Family caregivers of persons with chronic disease and disability are at risk for increased problems with distress and illness. Family members who provide care and assistance to persons with spinal cord injuries (SCIs) report more distress than non-caregivers. Caregivers who report more problems with depression, anxiety, and ill health often experience an exacerbation of these problems over the course of a year.

Despite the apparent deleterious effects of caregiving following SCI, recent research indicates that effective social problem-solving abilities are predictive of less distress among family caregivers of persons with SCI over the first year of the caregiving experience. Caregivers who lack effective problem-solving skills are at risk for developing clinically significant problems with depression. Other data indicate that problem-solving abilities are predictably associated with caregiver adjustment across the life span, including mothers of children with disabilities and spouses of persons who have experienced a stroke. Social problem-solving abilities appear to be a better predictor of caregiver depression than social support (such as having someone to talk to about problems, belonging to a group, or receiving physical assistance). There is also compelling evidence that persons with SCI who live with family caregivers who possess ineffective problem-solving skills are at significant risk for pressure sore occurrence.

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Problem-solving interventions have demonstrated considerable efficacy in the treatment of depression and in the promotion of self-management skills. Problem-solving training is as effective as antidepressant therapy in the treatment of depression in primary care settings and is cost-effective. Randomized trials have found that problem-solving training is effective in lowering distress among caregivers of persons with stroke and caregivers of children with cancer.

Problem-solving principles can be incorporated into family education and caregiver preparation programs, and these can be delivered in community sites and in the home. This is a critical feature, as many caregivers face overwhelming problems with transportation, mobility restriction, distance, and time management if they are to meet the demands imposed by traditional methods of service delivery. Yet accumulating evidence indicates that psychosocial interventions can be delivered effectively with long-distance technologies as commonplace as the telephone. Other information technologies such as the Internet, CD-ROM, and video have been used to provide services to hospice patients and persons with dementia, HIV, and diabetes. Moreover, families often prefer these modalities over traditional face-to-face visits in the outpatient clinic.

A recent review outlined several reasons for the increased use of telecommunication technologies in the field of health care in general and rehabilitation medicine in particular. The first is the improved accessibility to health care information and services provided by these alternative formats to individuals who may otherwise be limited by mobility problems, compromised health status, or prohibitive distances to hospitals or clinics. Consumer-driven demand for efficient and timely services provides the second reason for the growth in telehealth-based programs. Finally, the need to increase cost-effectiveness while maintaining quality, particularly for populations that require frequent use of health care services, has required creative problem solving on behalf of health care providers and administrators in order to increase the availability of alternative avenues of effective service delivery. The various devices and methodologies used in the delivery of telemedicine have, for the most part, addressed the first and second reasons listed above. However, the determination of efficacy and effectiveness of a particular approach ultimately requires rigorous scientific inquiry.

Description of Project FOCUS

Project FOCUS is a 5-year, community-based research study specifically aimed at determining the effectiveness of videoconferencing technology and problem-solving training on caregiver distress and secondary complications of the care receiver. The traditional five-step model of problem solving used in this study consists of (1) defining the problem, including identifying circumstances and events surrounding the occurrence of the problem; (2) achieving a positive frame of mind to allow maximum cognitive flexibility; (3) generating possible solutions; (4) implementing a solution with the greatest potential for efficacy; and (5) evaluating the results. Project FOCUS provides an acronym for the five-step method of problem solving taught to study participants. Using a problem that has been identified by the caregiver during the structured period of assessment, the intervention-
ist, who is typically a master’s level psychologist, counselor, or nurse, illustrates the principles of obtaining Facts and being Optimistic, the benefits of Creativity, the importance of Understanding all aspects and consequences of a potential solution, and the steps associated with Solving the problem. The training approach is inclusive and encourages active participation from the caregiver. Numerous visual materials and worksheets are used by the interventionist to assist the caregiver in understanding and integrating the information provided. All aspects of the caregiver’s behavior are utilized for maximum therapeutic effect, including resistance or denial. For example, caregivers typically respond with amusement when common cognitive distortions such as generalizations and negative filters are illustrated in their actual statements or when unrealistic and silly suggestions are provided during the brainstorming component of the training session. This playful, nonthreatening approach to presenting information strengthens rapport and reduces defensive postures that can hinder learning.

