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Family caregiving of persons following neurotrauma: Issues in research, service and policy

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Abstract

Family caregivers of persons following neurotrauma function as *de facto* extensions of our health care system. Their challenges may result in negative consequences for their physical and mental health, which directly impacts the well-being of their care-recipient. In this paper, we survey current practices in providing caregiver support, outline considerations for developing collaborative interventions, and make recommendations for assessing intervention effectiveness consistent with the nature of the adjustment processes among caregivers and care recipients.

Keywords

Caregivers; neurotrauma; spinal cord injury; brain injury; rehabilitation

1. Introduction

Despite modern society's advancements in healthcare, family members remain the primary long-term caregivers of individuals with chronic disease and disability [5]. These family caregivers function as informal extensions of the health care system by performing complex medical and therapeutic tasks [34]. Whether family caregivers are needed for 24-hour care or weekend visits, they provide support on behalf of the care recipient in a variety of ways including basic activities of daily living (feeding, dressing, bathing, toileting, mobility), instrumental activities of daily living (transportation, shopping, housework, arranging services), medical care (locating a medical specialist, physical therapy, administering medication), administrative care (mediating, negotiating, scheduling, managing finances, legal affairs, and insurance issues) and emotional care (maintaining systems of social support, providing encouragement, and attending to spiritual needs) [17].

Persons who incur severe neurotrauma necessitate life-long commitments from a family member to assume a caregiver role more than ever as improved emergency care has increased accident survival rates and improved ongoing health care has enabled longer life expectancies [24,34]. The market value of their work exceeds that spent on nursing home care and formal health care [37]. Although family caregivers function as extensions of formal services, they are essentially *de facto* health care providers without formal training or support, and often without routine access to the health care systems that rely on their performance [31].

The subsequent declines of the physical and mental health, quality of life, and financial status of caregivers is now well documented [7,36,37] and ultimately impact the care recipient. Consequently, the well-being of family caregivers of persons following the onset of disability is a priority in public health [34] and mental health policy [33]. *Healthy People 2010* [35] urges behavioral and social initiatives to promote the health and quality of life of family caregivers.

Empirical research confirms that many family care-givers of persons with acquired brain and spinal injuries experience problems with distress, quality of life, and lifestyle changes [2]; many of these problems are evident many years after injury onset [26]. Nevertheless, research has yet to identify unique psychological interventions that effectively benefit caregivers of persons following neurotrauma. Very few intervention studies have been conducted with family caregivers of persons with either spinal cord injuries (SCI) or acquired brain injuries (ABI). Randomized clinical trials (RCTs) that have been conducted reveal intriguing results that have implications for future research and program development. Evidence supporting caregiver interventions, generally, is available in other clinical areas, but the degree to which this work can generalize to caregivers of persons with SCI or ABI is open to debate and further study.

In this paper, we will survey current practices in providing caregiver support following neurotrauma, outline considerations for developing collaborative interventions, and make recommendations for assessing intervention effectiveness consistent with the nature of the adjustment processes among caregivers and care recipients.

2. Current practices

Although it is clear that family caregivers serve a critical function as extensions of the healthcare system, health policy has not yet sufficiently addressed caregivers as a major component of effective treatment. The literature suggests that considerable variation exists in the training and ongoing support provided to caregivers from rehabilitation programs. In a brief amount of time, they need to gain caregiving expertise to keep the care recipient healthy. This includes information on the condition, instruction on medical and therapeutic regimens, and preparation for scenarios they may encounter in the community, but third-party payers do not routinely reimburse clinicians for time spent with family caregivers and the provision of a comprehensive continuum of services for caregivers in rehabilitation programs is far from consistent.

Most rehabilitation programs relate to family caregivers from a relatively limited perspective, largely unaware of historical family dynamics, issues and strengths, and the context of rehabilitation (particularly following neurotrauma) presents the family to staff under extremely stressful and extraordinary circumstances. The nature of the rehabilitation enterprise and budget constraints restricts the focus of many programs to the immediate needs of care and not for adequate care following discharge to the home or community placement. Consideration of the issues and strengths unique to the family is often limited and available intervention research reflects this perspective. Interventions are focused on medical management and tailored to the nature of each specific disability while the psychosocial and shared health care issues of family caregivers across disabilities are left largely unaddressed. Consequently, the demands of initial rehabilitation and impending discharge do not adequately prepare family members for the full array of needs and issues caregivers will face as the family tries to resume personal, social and occupational roles in the community.

