

Grant #13-60-99014

Title: A Telerehabilitation Network to Support Community Re-entry Following Catastrophic Injury

Project Evaluation Report

September 29, 2004

Two evaluation studies were conducted to determine the project's effectiveness in helping patients achieve successful community re-entry and avoid secondary complications. These studies sought to answer the following evaluation questions. Does the intervention, a planned protocol of videophonic visits post-discharge and ongoing access to on-line instructional materials and resources, a) reduce secondary complications and rehospitalizations after discharge and, thereby, reduce overall health care costs; and b) result in greater self-efficacy and satisfaction with health-related quality of life as reported by patients and their families.

Evaluation of Learning Connections

The first evaluation study examined overall utility of the on-line instructional and resource materials developed as part of this project. This study involved 1) compiling statistics concerning use of the on-line resource materials, 2) collecting information from patients and families about their overall satisfaction with the materials and the usefulness of various components of the package, and 3) examining differences in reported outcomes of the educational program for patients/families who used the on-line materials versus our conventional printed materials.

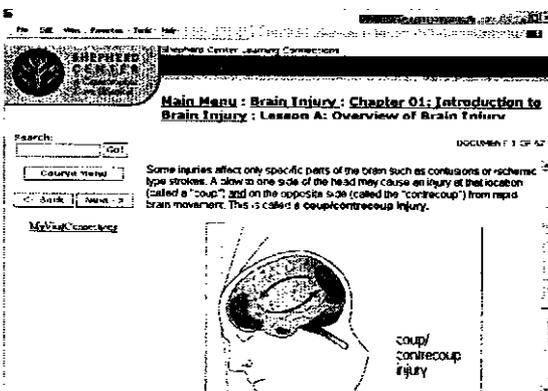
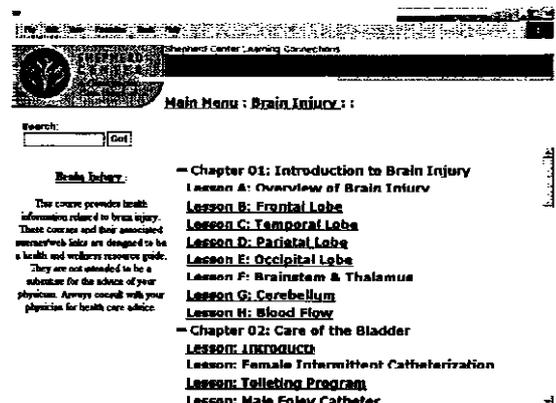
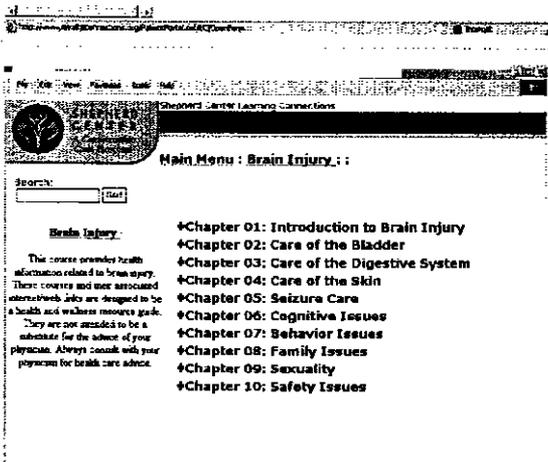
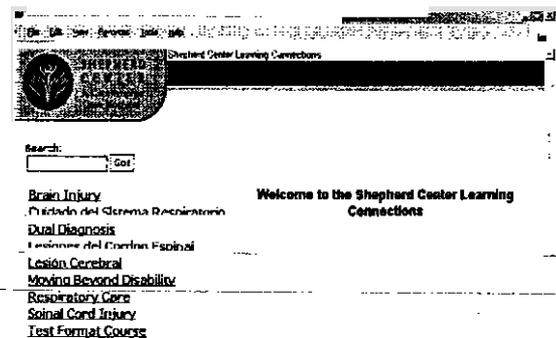
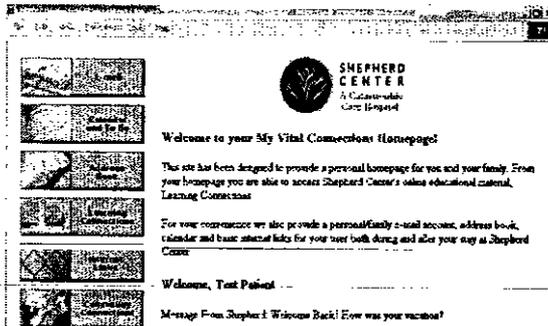
My Vital Connections (Figures 1 and 2 below) is a dedicated patient portal accessible via a link on Shepherd Center's website (www.shepherd.org). The site supports several "desktop" functions for patient use such as e-mail, daily appointment calendar, and a "consumer's desk reference" to common medications that may be prescribed for patients. The portal also provides access to *Learning Connections*, multimedia instruction that is based on the patient and family training provided during inpatient and post-acute rehabilitation. *Learning Connections* includes customizable lessons, available in English or Spanish, related to self care and community reintegration following catastrophic injury, and a database of local organizations throughout the southeastern US providing services and assistance to people with neurologic impairments.

