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Telehealth for Persons with Severe Functional Disabilities and their Caregivers: Facilitating Self-care Management in the Home Setting

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Abstract

Persons with severe functional disabilities are the highest users of health care services. Caring for the needs of this population represents a significant percentage of our national health care costs. A growing body of research has demonstrated the efficacy of self-management strategies and caregiver engagement for effective long-term care for individuals with chronic medical conditions. Economic forces over the past decade have led to new challenges and resulted in major changes in health care delivery resulting in shortened length of inpatient stays and greater limits on the length of outpatient treatment. Telehealth is an innovative method for health care delivery and a means of meeting this new challenge. This paper highlights the findings of three pilot studies on the use of telecommunications technologies in promoting self-care management and enhancing health care outcomes in persons with severe disabilities and their family caregivers. The importance of matching technology to the needs of this population, lessons learned from these investigations, and future directions for research are addressed.

Keywords

telehealth; functional disabilities; caregivers; self-care management

The growing complexity and high costs of today's health care environment have made it increasingly important for persons with severe functional disabilities and their caregivers to engage in self-management practices and assume a more proactive role in organizing, monitoring, and tracking their health care outcomes. This is particularly important for the one in 10 Americans who have a chronic medical condition, such as stroke, diabetes, heart

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disease and mental illness. Chronic illnesses cost the U.S. approximately \$1.3 trillion annually, of which \$1.1 trillion/year is associated with lost productivity and \$277 billion/year is spent on treatment (DeVol et al., 2007). The largest proportion of these health care and lost productivity expenditures result from individuals with severe functional disabilities, such as stroke and traumatic brain injury. Although these populations are fewer in number than other medical conditions, they typically require more intensive medical treatment, ongoing specialty care and significant family caregiving assistance (Shigaki, Johnstone, & Shopp, 2009; American Health & Drug Benefits, 2009).

Active engagement in self-management strategies (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Woolf et al., 2005) and family participation (Shearer et al., 2007) are critical for the treatment and effective long-term care of chronic disabilities. Effective self-management hinges not only on promoting informed choice, but also in engaging individuals with chronic illnesses and their family caregivers in the development of problem-solving skills and coping strategies (Bodenheimer et al., 2002). Key components of effective self-management include the development of behavioral skills in performing recommended strategies for optimal health (e.g., blood pressure monitoring, exercise, and problem-solving skills), negotiating with health care professionals on effective intervention methods, and adherence to treatment regimens. Previous research has documented the efficacy of self-care management for chronic illnesses across a variety of outcomes, such as improved coping, improved quality of life, and disease control (Del Sindaco et al., 2007; Gately, Rogers, & Sanders, 2007; Hurley et al., 2007; Kennedy et al., 2007).

With increased emphasis on self-care management, family caregivers are often required to assume an active role in promoting and helping manage care recipient adherence to self-care management tasks (Elliott & Shewchuk, 1998). Research has indicated that family functioning and perceptions are key determinants of therapeutic alliance for individuals with severe disabling conditions, such as traumatic brain injury (TBI), and promote adherence with interventions (Prigatano et al., 1994). Therapeutic alliance is a concept derived from the psychotherapy literature and has been applied to the therapeutic process in the rehabilitation setting. This collaboration between client and provider serves as a mechanism to promote adherence with treatment goals and can also apply to collaboration among therapists, persons with disability, and caregivers. The research of Shearer et al. (2007) evaluated the influence of strength of therapeutic alliance and found that family alliance with the care recipient facilitated the latter's adherence to the treatment regimen.

A promising development in self-care management has been the growth in the use of telecommunication technologies to increase access to treatment, reduce cost, and enhance intervention adherence. Telecommunication technologies, especially Instant Messaging (IM), the videophone, and the regular telephone, have the capacity to extend the reach of self-management education programs to individuals with chronic illnesses and their caregivers in a number of ways. These technologies are robust, low cost and widely available in facilitating access to health care services, and are capable of overcoming geographic and time barriers.

In their recent comprehensive review of 71 randomized clinical trials, Glueckauf and Lustria (2008) found that technology-based delivery of self-care programs for managing chronic illnesses (e.g., diabetes and cardiac disorders) were significantly more effective than routine, in-person medical care. Furthermore, in the subset of investigations comparing the same self-care management programs, in-person versus telehealth-based (i.e., Carlbring et al., 2005; Rotheram-Borus et al., 2004; Verheijden et al. 2004; Woollard et al., 2003), all four studies showed positive and similar improvement between groups on a variety of health outcomes. Note, however, that most of the 71 randomized trials in Glueckauf and Lustria's

review focused on tertiary prevention and thus, included participants with only limited restrictions in activities of daily living.

Although these findings are encouraging, the prospect of extending telehealth, self-care management programs to individuals with severe functional disabilities has not been realized. This consumer group and their family caregivers are high users of health services, tend to bear disproportionately larger health cost expenditures and are underrepresented in telehealth self-care management studies. Thus, the primary purpose of this article is to present the findings of three recent pilot studies addressing the self-care management requirements of this underserved population using telehealth technologies tailored to the special needs of this group.

The plan of the paper is as follows: First, the trends in health and rehabilitation care for persons with severe functional disabilities will be discussed, as well as matching the technology to the specific characteristics of this population. Second, three pilot studies will be presented. The first study (IM-based) will address self-care management for individuals with acquired brain injury (ABI). The second study (videophone-based intervention) will examine the effects of home-based, self-care management for persons with stroke assisted by their family caregivers. The third study (telephone-based intervention) will focus on home-based, self-care management for family caregivers of older adults with dementia. Last, lessons learned from the three investigations and future directions for telehealth research with individuals with severe disabilities will be explored.

Trends in Health and Rehabilitation Services for Persons with Severe Functional Disabilities

As the U.S. population ages, health care organizations will provide rehabilitation services for increasing numbers of people with severe functional disabilities to enhance their participation in employment, community activities, and interpersonal relationships (Elliott & Shewchuk, 1998). Such individuals may be born with a disabling impairment or acquire one later in life, such as spina bifida, musculoskeletal disorder, heart disease, mental illness, or other neurological disorders, such as stroke and epilepsy. Functional limitations refer to physical or mental conditions, which impair, interfere with, or impede one or more of the individual's major life activities and instrumental activities of daily living (World Health Organization, 2001). A severe disability may seriously limit three or more functional capacities such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills.

