Recognizing the family caregiver: integral and formal members of the rehabilitation process

Timothy R. Elliott\textsuperscript{a,}\textsuperscript{*}, Richard M. Shewchuk\textsuperscript{b}

\textsuperscript{a}Department of Physical Medicine and Rehabilitation, University of Alabama at Birmingham, Spain Rehabilitation Center, 1717 Sixth Avenue South, Birmingham, AL 35233-7330, USA

\textsuperscript{b}Department of Health Administration, University of Alabama at Birmingham, Spain Rehabilitation Center, 1717 Sixth Avenue South, Birmingham, AL 35233-7330, USA

Accepted 1 December 1997

Abstract

Radical and emerging changes in health care service delivery systems and steady increases in the number of chronic health conditions have shifted more responsibility to family caregivers of people with disabilities. These caregivers essentially operate as formal health care providers who receive little or no recognition, support, or preparation from health care systems. In this article, major societal and psychological issues in caregiving are discussed. We also explore interventions to prepare and assist caregivers that effectively integrate them into the rehabilitation process. © 1998 Elsevier Science Ltd.

Keywords: Caregivers; Family; Rehabilitation; Physical disability; Health care providers

1. Introduction

For the past two decades, the independent living movement in the United States has emphasized the rights of people with physical disabilities to pursue independent life styles and have financial and environmental accommodations to promote such independence in professional, social and interpersonal roles (e.g. DeJong, 1978). However, the fiscal realities and budgetary constraints imposed by the recent corporatization of American health care have not supported programs and services that would otherwise promote independent living for people with severe physical disabilities. With limited formal services available, family members have become the primary caregivers for people who have severely disabling conditions.

Once regarded in a patronizing fashion as 'in-
formal' extensions of the healthcare service delivery team (Kane and Kane, 1987), caregivers are now an integral component of the healthcare delivery system, due to changes in resource allocation and increases in chronic disease and disability (Council on Scientific Affairs, 1993; Barrett et al., 1994). Fundamentally, this means that family members — who may be spouses, parent, daughters, sons or 'fictive' kin — are thrust into a new career when a member of the family incurs a disabling condition. In this new position, family members are typically responsible for a wide range of services that were formerly provided by traditional health care providers. With the emergence of managed care as the dominant model in health care delivery, there are new expectations for family members to take an active role in promoting adherence to behavioral self-care regimens. Accumulating empirical evidence links family and other sources of interpersonal support with greater disability and greater likelihood of secondary complications among people with severe mobility impairments (e.g. pressure sores, recurrent infections, etc.). When caregivers are unable to meet the role demands as de facto health care providers, the risk of disability, secondary complications and greater health care expense increases. Furthermore, with the increasing number of chronic conditions in the American society — in concert with the reluctance and unwillingness of managed care plans to provide necessary services to people with these conditions — we will likely see more family members in caregiving roles than ever before (Hoffman et al., 1996).

In this article, the major issues concerning caregiving for people with spinal cord injuries (SCI) who are involved in the rehabilitation process will be reviewed; we will address the problems often encountered by caregivers. Firstly, the personal costs of caregiving will be reviewed and the apparent effects on the emotional and physical adjustment of people with SCI will be discussed. Then salient ethnic and minority concerns that relate to the caregiver experience in predominately Western societies will be addressed. Finally, ways in which caregivers can be integrated into the rehabilitation process will be discussed.

2. The personal costs of caregiving

Much of the previous research in caregiving has focused on the classical stress-burden paradigms — from a contextual perspective — and this has been largely limited to the study of caregiving in chronic disease episodes such as Alzheimer's dementia, or more recently to people with AIDS (Folkman et al., 1994). Yet, to a great extent, these experiences are ultimately time-limited, contingent upon the ultimate progression of the disease. This is unlike the chronic, ongoing stress of caregiving for people with permanently and severely disabling conditions who have considerable life expectancies (e.g. spinal cord injury, severe developmental disabilities, cystic fibrosis, etc.). In many situations, chronic disabilities often thrust caregivers into non-normative activities which force them to deal with 'off-time' life events (e.g. Neugarten, 1979) that compete with and impede the attainment of more normative social, personal and vocational roles (Moen et al., 1995).