Learning Connections includes both text and graphic content, organized into modules or courses for specific diagnostic groups (ABI, SCI, dual diagnosis) or specific rehabilitation topics (e.g., community re-integration [*Moving Beyond Disability*], respiratory care). Streaming video is used to illustrate specific care activities. Audio description is also incorporated to address literacy concerns.

All patient rooms at Shepherd Center have been configured with a network connection, providing access to *My Vital Connections* and the Internet during the inpatient stay. All inpatients and their families are given password access to the network throughout the

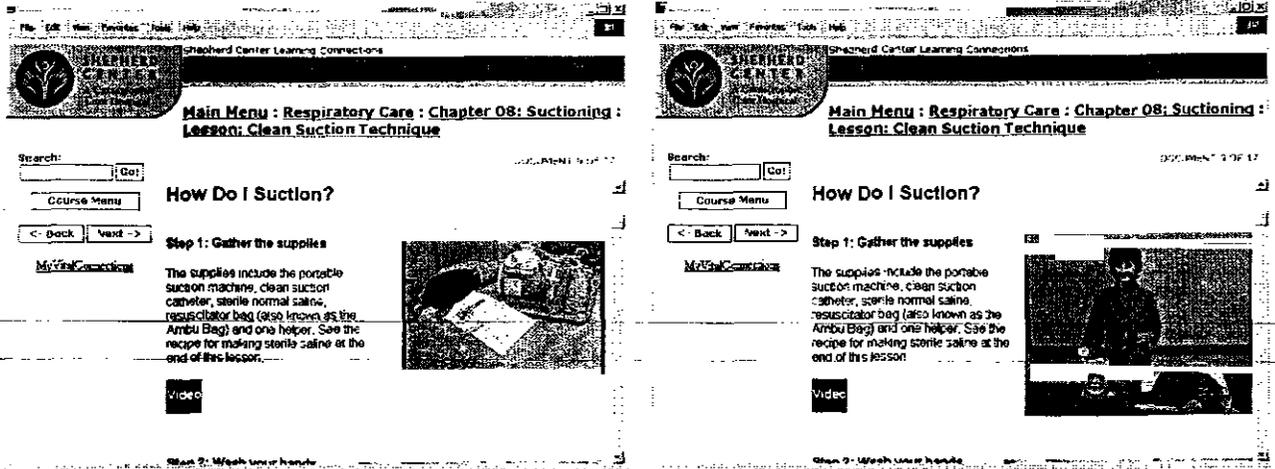
inpatient stay and for one year post-discharge at no charge. After discharge, patients continue to access these resources via the patient portal link on Shepherd Center's website.

Figures 1a-1e. Sample pages from *My Vital Connections* and *Learning Connections*.



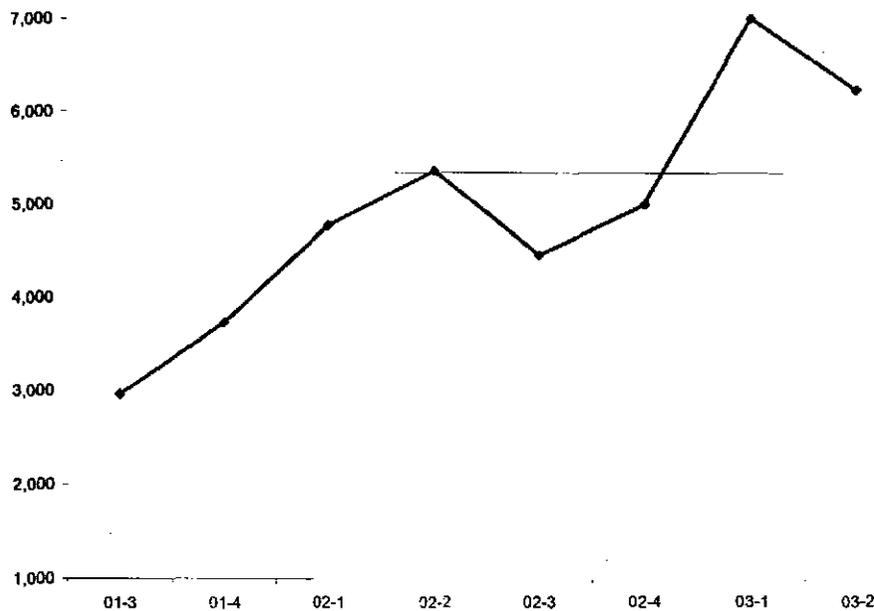
Figures 1a-e. These figures illustrate *My Vital Connections* and the *Learning Connections* instructional materials. Figure 1a is a sample "home page" for a patient, providing access to several desktop applications, *Learning Connections*, selected web sites, and *Community Connections*, an information and referral database. Figure 1b shows some of the courses available on *Learning Connections*; the selection can be tailored to a particular patient's needs (e.g., SCI or ABI, English or Spanish). Figures 1c and 1d show the table of contents from the brain injury course, listing chapters and lessons within chapters. Figure 1e shows content within one lesson. Note the Search capability and multiple navigational tools (Back and Next keys, return to Course Menu, and navigation string along the top).