Rehabilitation therapies typically involve a cadre of health care professionals, such as psychiatrists, physical therapists, occupational therapists, speech-language pathologists, medical social workers and rehabilitation psychologists. This team of interdisciplinary professionals works collaboratively to help rehabilitate people with impaired motor, cognitive, perceptual, and social abilities on how to compensate or regain function. This is often a long-term process, sometimes taking months or years to reach optimal outcomes. Due to the extended length of recovery from severe disability, family caregivers are also an integral member of the team to ensure that their care recipients continue to make progress toward the treatment goals once discharged from the medical setting. The role and resiliency of the caregiver are instrumental to the successful re-integration of the person with disability to the home and community (Forducey, 2006).

Multiple and complex health care changes over the past few decades have altered significantly how rehabilitation is conducted across the continuum of care from the acute inpatient rehabilitation hospital, to the outpatient rehabilitation clinic environment and

within the home setting. Historically, rehabilitation therapies had been paid under a cost-based reimbursement plan, enabling a rehabilitation facility to charge for all services rendered separately. In January 2002, the Centers for Medicare and Medicaid enacted the prospective payment system (PPS), which provides a single payment to an acute inpatient rehabilitation facility to pay for healthcare needs. Since then, private insurance payers have followed suit with similar reimbursement structures. The payment given is based on the clinical characteristics of the individual and expected resources that will be needed for care, rather than on actual reasonable costs incurred. Financial constraints and decreased lengths of stay imposed by PPS have challenged rehabilitation facilities, requiring these facilities to re-examine resource utilization and organizational effectiveness.

Another reality is that most comprehensive rehabilitation services are typically available in urban areas, often some distance from persons in most need of them. As a result, many persons with severe functional disabilities are often a considerable distance from the concentrated rehabilitation services that may most benefit them during their recovery process. Telehealth is a viable and innovative alternative to manage the ongoing care and recovery of individuals with severe disability and their caregivers who reside in communities where there is limited to no rehabilitation services or to consumers who lack transportation to urban-based rehabilitation (Forducey, 2006; Palsbo, Dawson, Savard, Goldstein, & Heuser, 2007).

Matching Technology to the Needs of Persons with Severe Functional Disabilities

Researchers have explored the use of telehealth technologies to provide follow-up self-care management and booster interventions (e.g., Glueckauf & Lustria, 2008; Pickett et al., 2007) and have demonstrated that home-based telehealth technologies can be used to optimize coping and community integration skills for adults with severe functional disabilities (Dorstyn, Mathias, & Denson, 2011). However, the key issue is how best to implement these telehealth-based interventions for persons with disabling chronic conditions and their family caregivers in the home. Since technology literacy and preferences tend to vary, it is crucial that telehealth investigators and providers collaborate with the person with disability and family caregiver to ensure that the telehealth technologies are tailored to their specific needs (Scherer, Sax, & Glueckauf, 2005). The result of a technology-based intervention extends beyond the device itself and involves a personalized blend of supports, including the technology, environmental accommodations and strategies, and support from significant others. The prerequisite task for achieving the appropriate balance of supports and accommodations is a comprehensive evaluation of the characteristics of the technology, the individual, and the relevant environments that may affect the match between the consumer and an assistive device (Scherer, 2002).

Another important factor to take into account in matching technology to the needs of the consumer is cost. A substantial proportion of persons with severe disabilities are economically disadvantaged and thus, may be unable to afford the costs of purchasing computer equipment and monthly Internet Service Provider costs. However, the majority of this population is likely to have telephone service in the home to coordinate care, to maintain close family relationships, and to facilitate socialization. The low cost, ease of use, and universality of telephone technologies make intervention with this modality especially attractive. Case in point, most telehealth research with family caregivers of persons with disabilities has been performed using a regular telephone and the overall results of these studies have been positive (Glueckauf & Noel, 2011). However, in organizing such family caregiver interventions, providers should assess whether the home environment is conducive to telephonic intervention. During the treatment process, external noise levels should be

sufficiently low to permit clarity of verbal exchanges; distractions from other family members should be kept at a minimum; and privacy should be assured in the home environment to protect confidentiality of caregivers' personal disclosures (Toseland, Maccarato, & Wray, 2007). If not managed properly these situational disturbances may lower the integrity of the telecommunications treatment intervention.

The following three studies represent a seminal effort in addressing the paucity of research on the use of telehealth for persons with severe functional disabilities and the shortcomings in matching technology to the needs of this population. These telehealth interventions were situated in consumers' homes to ensure continuity of clinic-based rehabilitation, such as cognitive rehabilitation (CR) for young adults with ABI, physical therapy (PT) and occupational therapy (OT) to enhance the mobility of persons with stroke, and training for family caregivers of older adults with dementia.

Telehealth for Persons with Severe Functional Disabilities and their Family Caregivers

Three pilot studies are presented to examine the potential impact of telehealth-based interventions for persons with severe disabilities using inexpensive, low-end telecommunication devices. These investigations have incorporated IM, videophone, and telephone-based technologies as a vehicle for extending specialty service into the homes of individuals with disability and their caregivers. Note that lessons learned from each of the pilot studies will be included in their respective Results and Discussion sections.

Study 1 IM and ABI

Both traumatic brain injury (TBI) and other types of ABI are an immense public health problem and a common cause of disability in the U.S. (Zaloshnja, Miller, Langlois & Selassie, 2005). Some of the most common symptoms and causes of disability following ABI are changes in cognitive functions, such as memory and problem-solving. While health care and rehabilitation services have seen significant growth in the last several decades, such services are typically available in urban areas, often some distance from persons living in rural settings. As a result, many persons with ABI are often considerable distance from services that may help them. There is increasing support of clinic-based treatment, such as CR, as a means of helping persons with an ABI to improve their functioning and level of independence (Cicerone et al., 2000). Telerehabilitation, defined as the application of telecommunication technology to provide support, assessment and intervention at a distance to persons with disabilities (Burns et al., 1998), may help provide services to assist individuals with ABI who live some distance from specialized rehabilitation centers to receive needed treatment.

One concern is that cognitive impairments common in persons with ABI may prevent them from using websites that have links to various training content. However, using a simple chat solution, such as IM, to facilitate CR training can simplify the process into a two-step procedure. It has the added advantage of displaying the thread of discussion with the therapist by simply scrolling up or down the window, thus helping to compensate for memory problems.