Previous reviews of interventions studied among caregivers of persons with SCI and ABI found no RCTs in this literature [2,28]. Although several studies of interventions for

caregivers of persons with ABI have been conducted, these reviews concluded that methodological shortcomings in this work limit the confidence in and generalizability of the results. In contrast, there are many controlled studies of interventions for family caregivers of age-related conditions (e.g., stroke, dementia, Alzheimer's Disease) that empirically supported treatments may now be apparent [6]. Table 1 presents the different types and formats of interventions that are typically examined in the caregiver intervention literature; to a great extent, these characteristics are quite common in programs developed for caregivers of person with SCI and ABI [6]. Interventions vary in terms of content and in terms of way in which they are provided.

2.1. Intervention content

In a recent chapter by Chwalisz and Dollinger [6], family caregiver interventions are described as typically featuring content intended to increase caregiver *knowledge* or their *skills*, to improve or change their *affect* and *promote their adjustment*, or to provide *support* to the caregiver. These are not mutually exclusive; some interventions provide information to increase knowledge and to promote coping skills, for example.

2.1.1. Knowledge—When knowledge is the essential content of the intervention, caregivers are often taught details about the care-recipient's condition, its management, and treatment options (during and following rehabilitation). Caregivers are also taught other information deemed important by rehabilitation staff for the caregiver to know (e.g., course/prognosis, secondary complications), general information seeking strategies, and potential sources of such information (e.g., professionals, books, internet, agencies). Developing information-seeking skills may be key to ensuring that the caregivers are prepared to deal with circumstances encountered in the community.

2.1.2. Skills—Interventions for caregivers can also focus on learning certain skills vital to caregiver performance and well-being, and to care recipient health and functioning. This may involve specific care-related skills such as use of medical equipment or assistive devices, adherence to regimens, or ways to assist in activities of daily living (e.g., assisting with transfers, dressing). Behavior management skills (e.g., managing impulsivity after TBI) may also be needed [4].

Affect and Adjustment. Caregivers often experience a wide variety of negative emotions (e.g., guilt, frustration, anger, sadness, grief). Some interventions help caregivers explore strategies to manage negative emotions, stress and burden. Given the stress that family caregivers seem to face, managing negative emotions that may result in depression or anxiety is key to ensuring caregiver adjustment and well-being over time. Stress or anger management, relaxation training, and cognitive behavioral therapy to confront irrational beliefs and negative affect may be implemented in affect-oriented intervention programs.

2.1.3. Social support—Social support oriented interventions tend to involve support groups, with the assumption that putting caregivers together in a group will enhance support. Interventions targeting social support aim to decrease the sense of isolation experienced by many caregivers. These interventions may also attempt to help caregivers increase the size and range of their support networks, improve their perceptions of available support (this includes identifying current and potential support), and learn how to get more help from a social network.

Two recent reviews of the relevant literature [2,28] independently concluded that most published studies of interventions for caregivers of persons with SCI, ABI, and other neurological conditions reported programs that focused on increasing caregiver knowledge

and skill-building; few were concerned caregiver affect and adjustment. Some of these were conducted in institutional settings (during the inpatient stays or at out-patient clinics). There were also some novel attempts to study long-distance technologies to provide supportive interventions (e.g. [3]). Several papers have appeared in the peer-reviewed literature reporting the results of RCTs. Two other papers have appeared reporting preliminary results from two innovative interventions for caregivers with long-distance technologies [29] and with a manualized protocol (integrating cognitive-behavioral principles and family systems theory) for use in an institutional setting [20]. The papers reporting results from the RCTs are particular germane to the present discussion.

2.2. Insights and lessons from RCTs

Three of the available RCTs were conducted with caregivers of persons with SCIs [9,11,30]. One was conducted with family caregivers of adults with traumatic brain injuries (TBI) [27] and two were conducted with parents of children with TBIs [38,39]. Interestingly, each study described an intervention that was provided to community-residing caregivers with home visits, long-distance technologies (e.g., telephone sessions, internet-based sessions) or a combination of face-to-face home visits and telephone sessions [9,30]. None relied on an institutional-based intervention that required travel to a facility for participation. All of the interventions had components to address caregiver adjustment, skill building, and information either about the care recipient condition, health, well-being, or behavior.