Figure 2. Instructional content incorporating streaming video.



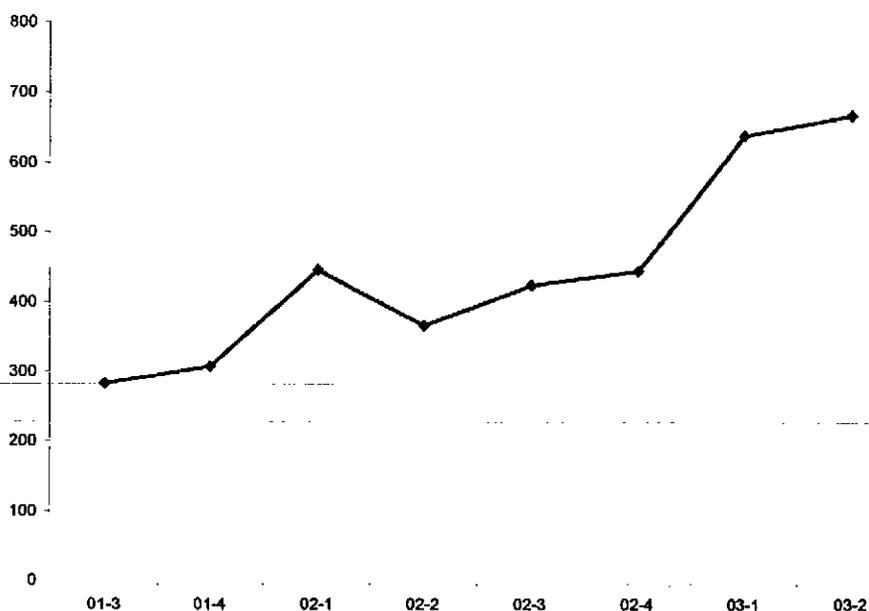
The *My Vital Connections* website has been operational since July 2001. We have been using WebTrends software to track the number of users and visits to the Learning Connections web pages since they were rolled into production. Figure 3 below presents the number of website visits each quarter since the website was launched. A total of 39,427 visits have been logged, representing over 600,000 “hits” on the

Figure 3. Number of website visits per quarter



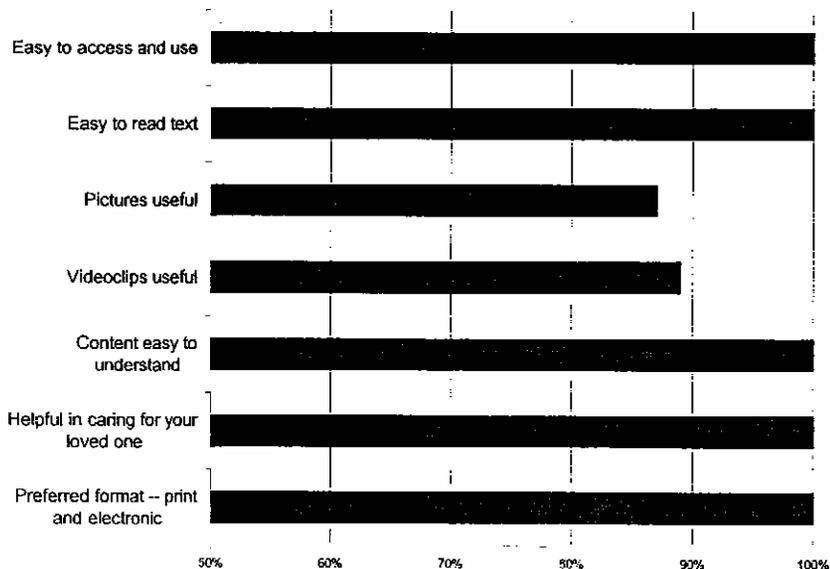
website since it’s launch. Figure 4 below presents the number of unique, recurring visitors each quarter who have visited the site. A recurring visitor is anyone who visits the site at least twice.

Figure 4. Number of unique, recurring users of the Learning Connections website each quarter since its launch in July 2001.