A second concern is whether CR can be conducted effectively within an IM system. Previous research has found that a sizable proportion of individuals with ABI report that they require assistance from others to use a computer (Ricker et al., 2002). This observation has been used to buttress the arguments by some that computer technology may not be a feasible approach to deliver therapy (Wade & Wolfe, 2005). However, only limited research

has been performed examining the ability of individuals with ABI to access Internet-based rehabilitation services.

In an initial study, our research team found that individuals with objective memory impairments after moderate-to-severe ABI were able to use IM to receive CR from a qualified therapist providing this therapy at a distance (Bergquist, Gehl, Lepore, Holzworth, & Beaulieu, 2008). In a second study, we investigated whether this intervention was associated with an improvement in functioning. A total of 21 participants were provided CR using IM. Following a total of 60 scheduled Internet therapy sessions, in which the focus was on independently keeping track of the scheduled online sessions, journaling and reviewing journal entries with the therapist, participants reported an increased use of compensatory strategies and family members reported improvements in mood and day-to-day memory functioning (Bergquist et al., 2009).

In the present study, we used a randomized controlled design comparing an active CR condition with a waiting list control condition. Based upon previous studies, we predicted that CR delivered via IM would be associated with an increase in level of independence and decrease in activity limitations. We also hypothesized that this increase would be associated with an increase in compensation strategy use.

Method

Participants—A total of 15 adults (8 males and 7 females) of 22 consented community dwelling adults with ABI completed the study. Descriptive summaries revealed no significant differences in demographic variables, living status, or memory performances between those who completed the study and those who did not. Participants were recruited over an 18-month period from various agencies serving persons with brain injuries and from electronic postings through regional brain injury associations in Iowa, Minnesota, and Wisconsin.

Inclusion criteria—Participants were included in the study if they: (a) had a medically documented history of moderate to severe ABI, (b) 12-months post-ABI prior to study initiation, (c) had a sixth grade reading level on the Wide Range Achievement Test (WRAT-3; Wilkinson, 1993), (d) had evidence of memory impairment on neuropsychological testing, and (e) self-report of memory complaints and associated reduction of participation in daily activities. Participants were excluded if they: (a) did not have a medically documented history of ABI, (b) were less than one year post-injury, and (c) were unable to demonstrate competency of the IM system after training was provided.

Of 15 participants who completed the study approximately half (53%) were male and 67% were married. They were on average 43 years old (range 22 to 63), 55% had at least some college education, and all had obtained a high school diploma. All participants were Caucasian. The majority (93%) lived with one or more family members and many (78%) were independent in basic activities of daily living (i.e. hygiene, grooming, and dressing). Sixty four percent were unemployed. A median length of time since injury was 56.5 months (range 13–457 months), with two participants recruited within 1 to 2 years post-injury, seven participants within 2 to 6 years post-injury, and seven participants within 10 to 30 years post-injury. In regard to compensatory strategies, 21% said they used a calendar or a planner at least once a day prior to study participation. Thirty one percent of participants who were diagnosed with either depression or anxiety were currently seeing a therapist, 41% were taking antidepressants, and 13% (3 individuals) were involved in both types of treatment.

Therapist and psychometrist training—One therapist provided intervention for this study. The therapist had a Masters degree in Psychology with extensive clinical experience

in providing CR. Several psychometrists administered the screening and dependent measures, all of whom had comprehensive experience in the administration and scoring of neuropsychological tests. Both the therapist and each of the psychometrists worked under the supervision of a licensed doctoral-level psychologist.

Procedure—All participants in this IRB-approved study signed the written informed consent form prior to participation. After providing consent, participants were randomized to one of two crossover conditions: active treatment (AT) vs. waiting list (WL). AT involved participating in a total of 30 sessions of calendar training in a crossover study design with half of the randomized individuals receiving AT first, while the rest were placed in a WL condition first. After an initial period of training, an experienced therapist conducted all treatment sessions via an IM system previously described in detail in Bergquist et al. (2009).

All participants underwent a brief neuropsychological evaluation to: (a) document the extent of memory impairment, and (b) to determine whether there was significant level of memory impairment required to be eligible to participate in the study. Based on demonstrated memory impairment, those eligible participants completed the other measures at baseline, and then again following the AT and WL conditions. Psychometrists, who were unaware of the participants' assignment to condition and of information obtained by the treatment therapist, administered all dependent measures. Dichotomously coded scores on the independent living scale were used to classify level of independence and served as the primary outcome measures.

AT involved participating in 30 sessions of calendar use, acquisition training based on the three-step procedure described by Sohlberg and Mateer (1989). Calendar use skills were introduced and practiced in one-on-one sessions with a therapist via IM system in order to develop more effective compensatory strategies use to aid independent functioning in daily life. The WL control condition did not involve any treatment. At the end of the first phase of the study (i.e. AT or WL), all participants were re-administered the neuropsychological evaluation. Following the second assessment, persons in the WL (control) condition started AT, while those who had received the AT first were then placed in the WL condition.

Dependent measures—The first dependent measure was the Repeatable Battery of Neuropsychological Assessment (RBANS; Randolph, 1998), which is a brief psychometric battery administered to subjects to assess cognitive functioning across five domains: (a) Immediate memory, (b) Visuospatial/Constructional, (c) Language, (d) Attention, and (e) Delayed Memory. The second measure was the Independent Living Scale (ILS; Malec et al., 1993), which is a 3-point ordinal scale that quantifies individuals' degree of residential independence. This scale assesses the participant's level of required supervision in daily life and includes 3 categories: (a) requires 24-hour supervision, (b) requires less than 24-hour supervision, or (c) is fully independent/no supervision required. The ILS was dichotomized as dependent (i.e. requiring some supervision) versus independent (i.e. fully independent/no supervision required) and was examined as a primary outcome variable. The final assessment tool was the Compensation Techniques Questionnaire (CTQ) (Kupachi, 2002), which is a self-report measure of compensation strategies use (e.g. calendar, planners, cue cards) with each compensatory technique rated on a 7-point Likert scale. Selected questions were used from this instrument based upon our prior research (Bergquist et al, 2009).