Following the onset of traumatically acquired disability, roles and functions may shift considerably and caregivers are often forced to assume greater responsibility for family decision-making and problem solving (Bishop and Epstein, 1980). The family caregiver operates as an extension of the rehabilitation team by providing expert care and maintenance to the individual with a disability. As such, the quality of this care may be directly related to the ultimate health of the client and eventual health care expenditures (Ware et al., 1996). The health and adjustment of the caregiver are germane to the delivery of rehabilitation service to the client, the health and well being of the client and to health care policy concerning the care of people with chronic and debilitating conditions.

Individuals who assume caregiver roles essentially enter into a career that is defined by the task in which they engage and the relationships they have with people who have ongoing or chronic diseases or disabilities (Aneshensel et al., 1995). The extant literature concerning caregivers has generally examined broad descriptive differences between caregivers and non-caregiving comparison groups or general population norms.
levels of emotional strain regardless of objectively-defined caregiving duties (Hooker et al., 1992).

In our ongoing research with caregivers of people with spinal cord injuries (SCI), we have learned that caregiver adjustment has many facets and problems in adjustment can compound or trigger other problems. For example, caregiver anxiety is significantly predictive of the development of physical symptoms over the course of the first year of caregiving for a person with SCI (Shewchuk et al., in press). We have also found that the development of depressive behavior and anxiety over the course of the year is significantly related to expressive support available to the caregiver. Additionally, this work has revealed that higher levels of positive affectivity are predictive of less depressive behavior among caregivers and caregiving for a young adult is associated with greater anxiety.

3. Caregiving and adjustment to physical disability

Given the substantial improvements over recent years in emergency care and early surgical intervention/stabilization, people who sustain SCI have life expectancies that approach that of the general population (Go et al., 1995). People with SCI may require varying levels of assistance for activities of daily living that can range from complete dependence on others (in the case of high tetraplegia) to complete independence (among people with incomplete lesions to the cord). When help with such activities as feeding, dressing, skin care, transfers and bowel and bladder care is required, family members are often the primary source of help, even when attendant care is available.

We know from converging research that emotional distress among people with SCIs is related to the occurrence of secondary complications. Such complications include pressure sores, poor self-assessed health status, decreased mobility, poor social integration, more days spent in bed and fewer days outside the home and greater use of care attendants and subsequent medical expenditures (Elliott and Umlauf, 1995; Elliott and
Frank, 1996). Social and family support has also been related to the emotional and physical health of persons with disability. Family member use of problem-solving, proactive coping strategies has been associated with less depressive behavior among clients (Leach et al., 1994). Higher levels of social support, generally, are associated with less distress among people with SCIs (Schulz and Decker, 1985). More specifically, relationships that reassure the worth of the person are associated with less depressive behavior and less psychosocial impairment secondary to the disability (Elliott et al., 1992a,b). Relationships that provide a sense of attachment and intimacy have been positively associated with more satisfying spare time activities among these people (Elliott and Shewchuk, 1995). Typically, family members are the primary sources of social support to people with physical disability.

The relations between social support and health complications have been less clear. Some types of social support have been negatively associated with documented incidents of skin breakdown and urinary infections; others might actually perpetuate an environment conducive to the occurrence of such complications (Herrick et al., 1994). There is evidence to indicate, for example, that caregivers who are overly-involved with client complaints and symptoms may inadvertently engender distress and reinforce greater psychosocial disability in the client (Turk et al., 1992). Caregivers in these situations might be too attentive to complaints and reinforce these behaviors in this process. In contrast, caregivers who harbor negative attitudes toward the client may elicit higher levels of client distress (Thompson and Sobolew-Shubin, 1993). This information suggests that caregivers should be aware of their own needs, their motivations and different ways of responding to client behaviors and concerns.