Approximately two months after launch of the *My Vital Connections* site, we asked patients and families to give us feedback on their overall satisfaction with the Learning Connections instructional materials. A total of 27 respondents provided feedback on the site, including such factors as ease of access and use, usefulness of text and video information, ease of understanding the content, and overall how helpful it was in caring for their family member with a disability. Respondents completed and returned a written survey that asked them to rate various factors on a numeric scale ranging from not at all useful/helpful/easy to use to very useful/helpful/easy to use. Figure 5 presents results of this preliminary evaluation. Percentage scores are presented with 100% indicating that

Figure 5. Respondents ratings of usability of the Learning Connections site



all respondents scored the item as very useful/helpful/easy to use. As the data clearly indicate, respondents rated most aspects of the *Learning Connections* materials as very useful/helpful/easy to use. Interestingly, the factors they rated least useful were the photos and videoclips (streaming video), the latter of which was one of the primary reasons for going with high-speed internet access for the Telerehabilitation Network. Based on further feedback from respondents, it appears that the usefulness of the streaming videos was diminished by the lag time in accessing the clip because the media player had to be opened and video stream downloaded. Over the course of the project, the media player software was upgraded and video formats were modified to improve the time and effort associated with viewing video clips. We also re-evaluated exactly what content warranted the use of video and reduced this to activities (such as specific care routines) that really benefited from having a video demonstration to follow.

Our third effort to evaluate the impact of *Learning Connections* consisted of collecting information at admission and discharge from a sample of patients' family members who reported using the *Learning Connections* resources and those who had not. This study is still underway and we intend to collect information from respondents approximately 6 months after discharge as well. Our preliminary analysis of results is encouraging. The brief written survey asked respondents questions about their learning experience at Shepherd Center and comfort level in caring for the patient. Specifically, the survey asked them to rate how strongly they agree or disagree with the following statements: 1) My learning experiences at Shepherd Center have prepared me for discharge, and 2) I feel more comfortable helping my family member. With respect to the first question, 67% of respondents who used *Learning Connections* indicated that they "strongly agree" with the statement while 55% of those using conventional materials strongly agreed with the statement. And with respect to the second question, 82% of respondents who used *Learning Connections* indicated that they strongly agree whereas only 50% of those using conventional materials strongly agreed with the statement.

The survey also asked respondents to rate their overall knowledge level about catastrophic injury and its consequences. Respondents were asked to rate 25 items pertaining to specific knowledge and understanding about brain or spinal cord injury and related consequences (e.g., "I know what a coma is and how long it usually lasts", "I understand what causes pressure ulcers and methods of preventing them."). Respondents rated each item on a scale from 0-4, with a score of "4" indicating that the statement was "extremely true" in describing their current knowledge and understanding. With 25 items, a total score of 100 indicates that the respondent rated all items "extremely true." At the initiation of family training, there was little difference between scores of respondents who used the *Learning Connections* (average score of 71.7) and those who used conventional materials (71.6). However, at discharge, there was a 4.5% increase in the average score for users of *Learning Connections* and a 10.7% decrease in the average score of those who used conventional materials.

Evaluation of the Telerehabilitation Intervention

We conducted a controlled trial in an effort to evaluate the effectiveness of the telerehabilitation intervention in preventing secondary complications and easing the transition back to the community. A total of 40 participants were recruited into the trial, with 20 individuals receiving the intervention (experimental group). These individuals were selected to represent a broad cross section of the patients served by Shepherd Center, including individuals from traditionally underserved populations. The one caveat in their selection is that they had to reside in a location with access to a high-speed Internet connection.

Each patient enrolled in the experimental group was subsequently paired with a matched comparison patient, who was re-recruited to serve in the control group. Control participants were selected on the matching variables of gender, age, education level, marital status, and type and severity of injury (e.g., brain injury, spinal cord injury). Each group was comprised of 12 males and 8 females, 13 individuals with spinal cord injury, 6 with traumatic brain injury, and one with Guillain-Barre syndrome. The average age for both groups was 32, with a range of 19-56 years old for the experimental group and 18-60 for the control group.

Because it is now part of standard practice, all patients had access to the *Learning Connections* resource. Additionally, patients in the experimental group received a planned schedule of videophonic "visits" with an advanced practice nurse according to protocols developed for different diagnostic groups or potential problem areas (e.g., prior to discharge, patient is judged to be at greater risk for pressure ulcers due, for example, to obesity or inability to complete self care routines).

Our plan is for detailed outcome data to be collected for each participant at regular follow-up intervals 3, 6, 12, and 18 months post discharge. All experimental participants have completed the intervention phase and 3-month follow-up. But due to delays in completing the intervention wrought by problems with access to high-speed Internet service, we have not completed 6, 12, and 18-month follow-up data collection for all participants. These data collection efforts continue and a more detailed evaluation study will be prepared and submitted for publication in a peer-reviewed journal. Following is a preliminary analysis of results from data collected at the 3-month follow-up interval.