Statistical analyses

Wilcoxon rank sum test or Chi-square test (or Fisher's exact test) were utilized as appropriate to examine the differences on demographic, memory, and primary outcome measure between those who completed the study and those who did not. Similar

comparisons were made between the two randomized groups of study participants to assess whether the groups were comparable at baseline. In order to examine treatment changes following this cross-over study design, the changes from baseline to end of the AT condition and from baseline to assessment following WL were calculated for each participant. Wilcoxon signed rank test compared these paired differences due to small sample size and non-Gaussian distribution of data. Spearman rho correlations examined the relationship between compensatory strategy use and independent functioning at baseline and following active treatment and control conditions. All statistical tests were two-sided and the alpha value of $p = 0.05$ was considered statistically significant.

Results—Changes in independent functioning after completion of 30 sessions of AT were compared to changes in functioning after the WL control condition. Wilcoxon signed rank test showed significant treatment differences in independent functioning following active treatment 'calendar training' condition compared to the control 'waitlist' condition ($Z=4.2$, $p=.04$). Specifically, 86% of participants were rated as independent following active treatment compared to 64% of participants rated as independent following control condition. Spearman correlations examined the relationship between independent functioning level and compensatory strategy use to describe the association between specific intervention related variable (i.e. compensatory strategy use) and outcome variable (i.e. independent functioning). Greater independence after treatment was positively correlated with more frequent calendar use at baseline and following treatment ($r=.59$, $p=.03$; $r=.58$, $p=.04$, respectively). Although there were no statistically significant differences on demographics, injury, or memory impairment between the completers and the non-completers based on the Wilcoxon rank sum test or Chi-square test, a trend was observed for those who did not complete the study to be single ($\chi^2=7.57$, $p=.06$).

Discussion and lessons learned—Our earlier research suggested that baseline use of compensation strategies, not level of cognitive impairment, was associated failure to complete the study. In the current study, greater improvement after treatment was associated with both more frequent use of compensation strategies at the beginning of the study and following completion of treatment. It may be that persons with some baseline level of compensation use are either more amenable to or better able to profit from IM-based treatment.

After demonstrating the ability of persons with ABI to independently use IM to receive therapy in previous studies, this randomized controlled study demonstrated a modest but significant improvement in functioning over the course of treatment. Although preliminary in nature, this research is promising and suggests that IM-based telerehabilitation with persons with ABI is associated with greater independence.

Turning to lessons learned, Malec and Basford (1996) have advocated that appropriate selection of a particular treatment approach should be based primarily on measures of activity and activity limitations rather than on the person's diagnoses or level of impairment. In other words, it is not so much injury, but the level of activity and activity limitations during therapy which should be the basis of making decisions about the staging of specific treatment approaches in post-acute brain rehabilitation.

The results of the current pilot and two prior, related studies suggest that telerehabilitation leads to significant improvement in the level of independence for persons with ABI. Our two previous studies found that treatment works best in persons who have achieved a baseline level of independence requisite for effective use of telerehabilitation in the home environment (Bergquist et al, 2009; Bergquist et al, 2010). We have yet to determine whether this finding was replicated in the current pilot study. As with other forms of post-

acute rehabilitation, it may not be sufficient to ask whether telerehabilitation is effective, but rather to determine which subpopulations of persons with ABI, and in which stage of recovery, will CR be most effective.

Study 2: Videophone for older adults with stroke and caregivers

Stroke is one of the most significant health problems in the U.S. and is the third leading cause of death and the leading cause of adult disability (Demaerschalk, Hwang, & Leung, 2010). Persons with strokes frequently experience decreased quality of life including impaired mobility and diminished levels of activities of daily living (ADLs). Common impairments experienced by individuals with strokes include hemiparesis, aphasia, apraxia, visual impairments, and decreased cognitive status. These impairments may result in multiple functional limitations including simple self-care deficits, problems in basic physical movement, difficulty relating to their environment, and alterations in their life roles and social interactions.

Providing good outcomes to older adults with strokes is time-dependent, labor intensive, complicated and requires coordination of multiple clinical services (Rymer, Summers, & Khatri, 2007). It is also crucial that the rehabilitation professionals coordinate stroke care with family caregivers since stroke affects not only the person with the disability, but also the family as a whole (Gordon & Hibbard, 1997; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002).

Coordination of stroke care can be compromised further by geographic barriers and by the lack of stroke rehabilitation specialists in rural parts of our country. Although many adults with stroke receive comprehensive and well-coordinated rehabilitation services in rehabilitation hospitals located in urban areas, these services often are not extended to the rural areas. Long-term interventions are usually required for persons with stroke to achieve optimal physical and psychosocial recovery. Family members who function as primary caregivers frequently serve as informal extenders of health care systems (Wagner, Austin, & Von Korff, 1996). With this trend in rehabilitation, telehealth may represent a viable and innovative solution to extend stroke care to rural individuals with disabilities.

The American Heart Association/American Stroke Association (Schwamm, et al., 2009) recently reviewed the evidence for the use of telemedicine within stroke systems of care. The organization concluded the evidence is sufficient to support the efficacy of telemedicine for acute stroke treatment, including hyperacute, and emergency department phases. However, there is limited research on the outcomes of telehealth-based interventions for older stroke adults following discharge from acute inpatient rehabilitation settings (Palsbo, Dawson, Savard, Goldstein, & Heuser, 2007).

Thus, the purpose of our pilot study was to compare the effects of home-based telehealth versus standard home care services on changes in emotional and physical health status for older persons with stroke. We hypothesized that rehabilitation services provided by a PT and an OT via telehealth would be as clinically effective as the current standard home care intervention, for individuals who sustained an acute stroke. Clinical effectiveness was defined as positive impacts on one's quality of life through functional improvements in the stroke patient's ability to ambulate and to perform ADLs.

Method

Participants—Based on census data from Samaritan, a home care agency of INTEGRIS Health, an Oklahoma-based not-for-profit health care organization, we anticipated a sample size of 32 persons with stroke (16 participants in the telehealth intervention group and 16

participants in the standard home care control group). However, only 16 adults with first time strokes were recruited over a 12 month period (see lessons learned below). Eleven of these participants were enrolled in the pilot study. Two dropped out following the first visit which left 5 standard of home care and 4 telehealth participants. Each person with stroke was targeted to receive a total of 12 treatment sessions, 6 PT visits and 6 OT visits. The average duration of treatment was six weeks (i.e., two treatments per week, one being from the PT and the other treatment being from the OT). On average, the telehealth subjects received 6.0 PT treatments and 6.75 OT treatments, whereas the standard of home care subjects received 10.6 PT treatments and 7.4 OT treatments.

