it the TBI?', aggression and unpredictability, dependency, responsibility and decision making, relationships between the person with TBI and the children, reduced communication, restricted leisure/social life and reduced sexual and emotional intimacy. Carers need an open

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door approach from services and not to be treated as patients. Specialist family services can help to manage short and long term needs of families in coping with the effect of TBI.

Watanabe et al (2001 CA0139:low) undertook a cross-cultural comparison study (UK and Japan) examining the impact on family members who care for an individual with traumatic brain injury (TBI). The impact on family members is not so well researched in Japan. In Japanese culture, for example, the disgrace associated with some behaviours common to those who have TBI is likely to cause families further stress. Data was generated via face-to-face interview as well as by questionnaire. In both cultures families felt a duty to care for the injured relative. In both cultures there was discomfort with other people's opinions of the injured relative but in the British sample there was significantly less concern with the opinions of other relatives. Both groups reported feeling tired and frustrated by the experience of caring. The British sample mostly felt that talking to each other or to neighbours or professionals was a useful coping strategy but only one individual from a Japanese family suggested any coping strategy. Both cultures valued information and training although awareness of how to access such services was lower in Japan. The Japanese families reported less stress than British families.

Oddy (1999; CA0160: low) reported that carers of people with aphasia do not experience a causal link between severity of condition and level of well-being. Factors that give rise to carer stress are; acceptance of change, attributions made to the person with aphasia's behaviour by the care-giver, loss of the sexual relationship, diminished marital satisfaction, carer no longer seeing the patient as a marital partner, a perceived fundamental change in the person and incompatibility of the carer role with a full marital relationship. The article states that the most common form of intervention offered to carers of people with aphasia is support groups.

Mapp (1995; CA0056: low) quotes a director of Headway who reports that relatives of people with head injury report the ten most difficult problems after head injury are: personality changes, slowness, poor memory, irritability, bad temper, tiredness, depression, rapid mood changes, tension and anxiety and threats of violence.

Firth (1996; CA0027: low) discusses a service set up in Northumberland to address the health and social needs of people with head injuries after they leave hospital. They found that they need to attend to carers' needs as well as those of the people with head injury.

Bowen et al (2001; CA0429: low) evaluated the effectiveness of a new rehabilitation service, compared with existing services, for carers of people with TBI. The aim was to reduce neuropsychological sequelae of TBI and to improve outcome for survivors and their carers. Ninety-six carers participated. On admission the injured person was assigned, according to a specified timetable, to one of three groups (new service pre-discharge, new service post-discharge and control). Extra recruitment to the first group meant that carer numbers were unequally divided at 41, 28 and 27 respectively. Two outcomes, carers emotional distress and how well informed they felt, were measured 6 months post discharge. Results show that the majority of the control group felt poorly informed when compared to both intervention groups. However, this did not reach statistical significance ($p \geq 0.01$). 52% of the control group showed significant emotional distress after 6 months. This was greater than both intervention groups but again it did not reach statistical significance ($p \geq 0.01$). The authors felt that by setting the p value so low they may have committed a type 2 error (not being able to reject the null hypothesis as false). That they did not use the Neyman- Pearson lemma suggests a poor grasp of statistical significance. These methodological shortcomings reduce confidence in the results, hence the attraction of a low rating.

Greenwood et al (1994; CA0212: low) used a prospective controlled, unmatched, non-randomised design to examine the effects of one model of early case management on patient outcomes, family functioning and provision of rehabilitation. No significant differences were found, for either patients or family carers, between the group who received this model of case management and the control group. Very little information is provided in relation to the way carers were included in the case-management model, but it appears that, apart from the early provision of advice and information, they did not receive assessments or interventions focusing on their specific needs or characteristics. Moreover the model of case management consisted of an independent case-manager with no budget or strong leverage on services. At the time of the study this would not be expected to generate significant additional practical or emotional support. The paper notes, however, that 19 of the 20 families who received the case-managed service found the case-manager 'helpful' or 'very helpful.

Oddy and Herbert (2003; CA0110: low) undertook a literature review and reported that families report a lack of information and feel the outside world does not understand their problems and difficulties. Cognitive and personality changes in the patient are the most difficult to cope with and denial is a factor in family responses. However, not all families are distressed after brain injury although many families feel

excluded by professionals. The implications for service providers noted are that during admission procedures in rehabilitation units there is a need to keep relatives involved and informed with regular contacts and inclusion in reviews.

McKee (1995; CA5030: low) is an informal case study of a mother who chose to remove her son with a severe head injury from a rehabilitation setting and to care for him at home. Key observations were that the mother felt stress increased over time from her son's psychological and behavioural changes. She was worried the injury would break up the family as her other son started having behavioural problems at school and her husband bottled up his worries. She became socially isolated. She could not cope with the stress, crying all the time and perceiving that everything she did was wrong. She felt her son did not readily slot into the system offered by the community and there were no other options available. She experienced that letting go of her injured son to enable him to move forward independently was the most difficult stage of the process.

Finally Williams et al (1997; CA0016: low) was also given a low rating since it contained so little detail on methodology. A Health Advisory Service (HAS) Team visited six districts in England and Wales and talked to service users and carers, as part of a HAS review to evaluate the state of mental health services for people with brain injury, Huntington's disease and early onset dementia. The authors note a lack of appropriate rehabilitation facilities and respite care and problems finding specialist help and poor communication. They also note that there is inadequate support for carers of people with brain injury; a need for early counselling, information and recognition that relatives affected by the injury may need help in their own right.

Other Locations
There are no T1 studies identified in other locations. Among the T2 studies highly rated, Harris et al (2001; CA0141: high) from New Zealand analysed factors that contribute to carer depression. Its key findings are that carers experience distress about behavioural and social problems and adverse effects on families. Adverse effects on the family after TBI are the sole predictor of carer depression (due to the impact on the carer from viewing the effects on the other members of the family). It was found that if carers appraise stressors as distressing their depression scores will be higher than people who perceive them as less distressing and the effectiveness of support moderates between adverse effects and depression.

Another New Zealand text, (Gronwall et al 1998; CA0012: high) is not a research article but a guide to what happens and what to expect based on views/experiences

of professional work and research with people with head injuries and their families. It maybe the sort of information that carers in other studies (for example Hubert 1995) have said they would like to see produced. The authors emphasise the often long term nature of recovery and the need for support for carers. Also both parties need some control over the situation and some privacy.

A study from Australia, (Fyffe et al 1996; CA0010: high) does not differentiate patient and carer views separately but reports on inappropriate communication and poor information from professionals, varied service quality and coordination, absence of services/support in patients' home locality, lack of support for family and carers, distance from services/professionals and transportation to visit hospitals or specialist clinic. There is also a need for local GPs to bridge the gap between patients and carers and community support services.

In terms of highly rated T2 USA studies, Spatt et al (1997;CA1002: high) focuses mainly on methodological issues Three sources contributed to the assessment; the patient, carer and neurologist. Carers' views are considered only in so far as they might contribute to an overall evaluation of psychosocial outcomes. This contribution is apparently particularly effective in providing information on social and behavioural domains where the injured person tends to have impaired judgement. In this case carers' views are purely functional in terms of the overall aim of the study and are not extensively sought or described. The authors conclude that neurologists must make use of carers' assessments in compiling their evaluations of treatment.

Albert (2002; CA0129: high) looks at the benefit of a carer support programme via telephone for carers of people with brain injury over the 12 months after discharge. They found that initially contact was for counselling for the carer, extending to more family based counselling as the patient moved beyond the initial discharge phase with an increase in enquiries about rehabilitation and nursing home care. The carers who received the support service reported significantly less 'burden' than those without and greater mastery of care-giving tasks. They also had higher global quality of life ratings.

Carnevale et al (2002; CA0125: high) reviewed the benefit of a behaviour management program for persons with TBI and their carers and the effect on reducing carer burden. They found that there were no significant changes in the measures associated with treatment.

McNeill et al (1997; CA0182: high) is a report of family involvement in TBI rehabilitation, using the Family Involvement Assessment Scale. This describes four dimensions of support and involvement;

- Involved and supportive,
- Uninvolved and supportive,
- Uninvolved and unsupportive,
- Uninvolved and supportive.

It is noted that there is a need to be aware that family member's involvement in the rehabilitation process may change due to factors such as patient recovery.

Brady et al (1994; CA5047: high) compares the adaptation of three groups of carers:

- Members of a head injury support group,
- Members of a mental illness support group
- Carers of people with mental illness who do not use a support group

The study found that carers did not differ significantly in adaptation strategies between client groups. The mental health support group carers experienced more guilt and stigma. Carers describe coping by use of prayer, faith and acceptance. The members of the support groups felt that they benefited from membership. Many carers reported grief for the loss of patient's potential and personality. Carers felt that services need to provide increased aftercare, meaningful employment opportunities, avoid over-medication and particularly for head injury patients and carers, establish systemised patient care.

Allen (2000; CA0149: high) reports that care-giver spouses with drug-controlled hypertension were involved in a controlled experiment where they were assigned pet dogs. Findings demonstrated a therapeutic role for pet dogs.

Kosciulek et al (1996; CA4207: high) used the Family Adaptation Concerns Questionnaire developed from larger Family Adaptation Concerns Index by a working group of eight family members of persons with Brain Injury. The study included spouses, parents and siblings of the patients. Each concern was rated for importance and satisfaction. Respondents were 82 primary care-givers of persons with brain injury contacted through family support groups of Georgia Head Injury Association. 24 items were chosen for the questionnaire. 22 out of 24 were given scores of greater than 50 out of 100 for importance but 20 out of 24 had satisfaction ratings of less than 50%. The survey could therefore be said to be about important

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items where there is quite a bit of dissatisfaction among carers. Important areas where satisfaction was highest were:

- Friends provide encouragement and support
- Family maintains a positive outlook about the situation
- A support group for families is available (selection bias)
- Family loyalty, unity and cooperation exist

Important areas where satisfaction was lowest were:

- Availability of appropriate services for the member with head injury
- Availability of breaks from caring responsibilities
- Appropriate living situation for person with head injury
- Leisure and recreation facilities suitable for member with head injury
- Disruption to family life caused by emotional or behavioural problems by injured family member

Care-givers also had high dissatisfaction with 'Individual members have time for activities outside the home' though this was not rated so important relative to many other items. From a family perspective, the most important threats to successful family adaptation are the lack of suitable services for the injured person, and the person's behavioural and emotional problems, whereas the strengths which contribute to adaptation are within family, or through friendship or peer support. The study is described as the beginning step in an agenda-building process to address the adaptation concerns of families of people with head injuries. Future steps are outlined.

Finally a highly rated study from Ireland, Hickey et al (1997; CA179: high) assessed longitudinally the implications of severe head injury for the quality of life of the injured person's primary carer. Data was drawn from the acute neurosurgical care period to one year post discharge from hospital. This paper is more concerned with psychosocial well-being resulting from the physical and mental changes in the person with severe head injury. This paper also evaluates the association between patterns of problem reporting by patients and carers, using The Psychosocial Adjustment to Illness Scale (PIAS), the Schedule for the evaluation of Individual Quality of Life (SEIQoL), and The Problem Checklist (PCL). 'Carer psychological adjustment and individual quality of life evaluations were significantly poorer than general population levels and did not change over a one year period. However, significant increases in the number of problems identified was quite low. Female patients reported significantly more problems than male patients. The study demonstrates increasing

problem profiles and differing perceptions of patients and carers over time.' Hickey et al (1997. 827).

In terms of medium rated USA studies, Allen et al (1994; CA0210: medium) report on 'burden levels' between carers who were parents and spouses. Key findings were that although both parents and spouses live with significant burden and stress particularly in the post acute period, parents are more concerned with lifelong care;

- Cognitive disability and social behavioural difficulties have greater association with burden than injury severity or physical disability;
- Spouses report a greater lack of personal reward than the parent carers;
- Female care-givers report higher levels of burden
- Aggressive behaviour is most significantly associated with burden.

The entire family balance is affected by having a person with TBI in the family. Overall parent or spouse carers do not differ significantly in burden level.