Client coping appears to be directly associated with the type of social support provided over the first year following discharge from the in-patient setting. McColl et al. (1995) found that while social support varied somewhat in the year following the return to the community among 120 people with SCI, support consistently predicted coping efforts during this time frame. To a great extent, these relations were dependent on the type of support provided: informational support was particularly important soon after return to the community, but at the end of year emotional support significantly augmented patient coping. Such findings illustrate the dynamic nature of social support on adjustment, as needs often change over time for a variety of reasons. This particular study also implies that providers of support need an expanded behavioral repertoire in order to respond optimally to patient needs.

The burden of care and the changes imposed by disability strains many relationships. We know, for example, that the divorce rate among people with SCI exceeds the national average (DeVivo et al., 1995); the likelihood of remarriage remains low throughout the lifespan for both men and women who acquire SCIs (DeVivo and Richards, 1996). Unfortunately, we have yet to understand why marriages fail following SCI. It is possible that experiences in caregiving may adversely affect the well-being of the caregiver and the relationship with the client. Preliminary evidence indicates that people with SCI perceive an increase in family adjustment from the in-patient setting to 1-year post-injury (Richards et al., 1997). This finding is inconsistent with other data linking caregiving with increased levels of distress during this same time period (Shewchuk et al., in press). We have yet to understand the dynamics between patient and family caregiver that influence health, well-being and stability of the relationship.

From a policy standpoint, the well-being of caregivers of people with SCI should be of paramount importance. If caregivers become physically ill or emotionally exhausted, they may be unable to care for the person with SCI. This, in turn, may contribute to a subsequent development of expensive and preventable secondary complications in the client. Attention needs to be given toward understanding the factors that help maintain the physical and emotional health of the caregiver over time with an emphasis on identifying avenues for intervention.

4. Ethnic and minority issues in caregiving

Ethnic and minority concerns have been largely
ignored in the rehabilitation literature; these issues are particularly important in understanding the caregiving experience (Uszwate and Elliott, 1997). The very constitution of family in minority ethnic groups can differ from in the majority. Whereas in many European–American families the close family consists of mother, father and children, in minority families this can include grandparents, aunts and uncles (Albert, 1990; Basic Behavioral Science Task Force, 1996). African–American families often include members not related by blood or marriage, but by shared values, norms and beliefs (Belgrave et al., 1994). Studies indicate that caregivers in African–American families can be close or distant relatives or fictive kin and that the quality of care does not vary with the closeness of blood relationship (White-Means and Thornton, 1990; Lawton et al., 1992).

The extended family structure and the collectivist spirit characteristic of many minority families suggests that these families might be able to cope better with a disabling injury to a family member than European–American families. Research comparing African–American and European–American families, in fact, indicates that African–American families may cope better with the challenge imposed by a disability than European–American families. Pickett et al. (1993) found that African–American parents of children with disabilities had higher feelings of self-worth and lower levels of depression than European–American parents with disabled children. Caregiving for Alzheimer’s Dementia patients has been associated with less depression and higher life satisfaction in African–American caregivers than in European–American caregivers (Haley et al., 1995). The diminished negative impact of caregiving in African–American families appears to be related to a view of caregiving as an expected family function (Haley et al., 1996) and a regard for elder family members independent of their cognitive and behavioral abilities (Dilworth-Anderson and Marshall, 1996). There is little research comparing other ethnic groups to the majority group or to each other on the impact of caregiving.

The limited amount of research on the relationship between minority status and marital status after a disabling injury suggests that cultural differences have a small or negligible impact on marriage and divorce rates. DeVivo and Richards (1996) — in a recent study of 6853 people with SCI — report that African–Americans and Latinos do not have significantly different marriage rates than European–Americans. The evidence on the relationship between minority status and divorce is mixed. In a study with 275 SCI people, DeVivo and Fine (1985) reported that African–American minority status is significantly associated with a higher divorce rate. In a more recent study with 662 SCI people, African–Americans and Latinos display higher, but not significantly different, divorce rates than European–Americans (DeVivo et al., 1995). The higher rates of divorce reported correspond to higher rates of divorce for these minority groups in the general population. The number of Asian Americans and Native Americans in these studies was too small to draw any statistical inferences.