The mean age of the sample was 60 years, with a range between 47 to 75 years. Of 11 stroke participants who completed the study, 5 were female and 6 were male. Nine of the participants were Caucasian and 2 were African American. Eight participants were married; 2 were divorced; and 1 was single.

Inclusion and exclusion criteria—Participants were included in the study if they: (a) had a first time medical diagnosis of acute stroke, (b) the onset of stroke was six months or less, (c) had either Medicare or Blue Cross and Blue Shield insurance coverage, (d) moderate deficits in the areas of self-care, functional mobility, transfers as documented by the Functional Independence Measure (FIM; Granger, Hamilton, Linacre, Heinemann, & Wright, 1993), (e) had a caregiver present to set up telehealth videophone device. Participants were excluded from the study if they: (a) had aphasia (unable to understand or express basic wants and needs), or (b) a Major Depressive Disorder as measured by the Beck Depression Inventory II (BDI-II; Beck, Steer, & Brown, 1996).

Therapist description and clinical experience—Six therapists participated in this study. One PT and 1 OT administered dependent measures to both intervention and control subjects. Another PT and OT provided therapy via the videophone to the intervention group, whereas a different PT and OT provided in-person home health care. The six therapists were required to have a minimum of 4 years of rehabilitation experience with at least 6 months of clinical experience within the home health setting.

Technology solution—The technology deployed in this study was a desktop videophone using standard telephone lines. This technology facilitated direct video calls between the care recipient and their caregiver and the PT and OT. The transmission quality of videophones has improved greatly and produces a sharper image and smoother motion with less time delay. The videophone equipment expenses were low and the technology was “user friendly” and, in many cases, less complicated than operating a remote control.

Note that the videophone device used by the PT and OT, who were located at INTEGRIS Jim Thorpe Rehabilitation Hospital, connected to the same device at the participants' homes, which was a H.324 standard compliant device. This unit operates with an array of external audio-video devices, cameras, monitors, and projection devices as well as television displays. The maximum transfer rate was 33.6 kbps with video streaming at 20 to 24 frames per second, which facilitated observation of the person with stroke's physical presentation and movement. patterns. The PT and OT were also able to adjust the frames-per-second to observe a clearer picture, although motion quality was somewhat reduced.

Dependent measures

First, the FIM, a widely-used functional assessment measure, was used to measure the degree of disability of the person with stroke (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993). The FIM includes 13 motor items (e.g., eating, grooming, and toileting) and

five cognitive items (e.g., comprehension, social interaction, and memory). This 18-item ordinal scale enables rehabilitation providers to document the severity of disability and burden of care. Individuals who score 1–2 are dependent on a caregiver; 3–5 indicates that the person requires varying levels of assistance from another person, and individuals who score a 6 or above are able to function independently.

Second, the Short-Form 12 (SF-12; Resnick & Nahm, 1996) assesses the mental and physical health status of adults and is a multidimensional generic measure of health-related quality of life. This instrument has a five-choice response ranging from “all the time” to “none of the time” and is widely used in routine outcome assessment because of its brevity and psychometric rigor (Brazier & Roberts, 2004). The SF-12 was developed to describe physical functioning components include physical role, bodily pain, and general health while the mental health component consists of emotional role, vitality, social functioning, and mental health.

Procedure

Following screening and informed consent, each subject was randomly assigned into either the intervention (videophone technology) or the control (standard home care) group. Before therapy began, each subject received the initial administration of the dependent measures. The treatment plan of care was identical for both groups and included education and highly structured intervention techniques for self-care (e.g., feeding, dressing, toileting and bathing); home modifications (e.g., equipment needs and education about home safety); functional mobility (standing tolerance and gait skills); and posture (trunk symmetry, trunk control and alignment). Treatment focused on restoration of impaired segments (arms and/or legs) through resolution of motor deficits. Specific strategies were left to the discretion of the PT and OT, but guidelines for sequencing and grading relative range demands, muscle demands, activity selection and input were employed. Written material regarding stroke risk factors, warning signs, and community-based support groups were provided to patients and their caregivers. One week following the completion of the study, the dependent measures were re-administered to both the intervention and control groups. Participants in the telehealth intervention group were offered standard of home care services.

Research design

The design of this institutional review board (IRB) approved study was a prospective clinical randomized, repeated measure design with multiple dependent variables. The key dependent measures were the FIM and SF -12.

Results

Between-group *t* tests showed no significant differences between the videophone intervention and the standard home control groups on demographic, medical, and background factors, as well as the pretest scores of the dependent measures (all *ps* > .05). Within-subject *t* tests were used to test for differences within treatment groups over time. Significant pre-post differences were found for both the videophone and standard of care treatment conditions on the FIM and SF-12 (all *ps* < .05). Both groups showed significant improvements on functional independence and mental and physical health status from pre- to posttreatment. In addition, no significant differences on the change scores of the two dependent measures were found between the videophone and the standard home care conditions. Furthermore, the number of treatment encounters was significantly lower in the telehealth intervention group than the control condition.

Discussion and lessons learned

Improvement in standardized measures of psychosocial and physical functioning were similar between those receiving telehealth and standard home care treatment. However, the number of visits required to achieve clinically meaningful outcomes was significantly lower in telehealth-based treatment than in standard home care. This pattern of results suggests that telehealth may provide a cost effective alternative to standard home care services. A key direction for future research will be to evaluate the incremental cost effectiveness of videophone versus standard home care in a large sample of persons who have sustained an acute stroke. Further investigation is also needed to determine whether the findings of this preliminary study will be replicated.

Three major lessons learned emerged from this pilot study. First, it is essential to educate both internal and external stakeholders (clinicians, administrators, technologists) of the potential benefits of telehealth. This pilot project was executed shortly before PPS, when there was a payment structure for rehabilitation education and development departments within rehabilitation hospitals. Once PPS became the reimbursement model for acute inpatient rehabilitation, the research and development department sponsoring this study was dissolved, including many of the staff that provided video-based PT and OT services. Thus, although this research initiative showed favorable preliminary support for telerehabilitation provided by PT and OT, we were delayed in building on the findings of the current pilot study and were unable to compare health service utilization and the treatment costs between the telehealth and standard home care groups.