Preliminary results are presented with respect to outcomes during the first 90 days post-discharge in three areas: 1) occurrences of specific secondary complications (pressure ulcers, bladder complications, bowel complications), 2) use of health care resources (unplanned physician visits, ER visits, and rehospitalizations), and 3) community re-entry indicators (getting out in the community at least three times per week, having established a work or school placement, and having returned to work or school). Table 1 presents findings from the 90-day follow-up and the early results are quite promising. In virtually every category, participants in the experimental group appear to be faring better than those in the comparison group. With respect to the three secondary conditions tracked here, slightly more participants in the control group are likely to have experienced early

complications. With respect to unplanned health care, there is a marked difference between experimental and control participants on all three indicators of care. With respect to community reintegration indicators, it does appear that control participants are getting out of the house on a more regular basis than their experimental group counterparts. The same number of participants in each group have established a work or school re-entry plan. This reflects comparability of the two groups because it is an indicator of whether the patient is an early candidate (at 90 days post-discharge) for return to school or work. Even though the groups are comparable in terms of work/school readiness, there is a remarkable difference in the number of participants who have already returned to work or school.

Table 1. Preliminary Results @ 90 Days Post-Discharge

| | Experimental Group | Control Group |
|--|-------------------------------|--------------------------|
| Total Sample Size | 20 | 20 |
| Secondary conditions within first 90 days | | |
| Skin breakdown or ulceration | 2 | 3 |
| Bladder complications | 4 | 6 |
| Bowel complications | 3 | 4 |
| Use of health care resources in first 90 days | | |
| Unplanned physician visits | 3 | 5 |
| Emergency room visits | 0 | 3 |
| Hospitalizations | 0 | 4 |
| Community reintegration indicators | | |
| Out of the house at least 3x per week | 15 | 19 |
| Work/school re-entry plan established | 14 | 14 |
| Returned to work or school | 12 | 9 |

We should caution that these results are preliminary—extended follow-up is necessary to determine the lasting impact of intervention efforts. We intend to continue with data collection and analysis until we have completed one-year follow-up with all participants. At that time, we will complete a more detailed analysis of outcomes, including quality of life, cost-utility, and satisfaction with service indicators. We will also compare outcomes as a function of the continued use of *Learning Connections* to determine its impact in promoting community reintegration.

**PO Analysis of Closeout Report for
NTIA Award Number 13-60-99014
Shepherd Center
Atlanta, Georgia**

Project Overview: Shepherd Center, Inc was awarded a \$460,000 grant in 1999 to establish a "Telerehabilitation Network to Support Community Re-entry Following Catastrophic Injury." The total project costs were \$935,133. The projected end date was September 2002 but was extended to June 2003. The project proposed to: (1) create a test-bed network in the metro-Atlanta area that emulates Next Generation Internet (NGI) capabilities, including high-bandwidth video conferencing, remote monitoring, environmental control, and high-speed delivery of interactive multimedia instructional programs; (2) develop and evaluate telerehabilitation applications; and (3) disseminate information to stakeholders and provide technical assistance in support of replication.

The authors of the project expected that individuals receiving telerehabilitation interventions would: (1) achieve greater success in community reintegration, (2) experience fewer secondary complications, (3) demonstrate greater independence and self-efficacy, (4) incur lower overall health-care and support costs, and (5) report higher satisfaction with health-related quality of life.

Project Accomplishments: The project did successfully create a test-bed network in the metro-Atlanta area that emulates Next Generation Internet (NGI) capabilities. They also developed telerehabilitation applications. They implemented *My Vital Connections*, a dedicated patient portal accessible via a link on the Shepherd Center's website (www.shepherd.org). The site supports several desktop functions for patients, including a consumer desk reference to common medications that might be prescribed. The portal also provides access *Learning Connections*, which is multimedia instruction based on patient and family training provided during inpatient and post-acute rehabilitation. The customized lessons (available both in English and Spanish) are related to self-care and community reintegration following catastrophic injury, and a database of local organizations throughout the southeastern U.S. providing services and assistance to people with neurologic impairments. Streaming video is used to illustrate specific care activities and audio description is incorporated to address literacy concerns. According to the evaluation report, "All patient rooms at Shepherd Center have been configured with network connections to provide access to *My Vital Connections* and the Internet during the inpatient stay. All inpatients and their families are given password access up to one year post-discharge at no charge. After discharge, patients continue to have access via the patient portal link

Based on preliminary demonstrations of the Telerehabilitation Network, the Marcus Foundation provided a \$17.6 million grant to extend the program for eight years and to all patients discharged after catastrophic injury. The Shepherd Center, the Georgia Centers for Telecommunications Technologies, and Georgia Tech have received a \$5 million, five-year grant to help make wireless technologies more accessible for people with physical and cognitive impairments.

With regard to spin-offs, the grantee has developed an additional line of instructional materials to be used by rehabilitation professionals, case managers, and home health agency personnel. They are also developing similar training and support materials for trauma center staff with regard to emergent care needs of those with catastrophic spinal cord and brain injuries.