Gardner (2002; CA4388: medium) is both a literature review and a retrospective study. It is concerned with the relationship between different 'problem behaviours' resulting from brain injury and the breakdown of the primary care-giver relationship. Carers' actual experiences or views are not considered. This study found that loss of self-control and substance use are the behaviours most likely to cause a breakdown of care-giving relationships.

Gervasio et al (1997; CA4186: medium) is a study of 116 co-resident care-givers from outpatients listed on the medical college of Virginia brain injury database. The study used self-completion questions, Brief Symptom Inventory and information from the database. Out of 89 female and 27 male care-givers, 44% met the criteria for 'caseness'; only 20% showed elevated depression scores, around 30% showed elevated (above population norms) scores on scales reflecting psychoticism, hostility and anxiety. This could be because they are feeling overwhelmed, isolated, inadequate, confused, unable to concentrate and as if they might be going crazy. The authors caution against interpreting BSI scale elevations as direct indications of psychopathology. Levels of self-reported perceived stress (Likert scale) did not differ between spouses and parents, but spouses were significantly more likely to achieve 'caseness'. Male care-givers of female patients had significantly higher GSI (Gobal severity index) score than other gender combinations. GSI reflects general psychological distress. No significant effects (on GSI or perceived stress) were reported of time since injury or length of coma. The interpretations of greater 'caseness' among spouses given by the authors are:

- Deprivation of reciprocal and equitable adult relationship, loss of emotional support
- Need to take on additional roles outside gender expectations
- Disruption of sexual relationships

Parents feel easier about explaining/living with foibles and behavioural problems of their children, and caring for their children is less of a role change even though it is stressful. The study acknowledges one difficulty - that they have no information about pre-existing problems and their distributions, and so analysis tends to assume that these were like those in the rest of the population – which may not be true if people with TBI are drawn disproportionately from certain groups. Clinical implications are as follows:

- The majority of carers did not report elevated distress levels; however support groups, individual or marital counselling could be useful for some;
- There is a need for support for families to continue to be available in the longer term;
- Services may currently be offered in early stages of recovery which people may actually need later;
- Particular attention to the needs of spouses and male care-givers is needed.

Chwalisz et al (1995; CA0200: medium) propose that a perceived stress scale is a better predictor of mental and physical health for carers than the traditional measure of carer burden and Carnevale (1996; CA0198: medium) reports that 'natural setting behaviour management' helps reduce patient aggression and enhance patients' control of their rehabilitation.

Ergh et al (2002; CA0128: medium) claim that:

- Neurobehavioural and affective problems of the patient are more likely to influence care-giver distress and family functioning;
- The more support received by care-giver, the less distressed they are;
- Family dysfunction is inversely related to perceived social support;
- Other factors such as alcoholic tendencies or socio-economic position of patient were not related to care-giver stress;
- Care-givers with lowest social support experienced highest distress, but also were caring for patients with most severe conditions. Those receiving moderate support experienced lowest distress and cared for patients with least severe conditions and family functioning improved with increasing social support.

Seibert et al (2002; CA2121: medium) in a study entitled, 'Brain injury; quality of life's greatest challenge' states that older patients reported better quality of life than younger patients. Men reported better quality of life than women in terms of their increases in spirituality and 'better driving ability'. Women reported being sadder than men after TBI. Families emphasised the family relationship, emotional control and ability to concentrate when considering overall quality of life, whereas patients did not. The more severe the injury the more likely relationships would terminate - men were more likely to leave women with TBI although women were more likely to stay with men who suffered TBI. Patients with TBI reported a low self esteem due to outsiders making decisions for them and not asking for their opinion or giving them choices. This caused a reduction in quality of life.

Kosciulek (1995; CA4223: medium) identified five clusters of family types coping with head injury in their family. The author categorised families as:

- 'Unpatterned families': family members appear unconnected or separate. Their normal functioning has been upset by the head injury.
- 'Fragile families': they have dysfunction in problem solving, communication, affective involvement and general functioning and have some problems with family roles. They lack family loyalty and hesitate to depend on the family for support.
- 'Pliant families': they have dysfunction in communication and they have difficulties with exchange of information within the family.
- 'Regenerative families': they function effectively.
- 'Vulnerable families': struggle with information exchange, emotional response and task assignment. Their overall functioning may be prone to deterioration if additional stressors occur.
- Clinicians need to be aware of how families may react to the impact of head injury

Kosciulek (1997; CA0184: medium) was a replication of an earlier descriptive study by the same author who recruited participant families from a different part of the USA (Georgia). The purpose of the study was to test the findings of the earlier study in relation to the dimensions that underlie family coping. The study was well designed and conducted but its quality is compromised in the following respects: its internal validity is compromised by the selection of the 30 coping behaviours used, as opposed to any other group of items; the findings are not generalisable because the sample was not a probability sample; the study was cross-sectional and the study did not attempt to assess the utility of different coping behaviours, only their use. It was

found that while there were similarities in the coping behaviours used in the earlier study, there were also differences – possibly due to the different social and service contexts of the two samples. Cognitive coping and head injury focused coping emerged as common. The author draws attention to the need to carry out longitudinal studies and research to assess the utility of different coping strategies. He also draws attention to the value of practitioners assessing family coping behaviours when designing interventions.

The final medium rated T2 study from USA (Curtiss et al 2000; CA2703: medium) looks at acute changes in family structure after head injury and changes in coping strategies before and after TBI. There was a significant change in family balance post injury. Balanced families pre-injury became extreme type families after injury and moderately balanced families pre-injury showed less cohesion and adaptability after injury. Post injury the extreme type families showed increased guidance seeking and problem solving coping patterns compared with pre-injury behaviour. This may reflect major role changes and changes in family structure. These families may benefit from family support groups. Balanced families post TBI used the same coping strategies except they used less emotional discharge and alternative reward seeking which suggested an emotional numbing or over-control of emotions. Moderately balanced families showed little change but did use more emotional discharge, alternative reward seeking and acceptance. This may suggest premature closure, which clinicians need to be aware of and provide information on the recovery process. Midrange families appear to be avoiding the consequences of TBI and are less likely to be involved with the treatment team than any other family type. Service providers need to be aware of families' coping strategies and likely changes in family dynamics after head injury and provide appropriate intervention.

Two medium rated studies were from Australia and the first of these, Stebbins et al (2001; CA0132: medium) reports on irrational schematic beliefs in care-givers (parents, spouse, siblings). The authors used the Irrational Beliefs Inventory and Brief Symptom Inventory to identify five key irrational beliefs: problem avoidance; rigidity; worrying; demand for approval and emotional irresponsibility. Characteristics of the patient were not found to be related to care-giver stress but this is not consistent with previous studies. This discrepancy may be because the study used single items to measure, but previous studies used a multi-item disability scale. It is also noted that
care-givers of people with TBI are vulnerable to high levels of stress and burden and

a reduction in adherence to certain irrational schematic beliefs (worrying and demand for approval) is likely to reduce psychological stress of care-givers and increase their physical health.

The second Australian study, (Anderson et al 2002; CA0304: medium) is highly technical and largely methodological and focuses on stress to explore the relationships between neurobehavioral problems associated with traumatic brain injury (TBI), family functioning and psychological distress in care-givers. The literature suggests that neurobehavioral problems are related to stress reaction in carers and this study supports these findings. The study hypothesised that family functioning will mediate the relationship between the neurobehavioural problems of TBI and psychological distress in the care-giver. Data was generated from respondents (sample size n=64) via a series of self-assessment scales and the variables operationalised via established test instruments. The carers' experience is described mostly in statistical form. From this it is apparent that carers experience distress grouped around behavioural, communication and social problems. No further insights from actual carer experience are offered. The authors suggest that gendered and ethnic elements need further study before they can claim more general authority for their findings.

A New Zealand study, Leathem et al (1996; CA0197:medium) was medium rated because, for a quantitative study the sample size is very small (18 parents and 11 partners) and there is a degree of bias in the sample selection methods. In addition, one of the scales used was developed specifically for the study and no account is given of its validation. The study's main objectives were to examine the nature and extent of role change experience, utilisation of and satisfaction with social support and stress levels experienced by both parent and spouse carers and to test the hypothesis that these would differ significantly between the 2 groups, with partners scoring more highly. The combined parents and partners group experienced moderate levels of stress and role change and a relatively small group reported health problems. Partners reported greater stress, role change and health problems than parents. Qualitative differences were found between the 2 groups in terms of sources of stress. There was little difference between parents and partners in source, utilisation or satisfaction with social support. Positive correlations were found between stress and role change and stress and health problems. The authors point to the need for further research on stressors after head injury, to lessen burdens and improve families' (and people in different relationships to the brain-injured person) capacity for involvement in rehabilitation.

A Canadian study, Smith et al (2000; CA0508: medium) is a small scale (n=8) qualitative study that examines carer experience of 'the system'. Data generated at interview reveals four main themes that account for the carer experience;

- The search for information;
- The search for support;
- The need to speak for the survivor and
- Navigating the system.

Much of the 'search for information' began at the emergency room where families felt that they were given information but could not relate it to their experience. There was a prevalent feeling that professionals tended to emphasise the seriousness of the injury, thereby denying hope, while all the families wanted was hope. Care-givers were generally not prepared for the long-term effects. They reported stress, burn-out and giving up, not because they did not care, but because they could not cope. Speaking of the changes in the injured person they spoke of loss and grief for the person they used to know. Care-givers felt the need to advocate for their family member and this frequently brought them into direct conflict with health professionals and sometimes with the TBI patient themselves. One individual reports that they needed someone who knew their way around the system 'because if you don't, you're sunk'. Much of the conflict here focused on the discharge of the TBI patient. Family members did not know how to access services. The authors conclude that family caring can be improved by the introduction of a case manager to coordinate the long-term care of TBI survivors and their families.

Another Canadian study (Acorn 1993; CA0214: medium) evaluates the needs of carers of people with head injury and the availability, usefulness and helpfulness of support groups in meeting these needs. It was found that the most stressful issues for carers were the person's decreased memory, problems with decision-making, mood swings and long lasting dependency. Carers need education about head injury and community resources with honest responses to questions. Psychologically they need to know what the future holds, to talk about their feelings, have hope and emotional support. They need time off including respite. They experience poor communication with healthcare professionals. There needs to be family support groups in rural areas. Support groups for carers need to provide education, information about services, emotional support, and social support.

A further Canadian study (Acorn 1995; CA0203: medium) reported that care-givers of people with a head injury benefit from an education/support programme with other care-givers of people with a head injury. It provides an opportunity to unburden, reduce isolation, support and share. Isolation is a key theme among care-givers

along with blame, guilt, anger, unresolved grief, stigma and social withdrawal. Care-givers need practical information on legal and financial issues as well as family and carer support and education on features and impact of head injury. Following an education/support programme care-givers developed a more positive supportive coping style.

The final Canadian study in this group (Engli et al 1993; CA1455: medium) is a follow up of a 1984 study which showed families of patients with TBI (in hospital) had higher needs than families of other patients. The study is based on use of the Critical Care Family Needs Inventory (CCFNI) plus one open question. This study was based in Intensive Care Units. Response rates were low (8 cases, with TBI; 6 cases, otherwise critically ill). Family members identified a need for information about treatment and prognosis as most important.

One Japanese study (Watanabe et al 2000; CA0574: medium) reported fairly high levels of stress in carers and states that they might be at increased risk of depression. There were higher levels of strain in carers of more impaired patients.

In respect of low rated T2 studies from the USA, the first of this large group is Gardner et al (1999, CA0162: low) which examines the changes after brain injury: behavioural, personality and emotional, that influence the stability and permanence of primary care-giving relationships. Loss of self control is the factor that correlated most strongly to changes in care-giver. Post injury substance use also led to changes in the care-giver. The results revealed that change is least likely when the care-giver is a parent. Loss of self-control and substance abuse make most relationships (that is with a parent or partner) prone to changes of care-giver.