Second, the funds were limited and the recruitment timeline was too aggressive for our pilot study, which adversely impacted our capacity to achieve our sample accrual target of $N=32$. Third, we learned it is paramount to closely align telehealth initiatives with organizational strategy, mission and vision. Our health care organization had multiple 'late adopters' not well informed of the benefits of integrating telehealth into service lines, such as rehabilitation. However, it should be noted that in the past two years with the advent of health care reform, our health care organization has begun to realize the value and viability of using modalities, such as videophone technology, to extend specialty rehabilitation services to persons with severe disability in the post-acute milieu. The adoption and success of other telehealth programs, such as our TeleStroke Network, which provides emergent stroke care management services to emergency departments in rural parts of Oklahoma, has also reinforced the value of using technology to increase access for individuals who have sustained stroke in medically underserved areas in our state. Thus, we anticipate that our initial pilot study is likely to evolve into a full-scale telerehabilitation in the near future.

Study 3: Telephone-based Cognitive Behavioral Therapy (CBT) for African-American Family Caregivers of Older Adults with Progressive Dementia

The vast majority of adults with dementia (87%) receive ongoing care and support in the home setting from family members (Alzheimer's Association and National Alliance for Caregiving, 2004). Family caregivers (CGs) are confronted with a variety of challenges in providing assistance to older adults with progressive dementia, such as monitoring hygiene activities and dealing with agitation and angry outbursts. Such intensive home care activities are performed at high cost to CGs who experience significant psychological distress, sleep fragmentation, reductions in social activities, as well as disrupted family relationships, leaving CGs at substantial risk for mental health problems, especially depressive disorders (Gallagher-Thompson et al., 2000; McCurry, Logsdon, Teri, & Vitiello, 2007) and compromised physical health (e.g., Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996). Across ethnicities, the prevalence rates of clinically diagnosable depression in dementia CGs ranges from 27% to 50% (Ory, Yee, Tennstedt, & Schulz, 2000). However,

African-American (AA) CGs are less likely to receive mental health services than majority White CGs for depression and other mood disorders (e.g., Pinquart & Sorensen, 2005).

Previous randomized clinical trials assessing the effects of psychosocial intervention for underserved, distressed AA CGs of adults with progressive dementia have been limited in number. These studies (i.e., Belle et al., 2006; Burgio et al., 2003; Glueckauf et al., 2007) used a variety of CBT strategies, such as basic information about dementia, relaxation, assertiveness skills training, and problem-solving counseling. Furthermore, all three studies included a non-Hispanic White comparison sample and a telehealth component (i.e., telephone) in delivering the CBT intervention, ranging from five of 16 sessions (Burgio et al., 2003) to 12 of 12 sessions (Glueckauf et al., 2007). Significant improvements in AA CG coping skills were noted across all three investigations (e.g., increases in caregiving self-efficacy and problem-solving skills). However, little or no change in depression, the key indicator of clinically significant improvement in distressed AA CGs, was found across these studies from pre- to post-treatment. In explaining similar null findings in dementia CG intervention research, Schulz et al. (2002) argued that CBT outcome studies should focus on CGs who meet criteria for clinical depression, thus promoting the use of CBT for dementia CGs at greatest risk for negative emotional sequelae (e.g., major depressive disorder) and reducing the possibility of floor effects on measures of depression in subsequent intervention research.

To address these significant health service utilization and methodological issues, Glueckauf (2008) compared the effects of telephone-based CBT versus in-person CBT on changes in depression and health status in distressed AA CGs. This ongoing investigation was divided into two major phases. First, a pilot study ($N = 11$) was performed to evaluate: (a) the preliminary effects of in-person versus telephone-based CBT on changes in subjective burden, assistance support, depression and health status in AA dementia CGs, and (b) CGs' appraisals of the intervention process and its impact on daily caregiving experiences. Second, an ongoing randomized clinical trial was initiated: (a) to test the equivalence of telephone-based ($n = 53$) versus in-person CBT ($n = 53$) on changes in CG depression and health status, (b) to examine the relationships among socio-demographic factors, caregiving stressors, CG appraisals of resources, depression, and health status, and (c) to examine patterns of utilization and costs of CG mental and physical health services between the two conditions. The key quantitative findings of the study are described below.

Method

The design of this IRB-approved study was a pre-post, two-group (i.e., telephone-based versus in-person CBT), randomized trial. Assignment to treatment was performed in two steps:

Step 1—After obtaining informed consent, prospective participants were screened over the telephone to evaluate their level of depressive symptomatology, caregiving responsibilities and stressors, care recipient location, as well as to obtain background medical and demographic information, and document any hearing and reading difficulties. In addition, prospective participants were asked to provide basic information about their telephone equipment and service, as well as needs for respite care and transportation to facilitate delivery of the CBT intervention.

Step 2—After completing the initial screening evaluation, an independent interviewer from the Florida State University (FSU) Survey Research Laboratory (SRL) scheduled a one-hour, follow-up phone call to administer the dependent measures to eligible participants. Subsequently, CGs were randomly assigned to either telephone-based CBT ($n = 6$) or f-to-f

CBT ($n = 5$). Post-treatment assessments were also administered over the telephone by an independent interviewer from the FSU SRL across both groups approximately one week after the 12-week CBT program. The interviewer was unaware of assignment to treatment condition.

Participants—Twelve AA CGs, six from Tallahassee and six from Jacksonville, Florida participated in the pilot study. Six were randomly assigned to telephone and six to in-person CBT. One female CG dropped out after the 3rd session due to physical illness. Of the 11 study completers, 10 CGs were female and one was male. In both the pilot and main study, CGs were recruited primarily from local AA church and senior center presentations, newspaper articles, and from the rosters of the Tallahassee Memorial HealthCare and Mayo Clinic Jacksonville Memory Disorder Clinics. Project counselors, a substantial proportion of whom were church elders and/or leaders in the AA community, performed the church and senior center presentations.