5. Integrating the caregiver in the rehabilitation process

Many potential problems could be prevented if formal health service providers find ways to interface with informal caregivers to ensure that they have the requisite skills to help those with chronic and debilitating conditions in order to maximize the health of the client and further reduce costs to the system. Failure to promote the emotional and physical well-being of the caregiver can have negative repercussions for the caregiver and client. Thus, interventions are needed to equip the caregiver with the necessary instrumental skills for care of the client and for maintaining an optimal level of personal well-being and health. Health care programs should be offered by managed care and health maintenance organizations to take into account the health and well-being of the caregiver as a matter germane to the health care of the client with the disability (e.g. Aneshensel et al., 1995). More formal assessment and structured interventions may be required for caregivers who display greater distress at the onset of the caregiving experience, as our data sug-
gest these people are at risk for more personal difficulties throughout the year.

Interventions can probably be very cost-effective when considered relative to the potential costs that might be incurred in prolonged care for secondary complications. One novel approach demonstrates the efficacy of integrating family members in psychosocial interventions during the in-patient SCI rehabilitation. Moore (1989) involved family members in structured individual sessions with patients during the in-patient stay and compared the adjustment of those patients to those who participated in a routine psychosocial intervention that did not involve family members. Those who participated with family members in psychosocial interventions demonstrated significant gains in socializability, self-acceptance and well-being and these were significantly higher than those who were in the standard program. Studies such as this one illustrate the potential of integrating family members in the earliest stages of the rehabilitation process.

Other data suggest that cognitive behavioral approaches may also have promise as useful interventions. Theory-driven research has revealed that self-appraised problem solving abilities are predictive of distress experienced by caregivers of people with disabilities. In a cross-sectional study, Noojin and Wallender (in press) found greater confidence in problem solving abilities and a sense of control over emotional reactions while problem solving was significantly related to the distress reported by mothers of children with physical disabilities. In a longitudinal study, we have found that abilities to regulate negative emotions and a pessimistic opinion of personal problem solving abilities were significantly predictive of caregiver depression, anxiety and ill health during in-patient rehabilitation and 3 months following return to the community (Elliott et al., 1997). The inability to regulate negative emotions has also been associated with depressive behavior among caregivers of family members with dementia (Brashears and Catanzaro, 1994).

These findings are consistent with theoretical models of social problem solving (D'Zurilla and Goldfried, 1971; Nezu and D'Zurilla, 1989; D'Zurilla and Nezu, 1990). From this perspective, self-appraised problem solving abilities were a vital function in the way a person processes information about the self, the environment and problematic situations encountered in everyday life. These abilities and the problem solving process can be conceptualized into the separate domains of problem orientation and problem solving skills (D'Zurilla and Nezu, 1990). Problem solving training has been effective in the treatment of clinical depression among adults (Nezu and Perri, 1989) and elderly individuals (Arean et al., 1993), distress among people with chronic illness (Roberts et al., 1995) and in improving self-management skills of undergraduates (Richards and Perri, 1978). This approach can easily be integrated into an intervention program for caregivers (e.g. Houts et al., 1996).

We believe that caregivers could benefit from problem solving training that enhances their ability to regulate their emotional experiences when encountering problems and that provides them with the cognitive-behavioral skills that constitute effective problem solving. Any rehabilitation program designed to include caregivers should take into account the unique concerns and ecology of each individual caregiver. This information is necessary so that interventions can address and target specific caregiver needs. As caregiving for a person with a disability is a dynamic career (Shewchuk et al., in press), caregiver needs and problems may change over time and on-going assessment is essential.

In the first post-discharge year, for example, we have learned in our focus groups with caregivers that many problems are experienced initially with client negative attitudes and interpersonal behaviors, time demands and management and personal distress (Elliott and Shewchuk, in press). Remarkably, few problems were reported with abilities to perform instrumental self-care tasks with the client. A greater concern was placed on the challenge of interpersonal problems with the patient and with meeting care demands within time constraints.