Furthermore, all but one of these studies provided a cognitive-behavioral intervention informed by the social problem-solving model [8]. This model posits that problem-solving involves self-efficacy, ability to gather relevant information, creativity in generating possible solutions, thoughtful evaluation of possible solutions, strategic implementation of solutions, and careful evaluation of outcomes. Social problem-solving abilities are an important predictor of caregiver physical and emotional health [12] and caregiver problem-solving may also be predictive of care-recipient outcomes (e.g., pressure sores [13]). Three of these studies relied on a protocol [21] that solicited specific problems unique to each caregiver and followed and outlined specific steps for training caregivers in problem-solving strategies to address these problems [9,11,27].

The other remaining study [30] relied on an established protocol developed in the largest multi-site clinical trial of psychosocial interventions for family caregivers of persons with dementia and Alzheimer's Disease (Project REACH [14]). Of the RCTs identified, this was the only one that had a multi-site trial or specifically targeted older caregivers and care recipients (with SCI) or had three comparison groups (two treatment groups, one control group) or featured an intervention for both caregiver and care-recipient. It also had the largest samples for participation and analysis.

Although each study reported beneficial effects for a treatment condition (compared to the control group), variations occurred across studies by outcomes and by magnitude. For example, Elliott and Berry [9] found a brief, three session problem-solving treatment (PST) combined with education had no significant effect on caregiver depression over the year of participation, in comparison to the usual-care control group. Caregivers who participated in the treatment group evidenced a significant decrease in dysfunctional problem-solving skills (which resulted in a large effect size) and they reported a steady increase in their social functioning (as caregivers in the usual care group reported a steady decrease; this was a moderate effect). Remarkably, this was the only RCT that recruited family members who had just assumed the caregiver role for an individual who had recently incurred SCI. It should also be noted that the usual-care control had a much higher attrition rate (26.7%) than the enhanced treatment group (13.3%), implying that a usual-care control condition may be

inadequate to maintain caregiver interest and commitment in a research protocol over the first year of the caregiver role (following acquired SCI).

A subsequent extension of this intervention (combining face-to-face home sessions with monthly video-conferencing) for caregivers in the PST and education-only control groups found significant effects for PST on caregiver depression (with a small effect to moderate size) and on care recipient social functioning (with a small to moderate effect size) over the year of participation [11]. There were several intriguing aspects to the overall results. First, the PST group did not report any significant differences in problem-solving abilities; consequently, decreases in depression could not be theoretically attributed to desired changes in problem-solving abilities. Similarly, significant increases in care recipient social functioning for caregivers receiving PST could not be attributed to changes in caregiver problem-solving abilities. Second, intention-to-treat and efficacy analyses revealed inconsistencies in the type of change in caregiver depression over time. ITT analysis (with multilevel modeling techniques [22]) indicated that this change was linear (i.e., a steady decrease over time in response to PST, a process often assumed in counseling and psychotherapy research [16]). Yet efficacy analyses suggested that the decrease in caregiver depression in response to PST was due to a quadratic change: Caregivers receiving PST reported a steep decrease in depression at the 6th month assessment, but the scores leveled out and no differences were evident with the control group at the 12th month assessment. Finally, it is worth noting that this study reported the highest overall attrition rate (26%) of the RCTs identified.

The Schultz et al multi-site trial [30] reported a large sample (N = 173 caregiver – care recipient dyads) and a very low attrition rate (12–14%) over the 6 months of treatment (and for the follow-up assessment at the 12 month). Unlike the other studies, however, primary analyses relied on change scores on the major outcome variables. Consonant with the Project REACH protocol and findings (reflected, in part, in Table 2) [14], caregivers assigned to the treatment group received a multi-component treatment protocol that was designed to target their specific individual needs, based on a risk assessment. Each participant received five individual sessions in the home and two by telephone, and five support group sessions via telephone over a 6-month period. In the dyad condition, the caregiver received this same treatment and the care recipient received the same number and type of contacts based on their risk profile, with an added component that discussed the impact of caregiving on the family caregiver. The control group received the same information packet provided to participants in the other treatment conditions and telephone contacts at months 3, 5 and 9. Caregivers in the dyadic treatment group had significantly fewer health problems than the other two groups, and less depression than the caregiver-only treatment group (and the effect sizes were in the moderate range). The use of change scores precluded an analysis of possible quadratic changes in the sample, and conveys an unsubstantiated impression that linear change occurred in response to the treatment [32].