Inclusion and exclusion criteria—AA CGs were included in the study if they: (a) were 18 years of age or older, (b) provided direct care to their care recipient for a minimum of six hours per week for at least six months, (c) reported specific caregiving problems amenable to change within a 12-week intervention frame (e.g., increasing CG social and recreational activities and managing effectively care recipient agitation and aggressive behaviors), (d) scored a minimum of 10 on the Patient Health Questionnaire-9 (PHQ-9) indicating a moderate level of depression (Kroenke, Spitzer, & Williams, 2001), and (e) reported no difficulties in hearing over the telephone.

Care recipients were required to have: (a) a medical diagnosis of probable Alzheimer's disease or other type of progressive dementia verified by a physician at a memory disorder clinic, (b) at least one limitation in basic activities of daily living (Katz, Down, Cash, & Grotz, 1970), or (c) two dependencies in independent activities of daily living (Lawton, Moss, Fulcomer, & Kleban, 1982). CGs were excluded if they: (a) met criteria for psychotic disorder on the Mini International Neuropsychiatric Interview (MINI) 5.0.0 (Sheehan & Lecrubier, 2006), (b) met criteria for moderate or high suicide risk on the MINI 5.0.0, or (c) had a terminal diagnosis themselves.

Counselors and counselor training—Four AA counselors were selected to participate in the study and subsequently randomly assigned by location to either telephone-based or in-person CBT. All counselors were required to have at least a Masters degree in a counseling-related profession, at least one-year of group intervention experience, and previous involvement in delivering elder care treatment. All four counselors regularly used CBT techniques (e.g., relaxation, effective thinking, and assertiveness training) in their clinical practices. The average age, years of education, and years of professional practice of the four African-American Alzheimer's Caregiver Training and Support Project (ACTS) pilot counselors across the two treatment groups were 66, 21.5, and 30.75, respectively. No significant mean differences across treatment groups and locations were found on these variables (all $ps > .26$).

Measures—The key dependent measures of the pilot study included the Subjective Burden subscale of the Caregiver Appraisal Inventory (CAI; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989), Assistance Support subscale of the Interpersonal Support Survey Checklist (ISEL; Rodgers, Anthony, & Lyass, 2004), Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) and the Physical Symptoms Subscale of the Caregiver Health and Health Behavior (Posner, Jette, Smith, & Miller, 1993). The seven-item CAI Subjective Burden scale measures the extent to which the CGs' health and

emotional well-being have been negatively affected by caregiving responsibilities. The 10-item ISEL Assistance Support subscale assesses CGs' access to instrumental support, material aid, and physical assistance. The CES-D is a 20-item self-report scale that measures depression in nonclinical community populations. It is the most widely used measure of depressive affect in CBT outcome studies with distressed CGs of older adults with dementia (Sorensen & Pinquart, 2005).

Procedure—We opted to use telephone over other technological solutions, such as Internet or point-to-point videoconferencing, for two primary reasons: (1) a sizeable proportion of participants, especially older AA CGs, do not operate a computer and/or feel uncomfortable using a computer to receive CBT (Glueckauf et al., 2005) and (2) the costs of telephone equipment and transmission services are typically low, thus increasing the feasibility and clinical utility of the intervention.

The CBT intervention consisted of a total of 12, one-hour, weekly sessions, seven group and five individual CG goal-setting and implementation sessions. All participants received a CBT guidebook (Glueckauf et al., 2008), a copy of the 36-Hour Day (Mace & Rabins, 2006), and information about local dementia care resources prior to the first training session. The contents of the CBT program included six major components: (a) overview of the basic characteristics of dementia, (b) relaxation training, (c) effective thinking about caregiving challenges, (d) building in pleasant daily activities as a guard against emotional distress, (e) assertiveness in difficult caregiving situations involving interactions with family members and/or health professionals, (f) developing problem-solving skills through personal goal setting, and (g) bolstering the CGs' social support network. Dependent measures were administered approximately one week before and one week after the 12-week CBT intervention.

Results—A two-stage approach was used to analyze the pilot study data. First, one-between, one-within factor ANOVAs were performed to test the effects of time (pre- versus post-treatment), group (telephone versus in-person intervention) and the group x time interaction across all four measures. Significant within-subjects effects for time were found across CG subjective burden (Wilks' $\Lambda = .55$, $F(1,9) = 7.54$, $p < .03$, $\eta^2_{\text{partial}} = .45$),¹ assistance support (Wilks' $\Lambda = .56$, $F(1,9) = 7.15$, $p < .03$, $\eta^2_{\text{partial}} = .44$), and depression (Wilks' $\Lambda = .63$, $F(1,9) = 5.26$, $p < .05$, $\eta^2_{\text{partial}} = .40$). Collapsed across telephone and in-person conditions, CGs reported significant improvements in subjective burden, assistance support and depression from pre- to post-treatment. In contrast, no significant within-subjects effect for time was found for CG physical symptoms (Wilks' $\Lambda = .91$, $F(1,9) = .91$, $p = .37$, $\eta^2_{\text{partial}} = .09$). Note also that no statistically significant effects were obtained for group (telephone versus in-person CBT) and the group x time interaction (all $ps > .05$) on any of the four measures.

Second, due to small sample size ($N = 11$), effect size estimates (i.e., partial η^2) were calculated for each pre-post comparison instead of conventional *F* and *t* statistics. Both telephone ($\eta^2_{\text{partial}} = .42$) and in-person ($\eta^2_{\text{partial}} = .50$) CGs showed moderate improvements in subjective burden from pre- to post-treatment. A similar, positive pattern was found between the telephone and in-person groups for assistance support ($\eta^2_{\text{partial}} = .49$ and $\eta^2_{\text{partial}} = .43$, respectively). Thus, mode of treatment delivery did not appear to exert differential effects on improvement across these two variables. Note that a different pattern of findings emerged for the primary outcome measure, depression. The effect size for telephone-based CBT was moderate in magnitude ($\eta^2_{\text{partial}} = .55$), whereas the effect size for in-person CBT fell within the low range ($\eta^2_{\text{partial}} = .14$). Last, the effect sizes for changes in physical symptoms over the past month for both treatment groups tended to be

small. However, improvement in physical symptoms was greater for telephone CGs than for their in-person counterparts (i.e., partial η^2 s = .27 and .03, respectively).

Discussion and lessons learned

The overall pattern of findings of the pilot study was encouraging. Although the magnitude of effects varied across measures, all comparisons were in the predicted direction, showing pre-post improvements across all four target measures. In addition, the majority (i.e., five of eight) of singular, within-group comparisons had partial η^2 s of .41 or higher. Note, however, that replication across the full study sample is required to evaluate the reliability of the pilot results, especially differences in gain scores between the telephone and in-person conditions.