McLaughlin et al (1993; CA1477: low) is a small-scale study that attempts to resolve the conundrum apparent in brain injury rehabilitation whereby professionals must simultaneously work positively with families while entertaining doubts over the likely outcomes they can offer. This uncertainty gives rise to conflict. In order to measure the amount of adversarial contact between families and professionals, data was generated from a questionnaire, from interview at admission and from a discharge summary form. From this it became apparent that there is increased risk of conflict where the patient is younger, the patient has a low level of cognitive function on admission and/or the patient has a low level of physical function on discharge. From this the authors have developed protocols for use within their own clinical area. Carer experience is not accessed directly but two scenarios summarise typical responses from families.

Another USA paper, Thaxton et al (2002; CA0310: low) examined the way care-givers cope with the sleep disturbance of the brain-injured person. A lengthy opening section on sleep and insomnia gives way to a catalogue of strategies to promote sleep. These are all of a general nature and relevance is claimed because TBI shortens sleep time and is implicated in the disappearance of deep sleep. Also discussed are the effects/side-effects of prescription and non-prescription medications. However, no actual carer views were sought, hence the low rating.

Sander et al (2002; CA0307: low) investigated the relationship of family functioning to patient's progress in a post-acute TBI rehabilitation programme. The hypothesis was that persons from families with unhealthy functioning would show less progress in rehabilitation than those from families with healthy functioning. The sample was small (n=37). Data were collected using two standard outcome measures. The results indicated that family functioning was significantly related to how well patients progressed in post-acute rehabilitation.

Perlesz et al (1999; CA0168: low) was another literature review of dubious robustness, which focuses on relatives' stress and burden, and how researchers have gathered and presented their outcome data. Authors include cross-sectional studies identifying high levels of distress in relatives of people with TBI, as well as longitudinal research tracking relatives' responses for up to 20 years, giving a slightly more comprehensive picture of outcome. Whilst some studies report that spouses and parents do not experience significantly different levels of stress and burden in caring for a partner or adult child with TBI, many authors continue to suggest that care-giving spouses in TBI populations are at greater risk for distress than care-giving parents. There is a short discussion of different family assessment measures used by TBI researchers, and their respective reported strengths and weaknesses. In the concluding section, the authors state that the findings from the studies included in the review confirm that TBI can have a negative impact on family members, however it is pertinent to note that not all families are necessarily affected in this way.

Holland et al (1998 CA0171: low) is a discussion piece proposing a model for educating families to help them adjust to caring for someone with TBI given the changes in the USA healthcare model which means patients spend a very short period in hospital. The authors argue that what is needed is a family educational programme that firstly satisfies the family's acute information needs, as they arise, and secondly standardises the delivery of information so that certain knowledge

criteria are met. This, they claim, should take the form of a three phase model of family and caretaker education.

Leach et al (1994; CA0207: low) sought to examine how changes in family functioning post trauma 'impacted' the adjustment of the individual with TBI. More specifically it sought to test whether poor family functioning was positively associated with depression in that person. The study found that social support was not predictive of depression – but that effective use of problem solving and behavioural coping strategies by families was significantly related to lower levels of depression in the person with TBI. This study is, however, very flawed. The accounts of family functioning were taken only from the brain-injured person; the sample is very small, self-selecting, contained larger numbers of women than in the general population of people with TBI, and is dominated by people with low and moderate levels of depression; it fails to define either coping or social support; the design lacks a 'before' baseline element; and does not use a control.

Kreutzer et al (2002; CA0120: low) is a discussion of the Brain Injury Family Intervention, which is a tool designed to address common issues, concerns and challenges for families accommodating brain injury. It addresses families' experiences of changes in work to care for the person with TBI, financial difficulties, increased responsibility, healthcare issues, communication and role changes. It is based on eight assumptions: brain injury causes drastic life changes for all the family; most people want their own life back; well informed people do better; every family member deserves respect and each is important; every adult family member has the right to make choices, good or bad; the family end up with most responsibility for helping the person with TBI; family members must take care of themselves effectively to help others. The treatment is based on steps that address carer experiences. However, the programme is based on a literature review, clinical experience and carer views and requires validation.

Kolakowsky-Hayner et al (2001, CA0136: low) aimed to assess the long term needs and quality of life of care-givers of people with brain injury. The study used a postal questionnaire (the Virginia Traumatic Brain Injury Family Needs Assessment Survey). This was sent to people identified via the 1995 – 1997 records of the Virginia Brain Injury Central Registry. The study reports diminished quality of life among care-givers after four years, compared to before the injury. Unmet needs persist and the authors claim that these change over time, though this is based on the perception that the rank ordering of needs differs in important respects from that found in studies conducted shortly after the injury (this was a cross-sectional study).

After four years Health Information (51.4%) and Involvement with Care (47.9%) needs were most often rated as met. Instrumental Support (31.5%) and Professional Support (28.3%) were most often rated as not met. The authors use their findings that carers quality of life declines over time, while needs change, to signal the importance of professionals recognising and responding to such longer term issues. However, as they acknowledge the study has limitations which call the robustness of their findings into question: it had a small (57) and self-selecting sample; unverifiable (sent and returned by mail) questionnaires; brevity of the quality of life assessment. In addition, the study's cross-sectional design means that change in needs over time was inferred, rather than directly observed.

Maitz et al (1995; CA0204: low) describes and illustrates family therapy interventions with families of people with TBI. This attracted a low rating as it is not an evaluation. The primary treatment goal after a TBI is to re-establish a workable family structure. A severe TBI compromises family members' ability to enact their roles and disrupts the balance of power and authority in the system. The text gives case examples to illustrate role changes, role strain, disruptions to power and authority structures and therapeutic intervention to help deal with same. Also discussed are issues of power and authority in relation to the treatment team and in the therapeutic relationship. However the authors do not present evidence per se.

Hosack et al (1995; CA0205: low) was rated in terms of 'robustness' as low because it is a discussion of the implications of a particular model of service provision in the USA, which has/had a set of particular and quite restrictive conditions for reimbursement – and therefore for the provision of services to support families. It may well be the case that the restrictions mentioned in the article no longer exist. Given this caveat, this article contains a useful account of the support that families are likely to need at different stages of the patient's experience and which is relevant to any country.

Struchen et al (2002; CA0127: low) investigates factor structure and concurrent validity of a 47 item scale and consequently reduces it to 35 items. Four underlying factors are named: perceived burden; care-giver relationship satisfaction; care-giving ideology and care-giving mastery (weakest factor). The authors check the factor scores against other scales intended to measure those concepts. The content of the scale could be of interest since it allegedly reflects research on carers, although this particular study did not ascertain from carers whether anything important had been omitted. An interview-based study was running concurrently but the results of it did not feed into this text.

Hickey (1993, CA5038: low) is a very brief study that sets out to describe the characteristics of primary family care-givers (n = 85) of head injured adults, including levels of anxiety, depression and family dysfunction. Five self-administered instruments were used to generate data over a six-month period. The findings are aimed at professional carers who care for persons with severe head injuries and their families. The actual carer experience is not immediately apparent. Results are not clearly flagged up but from the discussion it appears that:

- Care-givers are at risk of long term stress and burnout
- Care-givers can benefit from discussing their problems with family members

The final low rated USA study (Machamer et al (2002; CA121: low) examined the caring experiences of 180 family members of people with moderate to severe TBI at 6 months post-injury. Burden and depression of the significant other was measured using standard psychometric tools. The TBI patient was assessed on severity, neuropsychological status and function. Data were then subjected to statistical manipulation. From this the following results are available:

- The majority of the relatives endorse positive experiences
- Most frequently reported concerns were around fear of the future, stress associated with caring and financial worries.

However, the results should be treated with caution. Less stress was identified in this study. The authors believe that this may be due to the severity of the TBI in the study or a lack of sensitivity in the instruments measuring stress. The sampling may also have influenced the overall reporting of positive experiences. The relatively early timeframe also suggests that a longitudinal study could reveal different results. The lifestyle of the TBI individual pre-injury also seems to affect the outcome for the significant other who reported more negative experiences where the TBI patient had a troubled history. The authors concede that the results 'may appear obvious'.

A low rated study from Canada, Brown et al (1999; CA0165: low) recognises the importance of the family member in the care-giving role for the long–term well-being of the brain injured person. It further recognises the stresses that family members suffer in this role and sets out to test two methods of offering education and support: the traditional on-site, face-to-face intervention and the telephone support group. It used a quasi-experimental design comparing two group types (telephone n=52 and face-to-face n=39) across time (9-10 weeks per group over two years). Three psychometric tools were used to test the mood profile of participants who were caring for an adult with a brain injury on a before, during and after basis. The areas addressed were family function, care-giver burden and care-giver distress. The

highly technical nature of this study means that carer experience is heavily mediated by the statistical analyses. Four hypotheses were advanced:

1. Participation will have a positive impact on family function
2. Participation will produce reduction in care-giving burden
3. Participation will reduce care-giver distress
4. Participants will report similar levels of satisfaction with the group experience

On point one a 60 item self-assessment checklist (FAD) was used to determine family function. There was no significant difference between telephone groups (TG) and on-site groups (OG) though both groups scored well when compared with non-clinical groups. At point two the Care Burden Inventory showed that TG reported significantly lower levels of stress and this was maintained over time. At point three, the OG again reported more distress than the TG. However, across time both groups reported a reduction in distress, even when measured against deterioration in the condition of the injured person. At point four, high levels of satisfaction were reported by both groups with TG showing slightly better completion and attendance. For rural dwellers it appears that a telephone support group can be as effective as face-to-face intervention. It is also very cost-effective. The authors want to see more research on why rural groups are apparently so self-sufficient (see CA020).

Boyle et al (2002; CA0123: low) (Australian) begins from the premise that family function can affect outcome for brain injured persons. Twenty-five carers completed two psychometric tests. Results were then compared with 32 individuals who had no brain-injured family members. Two hypotheses were advanced. Firstly, that families with a brain-injured member will exhibit increased levels of conflict, control and communication problems and secondly, that these difficulties will result in families participating less in recreational, cultural and intellectual activities resulting in lower cohesion and independence than control groups. After statistical manipulation the findings suggests that:

- The most common problems reported were loss of relationships with family and friends and reduced participation in former activities
- When compared with the control group the carers reported consistently lower scores across all domains save for 'control' which suggests that carers rely heavily on established procedures and patterns to cope with their situation
- Results suggest that carers have particular problems in the areas of expressiveness, recreation, control and depression/dejection.

Quine et al (1993; CA1390: low) in another Australian study reports carers' experiences of being used as therapists in an innovative new treatment program with patients in the coma stage of TBI. They met with social workers on an ad hoc basis

and discussed current stresses both generally and with the treatment program. Relevant findings were:

- Carer stressors were: domestic, fatigue, financial, long term implications
- Carers are more concerned with patients' condition than treatment particularly severity and extent of injury and future quality of life
- Concern for quality of life increased over time
- Carers found being involved as lay therapists very stressful and this was compounded by poor organisation

Junque et al (1997; CA0986: low), (Spanish) set out to evaluate the families' need for information concerning the consequences of TBI. 65 families completed a questionnaire on their perceptions of the patient's condition. The three main changes noted were in cognitive deficits (90%), physical changes (88.9%) and behavioural changes (89.8%). As such this study does not specifically address the carer experience in terms of how it affects their own lives save for some very general remarks in the discussion.

A study from Belgium (Laroi 2003; CA0112: low) does not have any reference to carers' experiences of caring for someone with brain injury but does argue for family therapy for families of people with brain injury to re-establish or redistribute roles.

A Portuguese study, (Santos et al 1998; CA0806: low) set out to examine the spontaneous complaints of survivors of TBI and to compare these with their relatives' accounts (n = 48). Data were generated by interview and then categorised and subjected to statistical analyses. However, study did not specifically target the carer experience and the responses do not contribute to our understanding.

Finally, a low rated T4 study, Degenefee (2001; CA0130: low) draws on an extensive literature to discuss the challenges faced by those providing long term care for family members with traumatic brain injury. Areas reviewed include the nature of care needs; stress and burden experienced; how families cope with care-giving demands. Building on this, the paper concludes with a discussion of what social workers can do to reduce the demands of family care-giving and improve care-givers' quality of life. No information whatever is given on the approach to the literature review, the way it was conducted or the quality, validity and reliability of the studies reported. Nor are theoretical perspectives (such as coping strategies or adaptation) used as a way of structuring the literature. The paper nevertheless provides a good overview of experiences, needs for support and implications for social work practice.