In our interventions, we target specific caregiver problems during in-patient rehabilitation and follow the course of these problems while providing problem solving training specific to
these concerns (see Elliott and Shewchuk, in press, for details). In this way, family caregivers are provided with the emotional, cognitive and behavioral skills in tandem with the basic and ongoing information necessary to meet the rigors of caring for a person with a severe physical disability. Some caregivers need assistance in generating alternatives for problems they are facing and we help them consider different solutions. In other cases, a caregiver may need more details about a particular medical or social problem, or about possible solutions (e.g. a referral for vocational rehabilitation services) before engaging in effective problem solving. Often we provide helpful instruction in stress management, assertion skills, social skills and time management.

6. Summary and recommendations

Caregivers assume an important role in the rehabilitation process. They are instrumental in providing quality, on-site and ongoing care to the person with a severe disability. More expectations are being placed on family caregivers as American health care delivery systems evolve and reconfigure. In order to optimally use available resources and provide the most beneficial service to people with disability, we must integrate the family caregiver into rehabilitation plans. This will include interventions and programs at all levels of service delivery.

A family member should be involved early in the rehabilitation process. To some extent, most in-patient rehabilitation units try to educate and train family caregivers during the initial phase of rehabilitation. This research indicates that this is largely inadequate and caregivers will likely experience considerable stress upon returning home. Contrary to clinical lore, the demands of caregiving do not abate with time; in fact, for many stress and strain exacerbate over time. Caregivers who are distressed during the initial in-patient phase are likely to develop more problems with ill health, anxiety and depressive behavior over the course of the first year of caregiving following return to the community (Shewchuk et al., in press).

Therefore it is imperative that patient educa-
tion and counseling programs include the family caregiver during initial in-patient rehabilitation. The caregiver should be acknowledged and respected as an new member of the health care service delivery team and the intervention program should respect the caregivers’ lack of preparation for this role and their corresponding needs for education, support and empathy. Some programs will find instruction in problem solving principles to be vital in preparing caregivers for coping and trouble-shooting with a host of problems after return to the community.

Home-based, community-oriented programs are essential for providing quality service caregivers post-discharge. Many people with a disability have considerable difficulty adhering to routine appointments at the out-patient clinic due to costs, distance and transportation problems (Canupp et al., 1997). Although some home-based services now exist, these should be expanded to include information, support and on-site counseling for caregivers. As we see in our current projects, it is crucial that the unique and specific needs of individual caregivers be addressed in order for these programs to be effective.

There are other avenues by which caregivers may be assisted at home. For example, some programs are experimenting with the use of telemedicine and telecounseling. These new (and still expensive) tools allow health care providers to interact directly with patients and their families in the home via the use of an in-house monitor and computer technology. Thus, a counselor could communicate as needed with a family caregiver to review concerns and provide guided support to augment coping. We know from other research that routine telephone contact can be very helpful in helping people cope with chronic medical conditions (Roberts et al., 1995). Outpatient, community-based programs should probably implement ongoing telephone contacts with caregivers as a basic and fundamental component of rehabilitation.

In summary, we believe health care providers should make fundamental changes in how family members are viewed in the health care service delivery. These individuals are extensions of health care service delivery and we diminish the
impact of our interventions by ignoring and discounting their health, well-being and function. It is imperative that health care plans include caregivers in terms of coverage, service and benefits, so that our policies recognize the important role of the caregiver in the rehabilitation process. This will involve basic changes in our health care policies concerning family members who routinely provide care to people with chronic and severe disabilities.

Acknowledgements

This article was supported by Grant No. R49/CCR412718-01 from the National Center for Injury and Prevention and Control and the Disabilities Prevention Program, National Center for Environmental Health. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Center of Injury Prevention and Control.

References


Elliott, T., Herrick, S., Witty, T., Godshall, F., Spruell, M.