To date, there is only one RCT of a psychological intervention concerning caregiving of adults following brain injury [27]. This problem-solving intervention was an extension of the Project FOCUS [21] protocol studied by Elliott and colleagues [9,11]. Caregivers assigned to the PST group received four face-to-face in-home sessions and 8 telephone sessions with an interventionist over a 12-month period. Participants in the control condition received monthly telephone contacts in addition to educational assignments. Trajectory modeling techniques [22] revealed significant quadratic interactions for the PST group over time. In their initial response to PST, caregivers experienced a heightened trajectory in their depression scores that subsequently evidenced a steep decrease at the 12th month assessment, indicating a favorable and significant response to treatment. In contrast, caregivers in the control group experienced a steady increase in depression scores over time

(and the effect size was moderate). Similar to the Elliott and Berry study [9], caregivers receiving PST evidenced a significant linear decrease in dysfunctional problem-solving styles over the 12 months and this effect size was large. Post-hoc analyses indicated that the beneficial effects of PST were not attributable to possible improvements in care recipient functional ability over time, and was some indication that decreases in depression in the PST group were associated with decreases in dysfunctional problem-solving styles, consistent with the theoretical model. However, the rather dramatic change in the trajectory of depression for caregivers in the PST group implies that caregivers may have experienced an increase in distress before the beneficial effects over time. It may be possible that these caregivers may have experienced difficulty implementing problem-solving principles or, at least, encountered some difficulty in changing their problem-solving approaches in their ongoing interactions with a care recipient with TBI.

The results of the Rivera et al study [27] is particularly intriguing in light of a parallel RCT that relied on the same design and method with an explicit focus on family caregivers of women with a variety of severe disabilities (including stroke, cerebral palsy, mental retardation, etc.) [10]. The caregivers assigned to the PST experienced significant linear decreases, unlike the quadratic change observed in TBI caregivers of the Rivera et al. study. Finally, an ad hoc analysis of the TBI sample revealed that care recipients with caregivers who received PST in the Rivera et al. study displayed a significant decrease in depressive symptoms overtime [1].

Upon close inspection, the studies by Wade and colleague [38,39] reported specific findings from the same RCT conducted with families of 46 children with TBI. The treatment group featured 14 sessions that were downloaded from a web-site at specified intervals. These sessions covered the fundamental components of the social problem-solving model, education about TBI and management of problems associated with pediatric TBI, and education about family communication skills. The control group had access to a web-page that made other educational and instructional materials on the web available to family members. In one report, Wade et al. [38] found that family members in the treatment conditions reported less distress, depression and anxiety at completion than those in the control group (and effect sizes ranged from moderate to large). In the second report [39], parents in the treatment group reported better child self-management/compliance than parents in the control group (with a large effect size). These studies featured two assessment occasions, so linear changes in response to treatment are assumed.

3. Issues and resolutions for practice, research and policy

Collectively, evidence from RCTs conducted to date indicate that psychological interventions for family caregivers of persons who have incurred neurotrauma can effectively lower caregiver distress (and perhaps, depressive symptoms) and improve their ability to solve problems that may be related to coping with everyday problems. There is also evidence that interventions directed at caregivers can have beneficial contagion effects on care recipients, although the theoretical reasons for how and why these effects may occur have yet to be clarified. There is also accumulating evidence that “usual care” or “treatment as usual” is inferior to enhanced interventions that address the problems experienced by caregivers and provide them with skills to resolve the issues they face.

These data raise other captivating issues. It seems possible that caregivers may benefit from interventions for reasons other than the presumed theoretical properties that guide the intervention [11]. Caregivers may vary in their response to treatment and this might be related to several issues such as the care recipient condition, relationship with the care recipient, or the nature of problems that are of immediate concern. For example, we do not

know why caregivers in the Rivera et al. study [27] evidenced an increase in their depression trajectory before they experienced a steep decline, indicative of a positive, beneficial response to treatment that was not apparent until multiple sessions had transpired. We suspect that these caregivers encountered some resistance as they tried to supplant routine behaviors with newly learned problem-solving strategies. These are issues that require further research.

More generally, we also believe that future studies should have multiple measurement occasions and conduct ITT and efficacy analyses that are sensitive to trajectories of change in response to treatment and possible mediators of change for both caregiver and care recipient. Not all changes in response to psychological interventions are conveniently linear; we know that real-life setbacks and dramatic improvements can occur (indicative of “quadratic” changes [16]). Sophisticated designs and corresponding analytic strategies will help us determine mechanisms of change for both caregiver and care recipient.