Summary of carers' experiences of providing care to a person with brain injury (highly rated studies only)

- In the UK social services for patients are patchy and for carers patchier still. Services for carers are aspirational rather than actual. This may be because they are not seen as a priority area.

- Carers experience distress about behavioural and social problems and adverse effects on families. Adverse effects on the family after TBI are the sole predictor of carer depression due to the impact on the carer of viewing the effects on other family members. Effective support moderates between adverse effects and depression.

- The long-term nature of the recovery has implications for the support of carers. Both parties need some control over the situation and some privacy.

- Neurologists must make use of carer's assessments in compiling their evaluations of treatment.

- Carer support programmes are beneficial.

- Carers report grief for the loss of patient's potential and personality and feel that services should provide increased aftercare, meaningful employment opportunities, avoid over-medication and establish systematised patient care.

- The most important threats to successful family adaptation are the lack of suitable services for the injured person and the person's behavioural and emotional problems. Strengths that contribute to adaptation are within the family, or through friendship or peer support.

Spinal Cord Injury

UK studies
There were no T1 studies or any highly rated T2 UK studies identified.

In terms of medium rated studies, Glass et al (1997; CA0978: medium) tested levels of agreement about changes in social adjustment (before and after injury) of the person with spinal cord injury (SCI). The majority of questions ask how often negative personality traits are observed. The 'modification' is that the scale originally measured current functioning and this one explicitly asks about changes. There is weak evidence that patients identify more problems than relatives, but this is only because patients identify more problems pre-injury. Whether people were seeking compensation or not seemed to have no effect on the levels of agreement between partners (but of course this was not part of the assessment for compensation). There was a 'reasonable" level of agreement. It is argued that the results demonstrate that patients and relatives are on the whole consistent in their judgements about social adjustment pre and post injury.

Hoad et al (1990; CA0019: medium) was actually outside our remit (pre-1993) but is included here as it is a central text in this field. The focus is on the meaning of SCI for family members (who were primary carers). In this study there were16 wives and 15 parents and a 60% response rate. In terms of the patients' experience in hospital the following are highlighted:
- Lack of privacy for husband and wife to sort issues out together.
- Lack of knowledge about spinal injury among professionals outside specialist facilities [for example those in receiving hospitals (A and E)].
- Views of Stoke Mandeville hospital were generally very positive.
- Availability of some accommodation for relatives is valued.

However there were some reservations about: blunt delivery of negative prognosis; visiting times precluded contact with medical staff which carers would have valued and limited interactions with social workers (though some were experienced as supportive). Someone with whom relatives could have a continuous relationship while person in hospital would be valued. The unquestioning assumption by professionals that carers would assume responsibility for care was not liked. Sensitive negotiation of caring activities is needed. Teaching sessions about physical care were, if they happened at all, generally too little too late. Bowel evacuations were a problem which should be openly but sensitively discussed, and taught to those who were going to do it. Two thirds of carers rated information provision inadequate. There was a lack of information on benefits, services,

physical/emotional impacts of injury, also sexuality and fertility. Some carers would have liked access to counselling. Post discharge the following were mentioned; having to change their role; the extent and meaning of role change influences how people perceive their lives; the importance of understanding the experience of the individual in the context of their social environment and the number of physical caring tasks performed tended to decrease over time (compared with immediate post discharge) except aid with bowel management and 'organisational' management. Also there were decreases in the percentage reporting disturbed sleep (1 in 4 at most) and a decline in leisure and social activities outside the home (for the majority). Inaccessible buildings were given as one reason, along with lack of toilets suitable for disabled people. Holidays are problematic. Many carers felt initially unprepared for extent of care which would be required, however just over half said the amount had decreased since discharge. Uncertainty was expressed over how much the person should be expected to do for themselves. 'A number' expressed a desire for counselling. A few had paid privately for it. Carers expressed some worries about the future and their own ageing. Also concern was expressed about keeping up care among those who were older. Most felt there had not been negative effects on children or siblings. Generally it was not an expectation that they would help with care, though they did some tasks they might otherwise not have done. Sometimes there were benefits to the family (for example from the father being around more). On the whole people reported the quality of the relationship with their injured spouse to be unchanged, though there were a few reports of deterioration, and a few of improvement. It was also noted that carers bear the brunt of any emotional outbursts/frustration and so on. Parents caring support each other (mostly) in relation to role change: it should be noted that this study included wives only, no husbands. Half took on more house maintenance, car maintenance and so on. A few of the husbands (with SCI) did more childcare than they had before. How much this mattered depended on how rigid gender divisions had been before injury occurred and what expectations prevailed in the social environment. Carers commented on the need to be aware of the possibility of taking over too much. Parents felt less role change but some had anticipated changes in retirement like greater freedom and more breaks which they now did not get. Informal networks are generally important sources of help/support. Public ignorance of spinal injury is a problem. Relatives usually have no real idea what is involved. In relation to community services there was a general lack of recognition of carers needs. GPs were variable but in general lacked specialist knowledge as well as detailed understanding of what routine care entailed. 62% were receiving service from district nurses but these were variable. Some were regarded as excellent. Timing services to fit with carers needs was often problematic. They are reported to be too happy to

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leave things to carers. It was found that District Nurses might not lift or change catheters because of 'risks' which carers were expected to bear. Fleeting contact with social workers was reported- most carers in the study (80%) were currently not receiving services. Few carers were getting domiciliary care. Some resentment was expressed about strict demarcation (for example no help with the family ironing or cleaning of communal areas like the living room), also about restrictions on the tasks they would do. People believed more physiotherapy might be helpful, but none got any (once out of hospital). Difficulties were found in accessing suitable respite/breaks. Spinal Injuries Association was helpful to those who belonged. None belonged to carers organisations, (but this was the late 1980's). In relation to housing: half had moved since the accident. 7% were not happy with current accommodation. There was variation in quality of the adaptations service and Occupational Therapists. They experienced long waits for work to be done when needed quickly and had difficulties in getting poor or inappropriate work rectified. Having some financial resources helped in being able to have some control. Long waits were experienced while compensation claims were pursued: 39% had pursued a claim, (a few more thought they should have). Most found this a struggle, especially when outside their previous roles. Problems arose when Local Authorities refused to provide adaptations because the case is in progress. In relation to equipment: 64% felt they had what they needed. In respect of employment and income there had been effects on the carer's career for some (percentage in work dropped from 78 to 45), lost promotion prospects, or own business. Others (few) took up work. Loss of income was usually greater than the eventual compensation, but financial hardship is greater for those who do not get compensation.   The report contained accounts of doing without entitlements for years before finding out about them.

The only other UK study, Holicky et al (1999; CA0285: low) was rated low and was a longitudinal study that describes 225 individuals with spinal cord injury (SCI) and assesses how marital status influences their quality of life. With this focus, the carer experience can only be inferred at best. Results suggest that married individuals (of either gender) with SCI tend to enjoy better quality of life than those who are not married. This ignores the impact of the condition on the carer.

Other Locations
Only one T1 study was found. This was the medium rated Lapham-Randov (1994; CA4241: medium) USA study in which the author writes as both a carer of a spouse with SCI and a health professional (nurse and case manager). She describes the

experiences of her family following a SCI to her husband Allen in a motorcycle accident. The following are noted as important:

- The emotional impact on the family: grief, worries about housing and work, worries about bladder and bowel problems, fear of future uncertainty, and the need to attend to children so that 'we had no time to reflect much about ourselves'.
- Getting through physical rehabilitation: in particular finding rehabilitation beds and even finding physicians who had significant knowledge of SCI.
- Learning: 'gaining a knowledge and understanding of rehabilitation resources and SCI issues has been a long and evolving process'.
- The importance of 'encouraging independence', through not helping too much, house/vehicle adaptation and the use of a service dog. Also, the author suggests that Allen's quick return to paid employment helped the family become a 'regular family' again.
- The importance of maintaining social and recreational lives.
- The importance of dealing with a shift in economic status (although not too downward in this case).

In terms of T2 studies, highly rated, five were from the USA and one from Hong Kong. Alexander et al (2002; CA0323: high) studied (USA) mothers with spinal cord injury and the impact it has on marriage, family and children's adjustment. The study evaluates how mothers with SCI adjust to parenting, the marriages and families. It does not have any focus on the carer-recipient dyad. However, there was one relevant finding; that partners of mothers with SCI expressed more life stress than partners of non-disabled mothers. The stress was due to situational circumstances beyond their control (that is, the impairment).

Elliott (2001;CA0279: high) studied carers' social problem solving abilities and their relationship to adjustment in the first year of care-giving. Relevant findings were:
- Carer negative orientation assessed during inpatient rehabilitation is an indicator of subsequent carer adjustment over the first year of care-giving
- Carers with higher negative orientation towards problem solving may show greater distress and depression
- Negative orientation in the carer impairs cognitive problem solving performance
- Carers who have more cognitive- behavioural resources exhibit fewer emotional difficulties adjusting to their role

- Carer problem-solving abilities predict emotional and physical health of carer and recipient

In terms of implications for healthcare this study suggests that interventions are required to help family carers address the everyday routines and tasks needed to run a family.

Weitzenkamp et al (1997; CA0290: high) noted that for many chronic conditions/illnesses there is a body of literature that considers the burden on spouses under headings such as emotional upset, role overload and health issues. They wanted to discern whether such findings are applicable in spinal cord injured patients and their spouses. They reason that since SCI sufferers are often younger adults there may be important differences in how people cope. Participants (n=124) were taken from a longitudinal study into long-term SCI outcomes. The majority (90%) were women. Four established rating scales were used to measure stress, depression, life satisfaction and quality of life. All were subject to statistical analyses. The overall purpose was to quantify how spouses were feeling. On depression it was found that spouses caring were generally more depressed than the injured partner (and more depressed than non-caring spouses). On quality of life and individual needs it was found that caring spouses rated the importance of having children higher than the injured partner. Further analysis showed that it was caring spouses only (n=80) who accounted for these differences (that is spouses who didn't perform a caring role reported no difference in needs, depression or quality of life). Caring spouses reported significantly higher stress, burnout, anger and resentment and poorer well-being. Despite the equal split between injuries incurred pre and post marriage (38/42) the only discernible difference was that spouses of partners who incurred the injury after marriage complained of more fatigue. The authors highlight the point that outside help in care-giving will ease the burden only if it is care-giving and not the severity of the injury that causes problems. They are also cautious about the gender imbalance (only 10% male in the sample) and the overall sample size.

The last USA highly rated study, Shewchuk et al (1998; CA288: high) investigates the developmental trajectories of health outcomes in carers of patients with SCI. It finds that care-giving can be seen as a developmental process over the initial year. The study found that anxiety is the best predictor of variability in the initial levels of physical symptoms reported by the carers. Physical symptoms also predicted anxiety and depressive behaviour in the carers. Younger carers experience more anxiety and low positive affect initially. Depressive behaviour was associated with lower positive affect and the authors suggest that this may be due to restricted social contact. Over time it is the emergence of expressive support that is the best

predictor of change in depressive behaviour and anxiety among the carers. Where more support is provided carers experience less anxiety and depression.

The final highly rated study in this group is by Chan (2000; CA0283: high) from Hong Kong and it set out to examine the sources of stress and the patterns of coping of spouses of persons with SCI in the Chinese population in Hong Kong. Sources of stress identified were: health issues, family/marital interactions, care-giving burden and work due to conflict between care-giver and employee role. There were three identified coping models:

- Externals: spouses with limited coping strategies and limited social support. had higher depression and care-giving burden and were considered the 'high risk' group. They were also characterised by being older with a longer period of marriage

- Internals: spouses with adequate coping strategies and social support. The 'well adjusted group'. These spouses scored low on care-giving burden, depression and social role dissatisfaction

- Multi-controls: mid-range coping strategies and adequate social support. These spouses had mid range adjustment scores and lower scores for depression and emotional care-giving than spouses in the external group. They were characterised by being younger with less years of marriage than the 'externals'.