Participants

Study participants are caregivers and persons with an SCI that have typically been recruited during the care receiver’s inpatient stay at a rehabilitation center. Study participants range in age from 19 to 84 years. Sixty percent of persons in the current sample are women and live in rural areas of Alabama, Tennessee, and Georgia. Thirty percent of persons in the sample are African American. Prior to enrollment in the study, the participants are randomized to the problem-solving intervention or to a no-problem-solving treatment control condition. The initial training takes place in the caregiver and care recipient’s home. Informed consent is obtained, and baseline assessments are completed. During this relatively structured period of contact, a critical relationship is established between the caregiver and the interventionist that often determines the level of receptiveness the caregiver will have to the problem-solving principles being taught and to the videophone technology used for the follow-up contact.

Telecommunication component

We selected the ViaTV Videophone (Model VC 105; 8x8 Inc., Santa Clara, CA) for this study because of its simplicity of use and minimal connection requirements. The technology provides audio and visual communication from the interventionist’s office to the caregivers’ homes through the use of a standard analog telephone line, a touchtone telephone, and a television set. These three components have all been available despite the extremely rural locations of many of our participants’ domiciles. Videoconferences are held with each participant on a monthly basis over the course of 1 year. At each contact, caregivers are asked questions about their own health as well as the health status of their care receiver. Of specific interest is the occurrence or worsening of pressure sores or depression in the care recipient, as these conditions have been directly associated with caregiver problem-solving abilities. During each videophone conference, caregivers are also presented with a different problem situation for which they are asked to provide potential solutions. There are 12 problem situations in all (see Appendix) that reflect common caregiver concerns, such as their care recipient’s unwillingness to keep a doctor’s appointment, caregiver illness or disability, difficulty communicating with
physicians, financial concerns, and so on. Although all caregivers are assessed in this manner, the participants in the treatment condition are prompted to think about the principles involved in brainstorming prior to offering their suggestions and, if they have difficulty doing so, these principles are reviewed by the interventionist. Finally, all caregivers are asked about any progress made in the resolution of the problem identified during the initial home visit and are given the opportunity to ask questions or discuss any pressing issues or new concerns. Positive reinforcement and encouragement are provided throughout the exchange.

Assessments

Social Problem Solving Inventory–Revised

A formal component of the baseline assessment is a measure of problem-solving orientation that also provides a perspective of the caregiver’s approach to problems and is used to tailor the intervention to the caregiver’s needs. The Social Problem Solving Inventory–Revised (SPSI-R) is used to determine whether a caregiver’s attitude and approach to problems have a greater tendency toward being avoidant, impulsive, negative, rational, or positive. The interventionist then uses this information, at every period of contact, to emphasize relevant areas of the problem-solving curriculum. For example, in training an individual who displays avoidant and impulsive characteristics, interventionists will emphasize steps 1 and 3 of the traditional five-step model of problem solving which consists of: (1) defining the problem, (2) achieving a positive frame of mind, (3) generating possible solutions, (4) implementing a solution, and (5) evaluating the results. This tailored approach emphasizes accurate problem definition to allow individuals to attain a greater understanding of the true components involved in the problem, and the approach assists individuals in developing a list of potential solutions for the problem, which mitigates avoidant and impulsive problem-solving tendencies and leads to the mastery of more functional skills.

Card sort technique

The second tool used to facilitate the implementation of problem-solving training for the caregiver is a card sort procedure. This unique, untimed task is instrumental in assisting caregivers in identifying problems they may encounter. Twenty-four commonly experienced problems, which were previously elicited by a nominal group technique approach during focus groups consisting of caregivers and persons with SCI, are listed on cards that are spread out on a table. Participants are asked to read each card and to place the 24 cards in as many or as few groups as they choose based on their own perceptions of the problems’ similarities. Once all the cards are assigned to a group, caregivers are asked to name or provide a title to each group that reflects the relationship among the cards. For example, a common title designated by many caregivers is “does not apply” and refers to cards that state problems that they do not experience in their caregiving situation. Other frequently identified groups are “caregiver problems” and “patient problems,” the first of which includes cards that reflect problems that primarily affect the caregiver and the second of which includes cards that more directly impact the care recipient. The process involved in this task facilitates the articulation and differentiation of the types of problems experienced by the caregiver and serves to identify commonali-
ties between problems. Such awareness is critical for eliciting potential solutions during the actual problem-solving procedure. The second stage of the card sort technique involves rank ordering the problems. This results in a continuum of problems that reflects the respondent’s perception of greatest to least concerns and can serve in the selection of a problem to focus on during problem-solving training, if a more immediate and pressing problem is not readily elicited.