Project Outcomes: Data to assess expected outcomes were to be collected at 3-, 6-, 12-, and 18-month intervals after patients were discharged. Because the project implementation schedule was delayed only data for the 3-month data point are available. The determination of whether or not outcomes have been achieved is premature. Nonetheless, the grantee does provide responses based on preliminary findings. A full evaluation of the project is expected to be complete by the end of the first quarter of 2004.

The Center is conducting a controlled trial. A total of 40 participants with 20 individuals in the experimental group. Each patient enrolled in the experimental group was paired with a matched comparison patient. Participants were matched on gender, age, education level, marital status, and type and severity of injury. There are 12 males and 8 females in both groups. All patients had access to the Learning Connections resource. The experimental group received scheduled video phonic visits with an advanced practice nurse.

Based on the preliminary findings, there is a tendency toward reduction in secondary complications being reported by newly injured individuals after discharge and a tendency toward increased patient and care giver participation in managing care needs. In the 90-day period since discharge there has not been sufficient time to measure reduced hospitalizations or success in easing patients back into the community. Data are still being collected to measure the cost-utility of the telerehabilitation network.

Community Impact: First, the project has changed the way all patients and their families participate in the rehabilitation process. Although the project did not target disadvantaged or undeserved populations, but approximately 25% of the patients admitted to the Center are indigent and/or un-insured and hence beneficiaries of the project services. Shepherd Center is now also able to provide connectivity gratis, thus expanding the resources of Shepherd Center to a broader group. They anticipate that as many as 2,500 users outside the center may benefit.

Grantee Lessons Learned: The most significant barrier, and unanticipated consequence, is related to the difficulty in obtaining high-speed Internet access for patients at home by the time of discharge. High-speed Internet service has only become widely available in the Metro-Atlanta market since mid-2002. For those having access, the lag time to having the service provided was 3 months. It was reported that the most important lesson learned concerns the disparity between feasibility and actual application of technology. In particular, between advertised and actual availability of high-speed Internet service and between promised and actual performance of networking software. The grantee recommends starting with a test-bed application is very useful for resolving technical issues.



Technology Opportunities Program

FINAL REPORT

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Award Number 13-60-99014

Accepted:

Section A: Project Outcomes

Information on project outcomes identified at the start of the project

Project Outcome: **Has it been achieved:** YES

Decrease secondary complications reported by newly injured individuals during the first year after discharge to the community.

Evidence/Next Steps: We conducted a controlled trial in an effort to evaluate the effectiveness of the telerehabilitation intervention in preventing secondary complications and easing the transition back to the community. A total of 40 participants were recruited into the trial, with 20 individuals receiving the intervention (experimental group). These individuals were selected to represent a broad cross section of the patients served by Shepherd Center, including individuals from traditionally underserved populations. The one caveat in their selection is that they had to reside in a location with access to a high-speed Internet connection. Each patient enrolled in the experimental group was subsequently paired with a matched comparison patient, who was recruited to serve in the control group. Control participants were selected on the matching variables of gender, age, education level, marital status, and type and severity of injury (e.g., brain injury, spinal cord injury). Each group was comprised of 12 males and 8 females, 13 individuals with spinal cord injury, 6 with traumatic brain injury, and one with Guillain-Barre syndrome. The average age for both groups was 32, with a range of 19-56 years old for the experimental group and 18-60 for the control group. Because it is now part of standard practice, all patients had access to the Learning Connections resource. Additionally, patients in the experimental group received a planned schedule of videophonic "visits" with an advanced practice nurse according to protocols developed for different diagnostic groups or potential problem areas (e.g., prior to discharge, patient is judged to be at greater risk for pressure ulcers due, for example, to obesity or inability to complete self care routines). Our plan is for detailed

Future Plans: At the time of submitting the close-out documentation, the operation. Plans are underway for the continued expansion and refinement of Connections to provide a more comprehensive and pervasive resource for re-integration for those sustaining catastrophic brain and spinal-cord injuries.

P.O. Observations and Lessons Learned: Most partnerships have worked well, but the partnerships with industry were not so successful, primarily due to security issues with providing healthcare over the Internet. Earthlink was not able to provide the service promised. This was remedied by forging a partnership with BellSouth. Lack of the ability to provide high-speed Internet connectivity to patients was the most significant obstacle. We were forced to revise implementation schedules and pay for the Internet service rather than either Earthlink or BellSouth. They were able to negotiate a reduced rate with BellSouth. The most salient lesson was with regard to the "advertised and actual availability of high-speed Internet service, between promised and actual performance of networking software." Without TOP funding, the grantee believes that the project would have had funding from alternative sources, but the range of services would have been reduced, they would have reached significantly fewer people, and project implementation would have been delayed. The grantee reported, "We would not have had the resources to tackle the project, particularly as an Internet-based resource, without funding from TIAP."