It was found that the spouse and persons with SCI experience the same processes of stress and adjustment. It is proposed that rehabilitation professionals need to attend to both patient and spouses' needs to ensure best therapeutic results. Counselling was advocated. The article also highlights that services need to be culturally relevant for Chinese persons with SCI and their spouses.

In terms of medium rated T2 studies from the USA, Elliott et al (1999; CA0286: medium) considered the impact of carer problem-solving abilities on the patient's adjustment and physical well-being. Relevant findings were:

- There is a link between the problem solving abilities of the carer and patients' psychological and health outcomes

- Impulsive/careless problem solving in the carer was associated with psychological adjustment on discharge and health outcomes at one year.

- Family members' characteristics impact on patient's reactions to severe disabilities. Rehabilitation professionals need to consider psychological interventions for family carers with early detection of those with impulsive/careless problem-solving traits.

- Patients in the study who experienced difficulty adjusting appeared to do so due to an awareness of their carers' difficulties with coping.

Richards (1997; CA0289: medium) reported on a study of 65 care-givers who completed questionnaires whilst the patient was in hospital, at one month, at 6 months, and one year post discharge. Both descriptive data and 'hierarchical linear modelling techniques' indicated high levels of distress which increased over time.

Su et al (2002; CA4281: medium) examined the experiences and perceptions of older carers of people with SCI in the community and implications for service delivery. Key findings were that: All respondents had had to change their lifestyle in response to SCI including reduced social life and holidays, no personal time, loss of contact with friends. Carers experience having to plan ahead to leave the house and family have to make appointments to see them. Wheelchair accessibility has to be part of their planning. Sleep disturbance is a common experience due to providing physical care during the night. Financial strain was described. Inability to have a sexual relationship was highlighted. Carers experienced the dependence of the person with SCI and the prioritisation of their needs. Carers experience negative changes to their health and experience stress-related emotions. Emotional distress/stress was described due to changes in physical abilities of the person with SCI and grief for their loss of physical identity, changes in the person with SCI's health and their frustration and anger. Carers reported worry about leaving the person and what will happen in the future. Other feelings of disappointment, reduced motivation, mental tiredness, and feeling sorry for yourself but also some positives were described. The impact of change over time was described as improving by some people in the study while for others it stayed the same or worsened. Carers worried about the future and all concerns were for the person with SCI. Carers described coping through help from family/friends and through distraction. The person with SCI's positive attitude helped them. Some did describe closing down emotion as a way of coping. There was a variable response to the support from SCI services with some carers having assistance and others being uncertain if they have had any support. Carers are helped by paid carers and respite services. They felt a crisis help line would have been useful and more services to help with household tasks. The study identifies the following strategies for support services for carers of people with SCI:
- Encourage carers to identify and acknowledge their own physical, social and emotional needs
- Identify and incorporate carers' needs and future plans in the long term plan for the person with SCI

- Provide carers with counselling services and educational programs on stress and time management
- Assist carers in regular health promoting behaviour
- Ensure carers are trained in manual handling
- Assist carers to engage in leisure and personal interests to promote a balanced lifestyle
- Assist carers in extending their social network by establishing links with support groups and so on
- Carers need to be encouraged to access services themselves not just for the person with SCI

The final medium rated study from the USA, Kreuter (2000; CA4118: medium) summarises literature on the impact of spinal cord injury on patient-partner relationships: the effect on those patients who have an existing relationship at the onset of SCI and the effect on the chances of single SCI patients in establishing a relationship. Partner experiences are not considered although the paper does call for future systematic research to put both the patient and partner problems into perspective and research into predicators and reasons for divorce after SCI.

Chan et al (2000; CA0280: medium) (Hong Kong) is a cross-sectional retrospective study which looked at the impact of care-giving on the spouses (n=40) of persons with spinal cord injury (SCI) (n=66). A plethora of psychometric tests (n=9) were applied to data generated via questionnaire and semi-structured interview. The authors note from the literature that a good marital relationship is an important factor in the positive psychosocial outcome for the injured person. They also note that Eastern attitudes to disability vary from those in the West. Key findings are:-

- Caring simultaneously increases the well-being of the injured person while it reduces it for the carer.
- Caring spouses who were married pre-injury experience more depression than those who married post-injury
- The composition of the extended family often means that the care burden is diluted yet female spouses still feel depressed
- Those couples who experienced marital separation as a result of the injury did so in the early stages. There are implications here for professionals in terms of the provision of counselling services.

The final medium rated T2 study is Chan (2000; CA2646: medium) (China). Confucianism ideology still represents a major strand of Chinese thought. It dictates that the man is the protector of the house and brings health and wealth to the family.

Disability is considered to be careless, ignorant and living inappropriately and is considered to be the consequence of divine punishment – not only for the individual but the whole family. Disability is perceived very negatively in Chinese society. Spouses found the main stresses to be caused by care-giving were feeling trapped, disruption of family interaction, revision of expectations of life quality and social isolation. People with SCI felt they had a very different life and wished they could have the same quality of life as they had before the injury in terms of their relationship with their children and colleagues. They were more likely to have disabled friends as a result of discrimination by non-disabled colleagues. One suggestion for improving the situation is to include family members in the rehabilitation process from the beginning. Good communication could improve the relationship between people with SCI and spouses - professional intervention may help with this thus reducing barriers put up by Chinese tradition.

Only two T2 studies attracted a low rating. The first of these, Boyer et al (2000; CA0281: low) is from the USA and examined 64 paediatric Spinal Cord Injury (SCI) patients and their parents (64 mothers; 49 fathers) regarding post-traumatic stress disorder (PTSD). There were 43 families with data from all three members, which was the sub-sample used for the analysis. Data was collected using measures. The authors report limitations to the study (small sample; no control group; using a self-report measure of PTSD rather than a structured interview). Authors reported various associations between PTS-PTSD and family members, for example mothers' PTS was strongly related to PTS in their children (patients) and their husbands/partners.

The other (also USA) low rated study is Shackleford et al (1998; CA0859: low) which found that males were more likely to have a parent or spouse to assist. Females were more likely to get assistance from a paid care-giver or relative who is not a spouse or parent. However it does not make it clear whether this just means that women are just more likely than men to use carers other than spouses or parents, or that spouse/parent carers are actually a minority group of carers where women are concerned. No actual figures were given.

Summary of carers' experiences of providing care to a person with spinal cord injury (highly rated studies only)

- Partners of mothers with SCI express more life stress than partners of non-disabled mothers and the stress is due to situational circumstances beyond their control (that is, the impairment).

- Carers with higher negative orientation towards problem-solving may show greater distress and depression and negative orientation in the carers impairs cognitive problem-solving performance

- Carers who have more cognitive-behavioural resources exhibit fewer emotional difficulties adjusting to the carer role

- Carer problem-solving abilities predict emotional and physical health of the carer and recipient

- Caring spouses reported significantly high stress, burnout, anger and resentment and poor well-being

- Outside help in care-giving will ease the burden only if it is care-giving and not the severity of the injury that causes problems to the carer

- Anxiety is the best predictor of the variability in the initial levels of physical symptoms reported by carers

- Younger carers experience more anxiety and low positive affect initially. Depressive behaviour is associated with lower positive affect and this may be due to restricted social contact. The emergence of expressive support is the best predictor of change in depressive anxiety among carers

- Spouses with limited coping strategies and limited social support have higher depression and care-giving burden, whereas spouses with adequate coping strategies and social support score low on these items

- Spouses and people with SCI experience the same processes of stress and adjustment. Rehabilitation professionals need to attend to both patient and spouse needs to ensure best therapeutic results

Group B: Carers of people with 'Intermittent/unpredictable long term conditions': Epilepsy

Epilepsy

UK studies

No T1 studies were identified.

In terms of highly rated T2 UK studies, the first is Espie et al (1998; CA0097: high) which details the principal concerns carers have about people with epilepsy, and the development of a useful outcome measure for use in clinical practice. The Epilepsy Outcome Scale was developed as a measuring tool for profiling and quantifying concerns about epilepsy among people with learning difficulties.

The only other highly rated study is Taylor et al (2001; CA00090: high) - a study of patient's aims for epilepsy surgery. The most frequently cited aims (of surgery) by patients and carers were cited as:

- To be working
- To drive a car
- Independence/ freedom/ Socialisation
- Relief from medication
- Change in behaviour [desired by carers on behalf of patients]
- Improvements in personal safety

In terms of T2 medium rated studies, the first is Baker et al (1999; CA0729: medium). The purpose of the study was to discover how well informed patients and their carers are about epilepsy. Data was compiled via self-completed questionnaires. Despite the stated aim of the study the carers' experience is entirely absent from the results and discussion.

The final medium rated UK study is from Loughran et al (2002; CA0316: medium) which is a study of epilepsy liaison nursing and which found that the epilepsy liaison nurse can be key person in supporting patients and their families, providing information about epilepsy and medication, and liasing with professionals to ensure the patient gets appropriate treatment. The Learning Disability Epilepsy Nurse's Forum developed an epilepsy nursing assessment tool which gives information about the individual's condition and acts as template with which epilepsy care plans can be drawn up.

One UK study was rated low. This is Coombes (2001; CA4508: low). It is a brief journalistic report that describes one case in which a teenager is heavily involved in caring for an older sibling who has epilepsy as well as other disabilities. The report highlights the role played by school nurses in providing counselling and advice for this group of carers. The teenage boy talks of the difficulties in maintaining a social life because of the heavy demands at home.

Other locations

Only one T1 study was identified. This is the low rated USA study, Byers (1995; CA4946:) which is a short first person narrative describing a family whose son has epilepsy. The seizures are so severe he needs to be hospitalised. Despite a professional background the mother talks of being totally unprepared for the realties associated with caring for her son. The title, 'One Day at a Time', refers to the constant anxiety of wondering when the next seizure will arrive.

In terms of T2 studies, highly rated, one from the USA is Froese et al (1999; CA00083: high) which uses as instrument (ISIS) to capture data from disabled people about their experiences. Disabled people reported a great need for social relationships, and this also held for 'significant people' (parents in most cases). They reported a need for more respite services. This study is important to give disabled people a voice and enable them to influence policy and decisions. However, the limitations of the study were:
- Participants have mild disabilities, not severe and
- Small and geographically-limited sample

The only other highly rated study comes from China. Kleinman et al (1995; CA0105: high) reported on a consultation with Traditional Chinese Medicine practitioners. It was found that the:
- Burden of patient is family burden. Family members give up work, but are blamed for causing epilepsy
- In Chinese society care of the patient is the responsibility of the family until marriage when it becomes the responsibility of the spouse
- Stigma in school, work, society. Thus patients are confined to home out of fear of disgrace.
- Addressing epilepsy means having interdisciplinary systems between health policy and social policy and social theory.

In terms of medium rated T2 studies, Lee et al (2002; CA00087: medium) from Hong Kong explored factors associated with quality of life and emotional states of the carers of people with epilepsy. The study was well designed and executed, but the findings cannot be generalised to the general population of carers of people in Hong Kong because there was:

- No control group of non carers;
- Sample drawn from a support group and questionnaires completed by people supporting members of a hospital/support facility;
- Homogeneity among carer group – all committed to caring for the person with epilepsy hence no less well adjusted individuals in the sample;
- Small sample size (65)

The study used rating scales of mood, quality of life and intensity of epileptic and psychosocial variables. About half of participant carers reported experiencing less satisfactory psychosocial adjustment than the general population. 22% had severe levels of anxiety and 14% severe levels of depression; 75% had below average scores on the quality of life measure. Contrary to findings of previous studies, care-givers of people with additional illnesses or learning disabilities were not more distressed than care-givers of people with epilepsy only. About 50% of carers reported receiving adequate levels of support – mainly from families but also from agencies. The latter contradicts the common belief that Asian families are reluctant to accept support due to the association between dependency and shame. Factors positively associated with carers' well-being and quality of life were: perceived level of support; and participation in social and leisure activities in the absence of the patient. Older age was a possible negative factor for psychosocial adjustment. In terms of medical variables, achieving better control of seizures was reported as the key to achieving better quality of life for both carers and the person with epilepsy. The researchers signal the importance of using measures of subjective experiences in studies of social and psychological aspects of epilepsy.