Additionally, caregivers and their care recipients are administered the Inventory to Diagnose Depression (IDD) and the Medical Outcomes Study Short Form Health Survey (SF-36) on three occasions over a 12-month period. Self-reports on the presence of pressure sores, bladder infections, and perceived health status are collected monthly.

**Case Example**

Mr. & Mrs. B were recruited to participate in Project FOCUS during one of Mr. B’s admissions to a rehabilitation hospital following flap surgery for pressure sores on his shoulder and sacrum. Mrs. B was a 38-year-old Caucasian female who was caring for her 41-year-old husband with C4 quadriplegia, which he incurred as a result of a swimming pool diving accident several years earlier. The couple had been married over 20 years and had three sons, one of whom was 10 years old and still lived at home. They had only SSDI as a source of income and received some charity from a local church. Having no lift or in-home assistance, Mr. B rarely got out of bed. This continuously aggravated his pressure sores and resulted in open, festering wounds during most of his participation in the study. He identified smoking and watching football as his only pleasures and was described as being angry and abusive to his family. He often threatened to kill himself despite having no means to do so.

In the first card sort exercise, Mrs. B selected “Patient asks to be killed or threatens to commit suicide” and “I’ve taken all the responsibility for the patient” as the two greatest problems she encountered as a caregiver. Results of the SPSI-R identified her problem-solving orientation as extremely negative and avoidant. The initial problem-solving training session focused on Mrs. B’s tendency toward avoidance and lack of follow through and used her husband’s angry behavior as the identified problem. Mrs. B was shown how to further define the problem, identify triggers, and set goals for the problem resolution. Thus, the problem evolved to “When left alone too long, husband starts thinking about what he can no longer do and becomes angry, paranoid, and abusive.” The process of redefining the problem helped Mrs. B identify components of the situation over which she did have control, and thus reduced the likelihood of her avoiding the entire problem altogether.

The next step in the training was to identify and evaluate Mrs. B’s previous coping methods. Mrs. B indicated that calmly discussing and explaining things, shouting back or ignoring her husband, and distraction were three methods she had used with differing degrees of satisfaction (not at all, a little, and somewhat, respectively). Because distraction had been her most effective technique, Mrs. B was taught how to brainstorm strategies for distraction. The exercise resulted in her proposing 12 different activities she could use to distract Mr. B and addressed her tendency to not follow through by providing her with a list of options to which she could refer. During monthly videophone calls,
problem definition and brainstorming skills were reviewed and reinforced.

At 6-month follow-up, Mrs. B listed “Patient asks to be killed or threatens to commit suicide” as a moderate problem despite an actual increase in the frequency of such verbalizations and the necessity of an intervention with Mr. B during which he requested information about the process of starvation. At 12-month follow-up, Mrs. B reported that Mr. B’s suicidal ideation was no longer a concern as a result of her assessment of the veracity of his threats, and she listed his lack of appreciation and hateful attitude as her latest biggest problem. In fact, her solution to the latter problem was to begin nursing home placement proceedings. Mrs. B’s 12-month outcome measures revealed an increase in her tendency to have a more positive and rational approach to solving problems as well as a decrease in her avoidant and negative orientation toward problem solving. Results of the SPSI-R also evidenced an increase in impulsivity. An informal 24-month follow-up revealed that although Mrs. B did not follow through with placement and they continue to live together, Mr. B’s pressure sores had healed well, and his suicidal threats were less frequent. In addition, Mrs. B reported continued use of the problem-solving strategies she learned in Project FOCUS and added that by not leaving Mr. B alone for longer than 2 hours she is able to prevent escalation of his angry behavior.

Future Directions

To date, Project FOCUS has enrolled 61 caregiver/care recipient dyads. Participant interest and satisfaction has remained high within the sample throughout the period of evaluation despite some technological shortcomings. The minimal connection requirements (analog telephone line, a touchtone telephone, and a television set) that made the ViaTV Videophone appealing for use in this study frequently result in poor or lost connections, and the rural conditions of many of our participants’ homes resulted in power fluctuations that have disabled many of the units. Future community-based studies that use telehealth technology may well consider establishing a centralized communication center in a church, library, or other administrative building that could safely accommodate computerized or other high-tech equipment without compromising physical or technological accessibility.