I inherited this project during the final quarter of the project and have no particular observations or lessons to add to this report. The close-out documentation has been submitted and includes, the evaluation report, the CD-281, and list of project expenditures. I recommend that this report be accepted.

outcome data to be collected for each participant at regular follow-up intervals 3, 6, 12, and 18 months post discharge. All experimental participants have completed the intervention phase and 3-month follow-up. But due to delays in completing the intervention wrought by problems with access to high-speed Internet service, we have not completed 6, 12, and 18-month follow-up data collection for all participants. These data collection efforts continue and a more detailed evaluation study will be prepared and submitted for publication in a peer-reviewed journal. Following is a preliminary analysis of results from data collected at the 3-month follow-up interval. Preliminary results are presented with respect to outcomes during the first 90 days post-discharge in three areas: 1) occurrences of specific secondary complications (pressure ulcers, bladder complications, bowel complications), 2) use of health care resources (unplanned physician visits, ER visits, and rehospitalizations), and 3) community re-entry indicators (getting out in the community at least three times per week, having established a work or school placement, and having returned to work or school). Table 1 presents findings from the 90-day follow-up and the early results are quite promising. In virtually every category, participants in the experimental group appear to be faring better than those in the comparison group. With respect to the three secondary conditions tracked here, slightly more participants in the control group are likely to have experienced early complications. With respect to unplanned health care, there is a marked difference between experimental and control participants on all three indicators of care. With respect to community reintegration indicators, it does appear that control participants are getting out of the house on a more regular basis than their experimental group counterparts. The same number of participants in each group have established a work or school re-entry plan. This reflects comparability of the two groups because it is an indicator of whether the patient is an early candidate (at 90 days post-discharge) for return to school or work. Even though the groups are comparable in terms of work/school readiness, there is a remarkable difference in the number of participants who have already returned to work or school. Table 1. Preliminary Results @ 90 days Post-discharge

| Experimental | Control | Sample size |
|------------------------------------|---------|----------------------|
| 20 | 20 | Secondary conditions |
| breakdown | 2 | 3 |
| Bladder complications | 4 | 6 |
| Bowel complications | 3 | 4 |
| Use of health care resources | 3 | 5 |
| Unplanned physician visits | 0 | 3 |
| Emergency room visits | 0 | 4 |
| Hospitalizations | 3 | 15 |
| Community reintegration indicators | 15 | 19 |
| Out of the house 3x/week | 15 | 19 |
| Work/school re-entry plan | 14 | 14 |
| Return to work/school | 12 | 9 |

Project Outcome: **Has it been achieved: YES**

Increase patients' and caregivers' participation and self-efficacy in managing patients' self care needs.

Evidence/Next Steps: Learning Connections, the on-line instructional materials and resources developed for patients and families, was launched in July 2001. Since its launch, the materials have been accessed by 3,575 unique, recurring users (those who have used the materials at least twice). Collectively, these users have logged over 39,000 visits to the Learning Connections website. A preliminary evaluation of Learning Connections was conducted to gauge its impact in promoting greater independence and self-efficacy among patients and caregivers in meeting patients' care needs. Information was collected at admission, discharge, and three months post-discharge from a sample of patients and families who used the on-line resource materials

and those who used our conventional materials. The brief written survey asked respondents questions about their learning experience at Shepherd Center and comfort level in caring for the patient. Specifically, the survey asked them to rate how strongly they agree or disagree with the following statements: 1) My learning experiences at Shepherd Center have prepared me for discharge, and 2) I feel more comfortable helping my family member. With respect to the first question, 67% of respondents who used Learning Connections indicated that they "strongly agree" with the statement while 55% of those using conventional materials strongly agreed with the statement. And with respect to the second question, 82% of respondents who used Learning Connections indicated that they strongly agree whereas only 50% of those using conventional materials strongly agreed with the statement. The survey also asked respondents to rate their overall knowledge level about catastrophic injury and its consequences. Respondents were asked to rate 25 items pertaining to specific knowledge and understanding about brain or spinal cord injury and related consequences (e.g., "I know what a coma is and how long it usually lasts", "I understand what causes pressure ulcers and methods of preventing them."). Respondents rated each item on a scale from 0-4, with a score of "4" indicating that the statement was "extremely true" in describing their current knowledge and understanding. With 25 items, a total score of 100 indicates that the respondent rated all items "extremely true." At the initiation of family training, there was little difference between scores of respondents who used the Learning Connections (average score of 71.7) and those who used conventional materials (71.6). However, at discharge, there was a 4.5% increase in the average score for users of Learning Connections and a 10.7% decrease in the average score of those who used conventional materials.

Project Outcome: Has it been achieved: **AMENDED**

Demonstrated cost utility of telerehabilitation network in expanding access to specialized health information and services.

Evidence/Next Steps: Data are still being collected and analyzed to determine the cost utility of the TIIAP project in expanding access to specialized health information.