Ideally, psychological interventions for caregivers are theory-driven (as the majority of the RCTs reviewed were). The Schulz et al intervention [30], however, was based largely on empirical evidence gathered from a larger project that examined interventions for caregivers of persons with age-related dementias. Many of the implications of this work are represented in Table 2 (and available from the Rosalyn Carter Institute for Caregiving, <http://rci.gsw.edu/>). One of the major insights from the Project REACH studies is that “more is better” for caregivers; essentially, programs that provide services, support, information, and skill building with a relative intensity (in terms of frequency and duration) have a greater positive effect than circumscribed, infrequent, and educationally based programs [14]. Although we do not know the degree to which data obtained from caregivers of individuals with age-related cognitive declines can be generalized to caregivers of persons who have experienced neurotrauma, the initial evidence from Schulz et al. [30] suggests that multimodal, home-based services designed to address the issues relevant to a motivated caregiver and care recipient dyad may be quite effective.

This observation should be tempered by two obvious factors. First, evidence from these RCTs are largely restricted to participants who share an interest in psychological interventions, and who are willing to participate in one. There are many scenarios in which caregiver-care recipient dyads are not receptive to psychological approaches to their situation. Furthermore, there are scenarios in which a caregiver may be receptive to a psychological intervention, but a care recipient may not be interested or capable of participating. Second, it is possible that the older participants in the Schulz et al. [30] were in rather stable relationships and were thus able to meet the time commitment of the research project that younger, or more recently-injured individuals, could not. The first year following neurotrauma is marked by many dynamic changes that overwhelm many caregiver – care recipient relationships. This may, in part, contributed to the attrition problems and limited effects of the Elliott and Berry study [9].

These matters raise another concern for research and practice. Many factors impinge on caregiver-care recipient well-being and functioning, and most of them will remain outside the control of any well-designed RCT. In the best of circumstances, these factors can only be managed among consenting participants with an effective randomization strategy, but their effects can still adversely affect RCTs that recruit small samples. Consequently, significant effects that occur in most RCTs for community-residing caregivers of persons following neurotrauma will likely result in small to moderate effect sizes. Alternatively, this reality makes the large effect sizes reported in some of the RCTs to date even more impressive.

The evidence to date also illustrates the potential of low-cost long-distance technologies in helping family caregivers. A variety of telecommunication technologies improve accessibility to information and services for individuals who are otherwise limited by mobility problems, compromised health status, or prohibitive distances to hospitals or clinics. These data clearly indicate that home-based services can employ telephone, videoconferencing devices, and internet-based protocols effectively, if in fact the material is strategically and appropriately tailored for the individual caregiver.

Programs developed to provide caregivers with ongoing, community-based assistance must fully embrace the reality that an individual's lifestyle and day-to-day choices – and the immediate social factors that influence these behaviors – will have more impact on the course of their health than services offered by any single health profession [15]. This perspective necessitates a calculated move away from a “top-down” view of service in which experts prescribe the core elements of ongoing care to one that promotes a participatory ethic with individuals and their families [25,31]. Effective program and policy development for families who live with disability and other chronic health problems may be realized when they are recognized as experts on their service needs, and they can exercise an element of choice, control, and direction in the delivery of services [19]. This ethic is necessary to circumvent environmentally imposed limitations and restrictions that contribute to the health disparities experienced by these families [23]. By seeking to empower the active role of family caregivers in promoting their own health and well-being, these kinds of programs are essential to developing collaborative partnerships with people who live with disabilities and their families [18].

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Table 1Types and formats of interventions often provided to family caregivers in rehabilitation settings^{*}

Intervention type	Intervention format
Psychoeducational	Lectures
	Discussion
	Worksheets
Counseling	Individual
	Dyads/Family
	Group
Supportive	Support Groups
	— Peer-led
	— Professionally-led
Care-recipient Focused	Training
Informational Resources	Professionals
	Books
	Internet
Multi-component	Combination

^{*} Derived from Chwalisz and Dollinger [6].

Table 2

Characteristics of effective caregiver programs *

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1. Contact with a helper over time
 2. Contact with a helper who has specific intervention protocols to follow
 3. Interventions and care plans tailored to the caregiver's specific needs
 4. Multi-component interventions that include a combination of knowledge, skill building, problem solving and counseling
 5. Interventions with higher intensity (e.g. greater frequency and duration)
 6. Using a combination of home-visiting, telephone follow-up, internet and telehealth technology to deliver
 7. Programs developed and implemented locally and involving agency collaboration
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* Available from the Rosalyn Carter Institute at <http://www.rosalynncarter.org/effective2/>.