Three major lessons emerged in performing the initial phase of our telehealth research program for distressed AA dementia CGs. The first lesson learned highlights the importance of focusing CBT intervention on CGs with clinically significant levels of depressive symptomatology. Our findings suggest that tailoring CBT intervention to AA CGs with moderate levels of clinical depression may lead to larger clinical benefit than those with low levels or no symptoms of depression. As discussed above, previous dementia AA CG intervention research found little or no change on this key outcome measure. Noting that CBT is one of two non-pharmacological treatments of choice for clinical depression (Churchill et al., 2001), tailoring the use of this modality to the CG population screened positively for the condition may be advisable both in terms of efficacy and efficient use of mental health services.

Second, the “buy-in” from community opinion leaders (e.g., local clergy, elder care advocates, and health care providers) is essential for ensuring successful recruitment and retention of AA CG participants. Only a limited number of ethnic minority dementia CGs are likely to take advantage of telehealth services unless these opinion leaders fully support the initiative and provide assistance in recruiting prospective participants (Glueckauf et al., 2005). It appears that the best methods for gaining the trust and support of such opinion leaders are: (1) to provide assurance that dementia CGs will be encouraged to rely on local resources for ongoing support and caregiving resources (e.g., church health ministries and local Alzheimer's organizations) after program termination, (2) to tailor intervention and treatment materials to the skills-building needs, socio-cultural preferences, and religious values of the CG population, and (3) to select telecommunication modalities (e.g., telephone) that are widely used, low cost, and easy to operate (Glueckauf et al., 2005; Glueckauf et al., 2007).

A final lesson learned focuses on the selection of telehealth providers. A major key to successful participant engagement and retention lies in selecting providers who share similar racial, demographic and spiritual characteristics as the target CG population. Semi-structured interviews with AA CGs (Glueckauf et al., 2005; Glueckauf et al., 2010) revealed the importance of choosing counselors who understand the AA community's expectations for caring for older family members with dementia, their religious commitment to the caregiving process, and the historical perspective of older AA women, particularly the limited opportunities for pursuing personal aspirations and career goals. Typical feedback included statements such as: “I was able to talk openly about issues and problems and [the counselor] was able to help me to deal with them. She understood where I was coming from personal experience.” “I felt like I could talk about anything, shared information I wouldn't normally have shared with another person. [The counselor] and I had so much in common.”

Summary and Future Directions for Research

The overall pattern of findings from the three studies suggests telecommunication technology may be an effective approach in empowering persons with severe disabilities and their family caregivers to 'self-manage' their own chronic health conditions. All three pilots showed improvements in psychosocial functioning and self-management skills.

With appropriate understanding of the unique challenges of the patient populations involved, IM, the videophone, and the regular telephone may be effective and efficient home-based modes of treatment for individuals with chronic disabling conditions. In each of the studies, investigators tailored their interventions to the preferences and needs of the target populations. However, further refinement of the tailoring strategies may be required to maximize positive treatment outcomes.

Note that with changes in health care delivery and reduced hospital lengths of stay over the past decade, family caregivers are serving increasingly as health care extenders. This reality must not be underestimated when incorporating technology into the home settings of adults with severe disabilities. Without the incorporation and education of family caregivers, adherence with treatment regimens and long-term recovery from severe disability may be compromised. For example, in Study 1, ABI dropouts tended to be single and not have a primary support system in their home setting.

It is not only fundamental to educate and ensure the cooperation of family caregivers, but also to obtain 'buy-in' of stakeholders in the organization and community where research is conducted. Incorporation these stakeholders in the research planning and implementation process, will increase the probability of long term success for telehealth promoting self-management skill adoption for individuals with severe disability and their caregivers.

Three directions for future research on the effects of telehealth for persons with severe functional disabilities are proposed. First, it is essential for telehealth outcome studies to incorporate meaningful control or comparison groups into the overall research design. Although this design is appropriate for initial clinical trials of the efficacy of telehealth interventions, it severely restricts the range of research questions that can be addressed. Similar to other forms of program evaluation, advances in telehealth outcome research are predicated upon the ability to test conceptually and pragmatically meaningful rival hypotheses (Glueckauf & Ketterson, 2004). For example, McKay et al. (2002) compared the effects of Internet-based peer support versus professional coaching versus information-alone on the psychosocial and physiological functioning of adults with Type 2 diabetes. This design permitted a rigorous test of the differential impact of two theory-driven, empirically validated interventions (i.e., professional coaching and peer support) against a third alternative (i.e., information only) that had shown only limited effects in previous intervention research.

A second direction lies in performing research to increase the understanding of the relationship between consumer perceptions of the desirability, ease of use, and utility of telehealth interventions and treatment outcome. There continues to be a lack of basic information about the social-psychological mechanisms that link intervention processes to telehealth outcomes. Only a few studies, to date, have examined the factors that enhance and reduce the quality (e.g., clarity, ease of use, distractibility, and comfort) of telehealth self-management skills training across modalities, age groups, minorities, and ethnic groups, and in turn, their relationship with treatment outcome (Glueckauf & Ketterson, 2004; Glueckauf, Pickett, Ketterson, Nickelson & Loomis, 2006). Furthermore, the relationship between potential mediators/moderators of treatment (e.g., adherence to treatment, therapeutic alliance, and session attendance) and treatment outcome remains poorly understood.

Finally, future studies on telehealth for persons with severe disabilities need to incorporate rigorous cost-effectiveness analyses within the context of the research design. Although a few telehealth studies (e.g., Emmons et al., 2005; Rotheram-Borus et al., 2004; Southard, Southard, & Nuckolls, 2003) have provided preliminary evidence of cost savings, the cost-effectiveness analyses performed in these investigations tend to be poorly delineated and rudimentary. Formal cost-effectiveness, cost-benefit, cost-offset and opportunity cost, or disease adjusted life years analyses (Whitten et al., 2002) should be included routinely in telehealth outcome studies, particularly those that focus on improving health status and psychosocial adjustment of persons with severe functional disabilities. Future research is needed to test the incremental economic benefits of home-based telehealth intervention over alternative forms of health delivery for this vulnerable population, who tends to be the high users of treatment services.

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