The final medium rated T2 study comes from the USA. This is Lane et al (1997; CA0102: medium) which suggests that care-givers of patients who have undergone surgery for intractable epilepsy risk increased care-giver burden regardless of surgery outcome.

Summary of carers' experiences of providing care to a person with epilepsy (highly rated studies only)

- The patients' aims for epilepsy surgery are to be working; to drive a car; independence/ freedom/ socialisation; relief from medication'; change in behaviour (desired by carers on behalf of patients and improvements in personal safety

- Patients report a great need for social relationships and this also holds true for carers (parents in most cases).

- Carers report a need for more respite services

- Addressing epilepsy means having interdisciplinary systems between health policy, social policy and social theory

Group C: 'Progressive long term conditions': Cerebral Palsy, Motor Neurone Disease, Multiple Sclerosis and Parkinson's Disease

Cerebral Palsy (CP)

UK studies

Only three studies were identified relating to cerebral palsy. None of them were highly rated. The only UK (T2) study, Mir and Tovey (2002; CA46: low) was rated low as it was felt that carers' views were heavily mediated to the point of exclusion by the central aim of the study which was to investigate whether or not cultural competency exists in professional services directed at South Asian carers of people with cerebral palsy.

Other locations

Magill-Evans et al (2001 CA82: medium), a Canadian T2 article confidence rated medium, aims to determine if young people with CP and their families have different experiences to families with no disabled adolescent. They found that there were no significant differences although it was noted that fathers and siblings may be most affected by having a disabled adolescent in the family.

Darrah et al (2002; CA2188: medium), also a Canadian T2 study, identified themes consistent with previous research. Families were frustrated and reported negative experiences of service provision (health, education, recreation, employment, transportation and housing), and often felt they were not listened to or valued. Bureaucracy and lack of funding may contribute to service users and their families not obtaining full or adequate information.

Summary of carers' experiences of providing care to a person with Cerebral Palsy (medium rated studies)

- Carers frequently have negative experience of service provision and often feel they are not listened to or valued.

- Bureaucracy and lack of funding may contribute to service users and their families not obtaining full or adequate information

- Fathers and siblings may be most affected by having a disabled adolescent in the family.

Motor Neurone Disease/Amyotrophic Lateral Sclerosis

Twenty-one articles relating to Motor Neurone Disease/Amyotrophic Lateral Sclerosis were identified. All were categorised as T2.

UK Studies

Jenkinson et al (2000; CA273: high) examined the quality of life of people with MND and their carers in Europe. The key findings from this study are that the health status of the patient has a dramatic effect on the health status of the carer and that services and MND charities need to take into account the impact of MND on the carer as well as the patient.

CA0001 (2002; high) and CA0002 (2003: high) are reports produced by the Motor Neurone Disease Association (MNDA) on the results of a questionnaire completed by carers of people with MND. CA0001 reports on the findings from people who had previously cared for people with MND, whereas CA0002 reports on current carers. The combined findings report that carers have significant issues to resolve around diagnosis and how it is handled by professionals. Carers feel they need much more information on what exactly MND is and how they can cope with it. Carers would also like much more guidance on benefits and professional help and more input on the provision of services and equipment. It was felt that services had to be 'fought for' with the result that many individuals felt they received too little too late. The issue of paying for equipment was prominent amongst former carers. Greater carer involvement in the decision making processes that accompanies treatment was seen as beneficial. It was felt that specialist organisations should be more proactive in supporting carers and that support from professionals should be regular rather than restricted to emergencies.

Goldstein et al (1998; CA0276: high), reported that carers experience anxiety and depression partly linked to functional incapacity of the person with MND, that carers level of strain correlated with perception of loss of intimacy predicted by cognitive/behavioural and communication changes and carers anxiety was greater the shorter their partner's duration of symptoms. Carers used more problem solving and orientation coping strategies when ambulation and alertness was more affected

Grice et al (1995; CA0026, medium) reported that palliative care is the mainstay of treatment currently available. This clinical assessment of disease progression was required every four weeks. Other issues arose therefore there was a need for a separate care facility which was established with support of George Barton Motor

Neurone Disease Trust, which serves 1.8 million residents in Lancashire and South Cumbria. The co-ordination of a multidisciplinary team was felt to be important, for example that referrals are made to the appropriate team member depending on the patient's specific needs.

Mowat (2000; CA0013: low) is an individual account of one carer's experience (hence its low rating). However, generalisable points that emerged from this piece include that the pace of change with disease progression means there is a need for constant adjustment as previous solutions no longer work. It was felt that services are not particularly good at coping with this. Communication is a key issue for patients and carers, particularly as the temptation to infantilise the person with MND is acknowledged.

Goldstein et al (1999; CA0274: unrated) reported that families noted a lack of support from the doctor around the emotional impact of the diagnosis. Social support is valuable in helping carers cope with the stress of caring for someone with MND. In the terminal phase families needed medical support. Families expressed frustration over the difficulty of getting satisfactory medical information and felt abandoned by the medical services once the diagnosis is given. Carers indicated that they had little knowledge available to them about MND or available resources. Families were concerned about the likely course of the illness but expressed helplessness witnessing the course of the disease and the worsening state of the patient. The families had concerns about the emotional and physical status of the patient and recognised that communication difficulties lead to carer frustration

Other Locations
Bolsmjo and Hermeren (2001; CA0267: high) challenges the view of some professionals in palliative care that people with MND perceive their illness in the same way as do their family carers. Patients and carers differ in how they perceive their own needs, in how they view, judge and evaluate the disease, and how they cope with its progress. In summary, it was found that carers tend to want more information about the disease. They feel insecure and feel a great need to talk about the burden of care. Some carers tend not to want to think about the future.

Bolsmjo and Hermeren (2003; CA0265: medium) reports that carers felt that information about MND and disease progression was not adequate and they did not like the way in which the diagnosis was provided.

The findings in Rabkin et al (2000; CA0156: medium) report a contradiction to the commonly held view that rates of clinical depression are higher amongst patients with

MND and their carers than the general population. It was found that carers are as likely to be clinically depressed as patients and access to psychiatric treatment seemed to be inversely related to care-giver 'burden'. Perceived 'burden' was positively associated with finding positive meaning in care-giving. These findings point to the importance of responding to psychological distress in carers, not only for their own sakes but because this may lead to an improvement in the mental health of patient.

Moss et al (1993; CA1471: medium) primarily looks at the benefits of home ventilation for patients, however, relevant carer experiences were that carers found benefit from home ventilation as it prolonged family life but also that it tied them down and was stressful.

Bromberg et al (2002; CA0321: medium) interviewed patients who used artificial ventilation at home and their carers. The issues identified by carers included the inability to influence disease progression and fear about being able to use the ventilator. Support groups were felt to be helpful.

Dawson and Kristjanson (2003; CA0264: medium) identified a number of key findings; the need for skilled, expert, support in the later stages of the disease, that gaps exist in supportive services, notably respite; the need for 'appropriately paced' information and that training for staff in acute hospital settings to improve their knowledge of MND was required.

Ganzini et al (2002; CA0308: low) aimed to chart the health care experience and palliative care needs of individuals with ALS in the final month of life. One hundred patients with ALS were interviewed and 91 of their care-givers, about their attitudes toward end-of-life care as well as their emotional and physical sources of suffering. Carers reported that patients do not want to burden their families. Despite this the carers in this survey were spending up to 11 hours per day with their family member. Advance care planning was successful in 88% of cases reported here. Advance directives on the other hand were seen by 50% as being either 'helpful' or having no effect on care. Carers report very favourably on the involvement of doctors in terminal care. There was some carer dissatisfaction (33%) with aspects of medical care (dyspnea, pain relief and general symptom management). Although most carers reported the patient to be at peace near death, distressing symptoms still affect the patient, even in a hospice setting.

Summary of carers' experiences of providing care to a person with MND (highly rated studies only)

- The health status of patients has a dramatic effect on the health status of the carer.

- Services and MND charities need to take into account the impact of MND on the carer as well as the patient

- Services/support provided at the time of diagnosis are important to carers who want more information on what MND is and what benefits and services are available.

- Carers feel they have to fight for services with the result that many individuals feel they received too little too late.

- Carer anxiety and depression is partly linked to functional incapacity of the patient.

- Patients and carers differ in how they perceive their own needs, in how they view, judge and evaluate the disease and how they cope with its progress

- Carers want more information about the disease. They feel insecure and feel a great need to talk about the burden of care. Some carers tend not to want to think about the future

Multiple Sclerosis

UK studies
Only one T1 study (Foley et al 2000; CA0067; unrated) was located in the UK. Foley et al did not receive a confidence rating as the report was not explicitly based upon research however the reviewer felt it contained useful advice notably on the impacts of MS on relationships, intimacy and sexuality. The majority of the report content emphasises the physical and emotional impacts of MS and indicates that carers can find it difficult to switch between the roles of lover and carer.

Three T2 studies were reviewed (Chesson 2002; CA0058; medium, Defriez et al 2003; CA0018; medium and Robinson and Hunter 1998; CA0062; medium).

Chesson (2002; CA0058; medium) reports on interviews with 60 family carers in Scotland. The study found that in most cases services were provided only where the person with MS was highly dependent and few carers indicated that comprehensive packages of care, including health and social care, were in place. Main concerns related to delays in services being provided, the need for information and difficulties in accessing services and allowances. Carers would have welcomed a more proactive approach on the part of service providers, as they or the person they cared for had been reluctant to seek help. Carers described feeling 'abandoned' at the time of diagnosis, even though they felt that their lives were affected too. Over two-thirds reported a lack of information at this critical point. Information was required on benefits, housing adaptations, equipment, relevant services, the disease and coping strategies. Some carers reported a need for emotional support and counselling. Several carers suggested that health professionals lacked knowledge of MS. Needs relating to housework and personal care were more likely to be met than those of a psychological nature. It appeared from the interviews that carers were more likely to feel 'on top of the situation' and less likely to highlight their own unmet psychological needs where services were in place. Several carers rated services very highly. Occupational therapists were often identified as particularly helpful. Even where regular help was obtained, carers often provided considerable assistance themselves and/or paid for additional services (for example cleaning) or items of equipment. Carers expressed dissatisfaction with respite care. It was seen as unsuitable for care recipients, who were then unhappy (and so were carers), one got an infection whilst using hospital respite facilities and came out 'worse than he went in'. Other criticisms included that respite was boring, with little stimulation or activities.

Defriez et al (2003; CA0018: medium) is a 'multi-stakeholder study' on the provision of care for patients with MS. Carers were involved in some interviews with the following findings:

- There was a general consensus that there was a lack of continued and co-ordinated care or no-one to overlook the whole process.
- Many carers were unaware of all their benefit and social service entitlements.
- The impact on carers of having a partner or relative with MS varied enormously.
- The majority of carers found caring for someone with MS time consuming and tiring.
- Many carers had to change their lifestyle.
- Several carers had retired early to care for their partners.
- Several carers had moved house to accommodate their partner's needs.