The case study provides evidence that individuals who assume responsibility for providing care to a family member with a severe/chronic physical disability need the skills to negotiate a wide array of problems. Furthermore, when caregivers are provided with a structured opportunity, such as the card sort task, they may be better able to differentiate between the types of problems they encounter and to assess the relative importance of each. This in itself is a first step in effective problem solving and can be used to enhance caregivers’ sense of self-efficacy and mastery over the situation. Alternatively, caregivers who evidence great discomfort or difficulty completing the task may require a more sensitive, personalized, and time intensive approach in order to facilitate their use of supportive services.

Preliminary analyses of the card sort data procedure have revealed a clear dimensional structure to the ways in which caregivers cognitively organize the problems associated with providing care to individuals with
severe SCIs. Multidimensional scaling analyses have produced a three-dimensional model that describes three dimensions along which caregivers categorize problems: caregiver-centered problems versus patient-centered problems, basic needs versus emotional demands, and time constraints versus caregiver emotional burdens. The card sort, which is a consumer-oriented task, provides a visual representation of the cognitive structures that caregivers use to provide semantic meaning to the problems they encounter. This technique can provide insights that result in more effective screening tools and targeted interventions; this technique encourages caregivers to approach problems according to type as a first step to solving them instead of approaching the problems as a list of distinct issues. Thus, crisis management, recruitment of other family members for assistance, or caregivers’ participation in counseling or support groups are some of the possible clinical interventions resulting from this methodology.

Critiques of the intervention research carried out in family health psychology observe that psychoeducational and cognitive-behavioral strategies are consistently more effective than other theoretical modalities, because these approaches address the specific needs of family members and actively involve family members. Effective interventions tend to address the problems experienced by families and that help families to become more active and skilled in their self-management, while operating as formal extensions of the health care system. Family caregivers and patients who live with physical disabilities have more influence on their day-to-day health than any single professional health care provider. Therefore, these persons should receive a degree of training, support, and skill development commensurate with the expectations and demands placed on them for adherence and performance of duties.

Unfortunately, current rehabilitation practices do not adequately prepare family caregivers for the demands they encounter. Community-based, in-home programs may be the most cost-effective way to assist and support family caregivers. Long-distance telehealth programs like Project FOCUS may constitute a strategic way to meet the needs of most family caregivers of persons with SCI. Nevertheless, these programs must strive to maintain a high degree of clinical expertise to identify persons at risk for severe complications or who exhibit ongoing maladjustment. Such individuals may require the services of health care providers in a more traditional format and setting. Program evaluation research and predictive models will help us identify family caregivers and care recipients who may respond optimally to telehealth services and those who may require more intensive therapeutic interventions from highly skilled staff.

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REFERENCES


APPENDIX

Telephone Follow-up Problem Scenarios

**Month 1:** You are having trouble making enough money to cover expenses (e.g., mortgage/rent, food, medical expenses).

**Month 2:** Loved one (care recipient) is feeling depressed and suicidal.

**Month 3:** Loved one (care recipient) is abusing alcohol and/or other substances and this is impacting family life.

**Month 4:** You have become ill (or disabled) and have difficulties caring for your loved one (care recipient).

**Month 5:** Loved one (care recipient) has lost interest in usual social activities.

**Month 6:** You are having problems communicating with the medical team.

**Month 7:** You have interpersonal conflicts with someone other than your loved one (care recipient) (e.g., co-worker, neighbor, friend, other family member).

**Month 8:** You are worried about maintaining your job because of your caregiving duties (e.g., missed work, decreased quality of your work, having to take time during work for phone calls regarding caregiving duties).

**Month 9:** Loved one (care recipient) needs to see the doctor but will not go.

**Month 10:** Loved one (care recipient) will not take responsibility for his/her own self-care to the extent that he/she is able.

**Month 11:** Loved one (care recipient) is having frequent bowel and/or bladder accidents.

**Month 12:** You are feeling overwhelmed with your responsibilities assisting your loved one (care recipient).