Robinson and Hunter (1998, CA0062; medium) is a draft report for the MS Society. Information was collected in six different areas of the country from people with MS, their carers and professionals. Male carers have particular difficulty in convincing professional staff (social services and nurses, for example) of their competence in relation to domestic and personal care. Carers face a more general problem in convincing professional staff that they have their own particular expertise based on experience. The impression of many carers is that, in most of their contacts with service providers, the main aim appears to be to prevent them from getting the services, aids and adaptations needed, even though they also appear to be eligible for them. There is too much 'battling with bureaucracy'. There are major co-ordination problems within and between health and social services. Services often appear to lack the 'common sense' needed to be able to adapt rules and procedures to the everyday needs of carers. There is concern about the increasing discrepancy between the rhetoric of 'patient care' delivered through 'patient's or 'client's charters' and what many carers experience in practical terms as a worse service on the ground. For example services, and access to those services, has not changed at all, and in resource terms might even have become worse. 'Out of hours' services can be very poor, yet MS and its problems are experienced 24 hours a day and have to be managed on that basis. Finding an advocate is often seen as the only way through the system, but it is not always possible to find one who supports carers' views rather than their own. Respite care is often welcomed in principle, but is a double edged sword in practice as concerns are expressed about the nature and quality of care in these settings. Carers might wish to join the person with MS in respite care and share the 'break', but this often proves difficult or impossible, which can put an additional strain on an already stressed relationship. Day care may be

undertaken as a 'warehousing' process for people with MS. Staff qualifications, experience and commitment may be very low, especially in some local authority day care centres. Medical and health problems may not be recognised or managed effectively in day centres. There can be major problems when younger people with MS are mixed with older people in respite care facilities. Carers can feel forced into seeking long-term residential care because of the lack of (modest) additional services in the community, resulting in a significant breakdown in the relationship and much extra public cost. Information needs are one of the most substantial and long term needs of carers. The communication process at the time of diagnosis is particularly important, and it is not helpful if doctors are over-protective and reluctant to give the diagnosis at an early stage, or communicate it in such euphemistic terms that the carers (and patient) do not know what has been communicated. A fast track to relevant information is important at this early critical stage, as it can impact on the whole process of dealing with MS in the first few months, and possibly the first few years. Carers wanted accessible and relevant guidance and support independently of government agencies, health trusts and authorities. Greater attention needs to be paid to establishing a standard and supportive information system at the time of diagnosis. Community based systems of information are very patchy and subject to change through changing policies and resource allocations. Male carers often felt that support groups and similar activities were not for them. They wanted immediate and practical help and a break from MS, rather than to keep talking about the disease and associated problems and issues. The value of counselling was questionable. For the most part, carers' immediate concerns were very practical. Many carers managed dealing with the problems and issues of MS through informal channels and processes, rather than through the more formal structure of counselling that many professionals see as a key first requirement.

Other Locations

Five T1 articles from outside the UK were reviewed, of these two were from New Zealand (Gregory et al 1996; CA1143;medium, Knight et al 1997; CA0223; medium) and three from the USA (Good et al 1995; CA1171;medium, Sato et al 1996; CA1065;low and Cohen et al 1997; CA0940; unrated,).

Gregory et al (1996; CA1143: medium T1) is based on a survey carried out in New Zealand with people with MS (80) and primary carers (31). The paper reports that the impact of MS on carers was found to be considerable; adequate support from external agencies was not frequently present; the carer's quality of life deteriorated over time, and mirrored that of their family member with MS, to a considerable extent. Whether carers felt they had a normal life outside caring was a strong predictor of

adjustment to their circumstances. The key role of nursing is emphasised in the paper, though this is reported as an 'impression' from the study rather than an explicit finding. The study points to the need for more consistent, and better resourced, policies and services for carers. Of particular interest to UK policy makers is the NZ attendant care programme, funded by the Department of Social Welfare, which facilitates the continued employment of some care-givers who might have to reduce working hours or withdraw from employment. This appeared to play a valuable role, even if it was not universally available.

Knight et al (1997; CA0223: medium, T1) aimed to document the nature of the burden experienced by spouses of people with MS and to assess whether the factors mediating burden were similar to, or different from, those experienced by care-givers of people with other degenerative conditions. The behaviours/impairments causing most distress to spouse carers were found to be motor problems, sudden mood changes, partner upsetting other people, incontinence and pain. Consistent with the Lazarus and Folkman model of coping, personal coping abilities and satisfaction with social support received were found to mediate the burden of care, and accounted significantly for individual differences of burden.

The purpose of the study reported in Good et al (1995; CA1171:medium, T1) was to investigate the gender differences in the social support of spouse carers of people with MS. Strong gender differences were found. Female carers scored significantly higher than males on the total number of resources available, perceived social support and the perceived availability of friends and self-help groups. The authors see the study's importance as lying in its potential to promote effective nursing interventions with the care-giver of the person with MS – though it has similar implications for those assessing needs for, or providing, social care. If the nurse uses knowledge about gender differences (particularly men's lower access to resources and social support), then the care-giver will be strengthened and it will be less likely that families will deteriorate, or even disband, in the face of chronic illness. However, they also draw attention to the potential of tools for assessing the strengths of networks and social support in general (for women as well as men) and intervening to develop these.

Sato et al (1996; CA1065: low, T1) details the use of an MS needs assessment tool. Relevant findings from this study include the importance for carers of breaks/relief and of support particularly with household chores. It was noted that nurses could help by teaching carers about the disease process and providing information on new developments.

Cohen (1997; CA940:unrated, T1) provides a care-giver's account of the strategies she developed, and found useful in, seeking help when the demands of caring had become overwhelming. The strategies she described including writing 'asking-for' letters, calling family meetings to recruit more help and networking to talk about the situation and seek practical help and emotional support.

Turning now to T2 studies, 20 were identified, of which seven were rated high, nine medium and five low (one was unrated). The majority of the studies are from North America (thirteen from the USA and two from Canada), while five were from Europe (three from The Netherlands and two from Italy) and one from Australia.

Gulick (1995; CA0228; high) identifies the coping strategies employed by the spouses/significant others in caring for people with MS. Carers tend to employ a systematic planning approach in caring for people with MS but some can become overwhelmed and need to withdraw temporarily. Dependency determined coping strategies. With more dependency more planning strategies were used and although seldom used significantly more distancing and escape/anger strategies were used pertaining to recreation/socialising and communication. Carers with their own health problems employed more distancing strategies. Spouses employ more ambivalent coping strategies compared to significant others possibly because spouses feel more responsibility for their partner's dependency needs. Significant others use more distancing and escape/anger strategies than spouses suggesting less commitment. Nurses need to explore how dependency needs are met and their impact on the family to enable effective information and counselling of the family.

Weinert et al (1993; CA0020; high) looks at the support systems in place for spouses of people with MS who live in rural areas. It was noted that there tends to be fewer services in rural areas and that these are more likely to be refused in preference to informal caring.

Hakim et al (2000; CA0219; high) identifies a strong correlation between the severity of the patient's disability and carer depression anxiety and psychosomatic conditions. The carers experienced changes/impact on their careers, that is, loss of job, becoming part-time, not putting in for promotion or change to a lower grade.

Chipchase and Lincoln (2001; CA218; high) report a two stage study that found that carers of people with MS identified the changes in the person with MS (from their former self) as a source of stress. Also identified was a need to change their own personal plans and financial strain. Difficulties flowing from problems with memory

and independence in activities of daily living were found to be a predictive of a strained carer.

Aronson et al (1996; CA220; medium) found that carers perceive greater care burden than the care recipient. Anderson (2001; CA4362; medium) is based on a literature review and the regular chapter visits within the MS society in Ontario. It suggests that the 'dilemma of disability faced by male care-givers' can be summarised in three observations.

1.   Male care-givers are expected to simultaneously be the care-giver, the primary breadwinner, the childrearer, and to do so without showing any signs of weakness (visible symptoms of stress or emotion).

2.   Male care-givers must deal with the perception that as men they are incapable of taking the role of primary care-giver and cannot be trusted to take on such responsibilities. This presumption is particularly predominant amongst professional female care-givers.

3.   There is a shortage of male care-giver role-models or mentors.

This can result in male care-givers asking for and receiving less social and professional support than their female counterparts.

Young (1994; CA0024; medium) contains findings from interviews with carers conducted as part of a wider study investigating many aspects of MS. The majority of carers (predominantly spouses) were under great stress but had no plans to leave their partners. There was a strong sense of commitment to caring, but little sense of fulfilment in doing so. Contact with the medical research team was appreciated. It was noted that carers often pay a high price in terms of their own health.

O'Brien (1993; CA1466; low) found that carers with more dependent care recipients were less likely to promote their own health and look after their own health needs therefore nurses need to be vigilant for this and need to develop interventions that guide carers in providing care to help ease their burden (particularly men).

Landoni et al (2000; CA0225; unrated) reviews the author's experiences of group psychotherapy with patients and their families. The paper observes that with good family relations there is a low level of criticism and hostility and consideration of patients needs but where there are poor family relations, the disease becomes a vehicle for critical and hostile attitudes.

Turning to the European articles, Pitaro and Reggio (2001; CA0314; high) reports on the first 'bottom-up' study evaluating the cost of MS in Italy looking at direct and

indirect costs. The costs were significantly higher for male patients who lost more work and this increased with age and disease progression. Care-givers' and patients' loss of work is significant to the Italian economy because unpaid carers still predominate in Italy.

Ybema et al (2002; CA0230; high) adopts a psychological perspective in order to explore the role of 'perceptions of inequity as mediating determinants of burnout' among partners of patients with severe illnesses (cancer and MS). The subjective notion of burnout is here preferred to other measures which collapse many variables into one scale. The authors then hypothesise that carers who experience underbenefit and underinvestment in their relationship will be more prone to burnout. They also appreciate that marital quality as a variable might influence perceptions of inequity in the relationship and so cast it as antecedent in determining burnout. By doing so they note that other causal/theoretical constructs are available. (The notions of underbenefit and underinvestment were constructed around domains identified by the participants themselves). Partners of cancer patients rated the quality of their relationship significantly higher than those with partners who had MS. Care-givers who regard their relationship in a negative light experience more inequity and the relationship between inequity and burnout is identical between the two groups.

Battaglia et al (2000; CA0541; medium) point to the large body of evidence that suggests that MS is one of the most expensive neurological diseases as a result of its early onset, long duration and significant impact on employment.

The sole Australian study, Pakenham (2002; CA0231; medium), sought to develop a scale relating specifically to carers' modes of coping with the care of relatives with MS. Generic scales, and scales adapted for caring for people with conditions other than MS do not explain a sufficient amount of the variation between care-givers of people with MS to be useful for this group. The scale developed confirmed previous research on the relationship between some coping strategies and adjustment. It also extended such research by revealing new relations between coping and adaptation to MS care-giving.

Duijnstee and Boeije (1998; CA0764; low) highlights the importance of home care nurses defining family carers as co-workers who experience significant problems in caring and adjusting to change in the relationship and the central importance of tailoring both practical and emotional support to the specific 'chemistry' of the relationship and the carer's individual needs.

Summary of carers' experiences of providing care to a person with Multiple Sclerosis (highly rated studies only)

- Carers tend to employ a systematic planning approach in caring for people with MS but some can become overwhelmed and need to withdraw temporarily.

- Nurses need to explore how dependency needs are met and their impact on the family to enable effective information and counselling of the family.

- There is a strong correlation between the severity of patient's disability and carer depression, anxiety and psychosomatic conditions.

- The carers experienced changes and impact on their careers, that is, loss of job, becoming part-time, not putting in for promotion or change to a lower grade.

- Changes in the person with MS (from their former self), cause carers stress. There is a need to change personal plans and deal with financial strain. Difficulties flowing from problems with memory and independence in activities of daily living are predictive of carer strain.

Parkinson's Disease (PD)

UK studies

Three studies were categorised as T1. Politynska et al (undated; CA0005: medium) presents preliminary data from a larger study designed to examine the impact of looking after someone with Parkinson's Disease, who in this case was usually a spouse. The findings are based on three scales (General Health Questionnaire, GHQ; Geriatric Depression Scale, GDSC; Gilliard Strain Scales, GSS) used to determine carer strain and distress. The results indicate that carers' well-being is influenced more by depression in the sufferer than by any physical symptoms and that carers suffer stress as a result of caring.

Politynska et al (undated; CA0006;unrated) is a literature review commissioned by the Parkinson's Disease Society and as such was not given a confidence rating. The report identified a number of attributes that influence strain on carers: gender (women are more likely than men to be stressed as they are less likely to accept formal help), quality of past and present relationship with patient and the degree of dementia the patient has (this is more significant than physical deterioration). It was noted that levels of carer strain do not necessarily correlate with the level of care-giving and that experiencing strain does not necessarily result in carers handing over their caring responsibilities to others.

McCall et al (1995; CA0007;unrated) is an article produced by the Parkinson's Disease Society's Information Officer. The article recognises the important role played by carers and suggests that valuing their experiences and involving them as partners in care will greatly improve the quality of life of carers and people with PD.

Turning now to T2 studies, 11 were reviewed. Miller et al (1996; CA0247: high) evaluated the effects that caring for someone with PD has on the carer. Carers have raised levels of distress and/or psychological disturbance. Physical cares contribute to objective burden. There was no link between distress and social support and depression in the person with PD was closely linked with distress and psychological disturbance in the carer. It recommends that services need to support the effective treatment of depression in people with PD.

Chesson et al (2000; CA0004; high) recognises the valuable contribution made by informal carers and was particularly focuses upon the contribution carers make to treatment. Based on information compiled via questionnaires and semi-structured interviews with carers the article reports that as well as undertaking the many

physical tasks related to the activities of daily living carers also report many examples of participating in activities more closely related to a professional/ therapeutic role (for example medication and exercise). Some carers reported that for practical or emotional reasons (their own poor health or the nature of their relationship to the sufferer) they did not want to be involved in these aspects of caring. Some people with PD did not want carer involvement in this area. From the professional perspective the role of the carer is recognised and valued, for example, carers can continue with therapy between appointments/visits and can feedback to professionals on how successful interventions have been. The relationship between the carer, the sufferer and the professional can be altered as the levels of intervention are adjusted. The study recommends that careful monitoring of carer involvement goes on to ensure carers are not overtaxed, that professionals remain sensitive to changing relationships between carer and sufferer and that professionals may require training to achieve this.

Thomas and Sweetnam (2002; CA4386: medium) describes the establishment of a 'Health care for carer's project' with around 1,000 carers in Cornwall. Carers stated that they wanted carer information groups throughout the county, a carer assessment tool so that they could undertake an assessment of their own 'needs' at a convenient time, a carer voucher scheme to buy respite care and 'a resource file specific to PD for all local GP practices so that they could fully understand the needs of people with PD and their carers'.

Lloyd (2000, CA0076: medium) reported that the majority of Parkinson's Disease patients were cared for by a relative with no outside support, that the level of outside care provided was not influenced by the health of the carer and that carers lack information about services. A possible solution to the difficulties of multi-agency working is for the service user and the carer to act as the care manager as they have contact with all the different systems.

O'Reilly et al (1996; CA1066: medium) reporting on a large-scale quantitative study set out to examine whether middle-aged carers of individuals with PD experience adverse effects on their social, psychological and physical health compared to the rest of the population. Standard tests measured outcomes on these domains and after statistical analysis it was found that subjective assessment of care demands can often be a better predictor for future ill-health than objective measures of disability. Consequently, General Practitioners should be proactive in identifying those who provide high levels of care.

Other Locations

All the studies identified from outside the UK were categorised as T2 and fall into two groups, North American and European based studies.

Looking first at the North American articles, Mcrae et al (1999; CA0259: high) looks at the aspects of caring that cause distress among carers of people with PD and explores the relationships between stress and family functioning. They found that stressfulness is related to aspects of care-giving that contain intrapersonal factors, for example, anxiety and fatigue. Aspects of care-giving that caused less stress appeared more interpersonal, for example, the patient's behaviour towards the care-giver. The article highlights that professionals need to be aware of the stress factors for carers and plan services appropriately. Assessing stress and well-being of the carer should be a priority for health care providers to identify and provide services for at-risk people

Wallhagen (1997; CA0263: high) examines the relationship of patient perceptions of control over aspects of disease with carer burden and well-being. Carers well-being was higher than the patients'; carer burden was associated with severity of PD but not well-being and perceived patient control over symptoms was linked with carer well-being and less carer burden. Therefore, helping the patient and family in managing symptoms will enhance perceived control and is an important aspect of quality of care which may enhance carer and patient well-being. Carer beliefs about the illness and its management need to be assessed as they influence patient and carers' well-being

Waite (2000; CA4617: medium) summarises aspects of the carer's perspective. The stages of physical decline are well described alongside the adaptations the carer has to make. It is suggested that pre-morbid personality and, in the case of couples, their relationship, can affect the way the patients view themselves. The satisfaction the patient feels with the support is often more important than the numbers of people involved in providing it.

Konstam et al (2003; CA0251:medium) noted that the literature regularly highlights the psychological cost to carers who look after family members with chronic conditions. Rating scales and checklists were completed by 58 carers and the results subjected to statistical analysis. This study aimed to account for why and how some care-givers experience benefits in performing the caring role. Specifically the study investigated how carers find meaning in general terms as well as finding meaning directly related to their caring. The authors hypothesise that those who can

find meaning in these two areas will have increased well-being. The results suggest that finding meaning in general is more important than finding meaning specific to the caring role. This is at odds with the emphasis in the care-giving literature that focuses on helping care-givers to develop coping strategies. The authors note that interviews would enhance the data since this would allow for more exploration of how carers experience their world. This would allow professionals to target interventions for carers.

Berry and Murphy (1995: CA1184: medium) explored the relationship between disease stage for people with PD and well-being in carers. The key findings are that carers' negative reports of their own health were associated with reports of their partner with PD's diminished physical functioning, carers social functioning declined as care needs increased and that carers social, psychological and financial well-being were associated with length of marriage and level of education. Longer marriages and higher levels of education seemed to sustain the carers. Therefore, health and social services need to recognise that the home is the centre of care. Services need to augment home-care fitting in with family routines and lifestyles during all stages of chronic illness.

In Edwards and Scheetz (2002; CA0305: medium) the care-giving experience is reported exclusively in numerical/statistical form (based on the Zarit Burden Inventory). Women in this study reported almost twice the burden as the male care-givers. Couples on lower income reported more burden than better off couples and the severity of the PD is directly related to increased assistance with activities of daily living and in turn this increases the level of perceived burden.

Turning to the European based studies, Aarsland et al (1999; CA602: high) examined the emotional and social distress of caring for a person with PD and the effects that the mental and motor features of the disease have on this distress. The study found that carers of people with PD experience high levels of emotional distress and stress in care-giving, spouses were more highly depressed than carers who were children or other carers and had low psychological health compared to healthy controls. Functional impairment was linked to carer stress but not emotional distress. It is the psychological aspects of PD especially depression, cognitive impairment and behavioural disturbance that lead to the most significant levels of carer distress and stress. Disease stage and severity of motor symptoms may not influence care-giver stress independent of mental disturbance. The clinical implications of this study are that the identification and treatment of mental disturbances is of major importance for patient and carer and may enable people to be cared for in their own homes longer.

Carter et al (1998; CA0256: medium) used cross-sectional data to test hypotheses of different kinds about the relationship between three aspects of the care-giver's response to her/his situation and the stage of the disease the person with PD had reached. The three aspects were: role strain; care-giver situation; and care-giver characteristics. Care-giver strain was found across all stages of the disease, but accumulated significantly as the disease progressed.

Happe et al (2002; CA0234: medium) focused on sleep disturbance amongst the spouses of people with PD. Sleep disturbance was found to be associated with PD symptom severity, being a female carer, the disturbed sleep of the person with PD, getting household support and the frequency of care-giving. It was concluded that interventions which improve the sleep of people with PD would also benefit carers.

Summary of carers' experiences of providing care to a person with Parkinson's Disease (highly rated studies only)

- Carers have raised levels of distress and/or psychological disturbance although there is no link between distress and social support. Services to support the effective treatment of depression in people with PD would have a beneficial effect on carers.

- In addition to daily living activities, carers often participate in professional/therapeutic activities. However, some carers reported that for practical or emotional reasons they did not want to be involved in these aspects of caring, furthermore some people with PD did not want carer involvement in this area.

- Stress in carers appears to be connected to aspects of caring related to intrapersonal factors such as anxiety. Professionals need to be aware of the stress factors for carers and plan services accordingly. Assessing stress and well-being of carers should be a priority for health care providers to identify and provide services for people at risk.

- Carers' well-being tends to be higher that that of people with PD, carer burden is linked with the severity of PD and perceived patient control over symptoms is associated with carer well-being and less carer burden. Therefore, helping the patient and family in managing symptoms will enhance perceived control and is an important aspect of quality of care which may enhance carer and patient well-being.

- The identification and treatment of mental disturbances is of major importance for patient and carer and may enable people to be cared for in their own homes longer.

Conclusion

Within the confines of a brief review of the available literature it has been possible to identify the main themes and issues that are important to carers concerning their experiences of providing care to a person with one of the target long term conditions.

In terms of main themes from the 'sudden onset' group (A) the following are identified:

- In the UK social services for patients are patchy and for carers patchier still. Services for carers are aspirational rather than actual. This may be because they are not seen as a priority area.

- Carers experience distress about behavioural and social problems and adverse effects on families. Effective support moderates between adverse effects and depression.

- Neurologists must make use of carer's assessments in compiling their evaluations of treatment.

- Carers report grief for the loss of patient's potential and personality and feel that services should provide increased aftercare, meaningful employment opportunities, avoid over-medication and establish systematised patient care.

- Carer support programmes are beneficial. The most important threats to successful family adaptation are the lack of suitable services for the injured person and the person's behavioural and emotional problems. Strengths that contribute to adaptation are within the family, or through friendship or peer support

- Carers with higher negative orientation towards problem-solving may show greater distress and depression and negative orientation in the carers impairs cognitive problem-solving performance. Carers who have more cognitive-behavioural resources exhibit fewer emotional difficulties adjusting to the carer role. Carer problem-solving abilities predict emotional and physical health of the carer and recipient

- Caring spouses report high stress levels, burnout, anger, resentment and poor well-being. Outside help in care-giving will ease the burden only if it is care-giving and not the severity of the injury that causes problems to the carer.

- Spouses with limited coping strategies and limited social support have higher depression and care-giving burden

- Anxiety is the best predictor of the variability in the initial levels of physical symptoms reported by carers

- Spouses and people with SCI experience the same processes of stress and adjustment. Rehabilitation professionals need to attend to both patient and spouse needs to ensure best therapeutic results

In respect of Group B, 'intermittent/unpredictable' conditions the main findings are as follows:

- The patients' aims for epilepsy surgery are to be working; to drive a car; independence/ freedom/ socialisation; relief from medication'; change in behaviour (desired by carers on behalf of patients) and improvements in personal safety

- Patients report a great need for social relationships and this also holds true for carers (parents in most cases).

- Carers report a need for more respite services

- Addressing epilepsy means having interdisciplinary systems between health policy, social policy and social theory

In relation to Group C, 'progressive' conditions the main themes are:

- Carers frequently have negative experience of service provision and often feel they are not listened to or valued.

- Bureaucracy and lack of funding may contribute to service users and their families not obtaining full or adequate information

- The health status of patients has a dramatic effect on the health status of the carer.

- Services and MND charities need to take into account the impact of MND on the carer as well as the patient

- Services/support provided at the time of diagnosis are important to carers who want more information on what MND is and what benefits and services are available. Carers feel they have to fight for services with the result that many individuals feel they received too little too late.

- Carer anxiety and depression is partly linked to functional incapacity of the patient. Patients and carers differ in how they perceive their own needs, in how they view, judge and evaluate the disease and how they cope with its progress

- Carers want more information about the disease. They feel insecure and feel a great need to talk about the burden of care. Some carers tend not to want to think about the future

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- Carers tend to employ a systematic planning approach in caring for people with MS but some can become overwhelmed and need to withdraw temporarily

- Nurses need to explore how dependency needs are met and their impact on the family to enable effective information and counselling of the family.

- There is a strong correlation between the severity of patient's disability and carer depression anxiety and psychosomatic conditions.

- Changes in the person with MS cause carers stress. There is a need to change personal plans and deal with financial strain. Difficulties flowing from problems with memory and independence in activities of daily living are predictive of carer strain.

- Carers have raised levels of distress and/or psychological disturbance although there is no link between distress and social support. Services to support the effective treatment of depression in people with PD would have a beneficial effect on carers.

- Some carers report that for practical or emotional reasons they do not want to be involved in professional/therapeutic activities and some patients with PD do not want carer involvement in this area.

- Stress in carers appears to be connected to aspects of caring related to intrapersonal factors such as anxiety. Professionals need to be aware of the stress factors for carers and plan services accordingly. Assessing stress and well-being of carers should be a priority for health care providers to identify and provide services for people at risk.

- Helping the patient and family in managing symptoms will enhance perceived control and is an important aspect of quality of care which may enhance both carer and patient well-being.

- The identification and treatment of mental disturbances is of major importance for patient and carer and may enable people to be cared for in their own homes longer.

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