Project Outcome: Has it been achieved: **YES**

Reduced-rehospitalizations among newly injured individuals during the first year after discharge.

Evidence/Next Steps: We conducted a controlled trial in an effort to evaluate the effectiveness of the telerehabilitation intervention in preventing secondary complications and easing the transition back to the community. A total of 40 participants were recruited into the trial, with 20 individuals receiving the intervention (experimental group). These individuals were selected to represent a broad cross section of the patients served by Shepherd Center, including individuals from traditionally underserved populations. The one caveat in their selection is that they had to reside in a location with access to a high-speed Internet connection. Each patient enrolled in the experimental group was subsequently paired with a matched comparison patient, who was recruited to serve in the control group. Control participants were selected on the matching variables of gender, age, education level, marital status, and type and severity of injury (e.g., brain injury, spinal cord injury). Each group was comprised of 12 males and 8 females, 13 individuals with spinal cord injury, 6 with traumatic brain injury, and one with Guillain-Barre

syndrome. The average age for both groups was 32, with a range of 19-56 years old for the experimental group and 18-60 for the control group. Because it is now part of standard practice, all patients had access to the Learning Connections resource. Additionally, patients in the experimental group received a planned schedule of videophonic "visits" with an advanced practice nurse according to protocols developed for different diagnostic groups or potential problem areas (e.g., prior to discharge, patient is judged to be at greater risk for pressure ulcers due, for example, to obesity or inability to complete self care routines). Our plan is for detailed outcome data to be collected for each participant at regular follow-up intervals 3, 6, 12, and 18 months post discharge. All experimental participants have completed the intervention phase and 3-month follow-up. But due to delays in completing the intervention wrought by problems with access to high-speed Internet service, we have not completed 6, 12, and 18-month follow-up data collection for all participants. These data collection efforts continue and a more detailed evaluation study will be prepared and submitted for publication in a peer-reviewed journal. Following is a preliminary analysis of results from data collected at the 3-month follow-up interval. Preliminary results are presented with respect to outcomes during the first 90 days post-discharge in three areas: 1) occurrences of specific secondary complications (pressure ulcers, bladder complications, bowel complications), 2) use of health care resources (unplanned physician visits, ER visits, and rehospitalizations), and 3) community re-entry indicators (getting out in the community at least three times per week, having established a work or school placement, and having returned to work or school). Table 1 presents findings from the 90-day follow-up and the early results are quite promising. In virtually every category, participants in the experimental group appear to be faring better than those in the comparison group. With respect to the three secondary conditions tracked here, slightly more participants in the control group are likely to have experienced early complications. With respect to unplanned health care, there is a marked difference between experimental and control participants on all three indicators of care. With respect to community reintegration indicators, it does appear that control participants are getting out of the house on a more regular basis than their experimental group counterparts. The same number of participants in each group have established a work or school re-entry plan. This reflects comparability of the two groups because it is an indicator of whether the patient is an early candidate (at 90 days post-discharge) for return to school or work. Even though the groups are comparable in terms of work/school readiness, there is a remarkable difference in the number of participants who have already returned to work or school. Table 1. Preliminary Results @ 90 days Post-discharge

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| Work/school re-entry plan | 14 | 14 |
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Information on additional outcomes not identified at the start of the project

Section B: Project Accomplishments

The accomplishments of the project

The project's most significant accomplishment or achievement

Perhaps the most significant accomplishment of the TIIAP project was realized early on with funding of the Marcus Community Bridge Program. Based on our preliminary demonstrations of the Telerehab Network, the Marcus Foundation provided a \$17.6 million grant to the Shepherd Center to extend the program for eight years and to all patients discharged from rehabilitation after catastrophic injury.

Changes in the way in which end-users performed their jobs or carried out their activities

Two major changes have been wrought by the TIIAP project, with respect to the way in which end-users carry out their activities. First, Learning Connections (our on-line instructional materials and resources for patients and families) are now used with virtually all patients and families who participate in rehabilitation. Second, with continued funding from the Marcus Community Bridge program, systematic follow-up support, including the use of telerehabilitation as needed, is now provided to all patients after discharge.

The impact of the project on the community at large

~~Evidence to date clearly substantiates the project's benefit with respect to reducing secondary complications, easing the transition back to the community and improving quality-of-life outcomes, such as return to work and school. The project did not specifically target disadvantaged or underserved populations but individuals with these characteristics are included in Shepherd Center's population of persons served (i.e., approximately 25% of patients admitted to the Center are indigent and/or un-insured), and therefore included in those served by the TIIAP project.~~

A description of unanticipated problems that resulted from the project

The most significant unanticipated problem in the project was the extreme difficulty we faced in obtaining high-speed internet access for patients at home by the time of discharge. We originally planned to implement the intervention phase of our clinical trial in early 2001. However, high-speed internet service has only become widely available in the metro-Atlanta market since mid 2002. In service areas where high-speed internet service was available prior to mid-2002, the time lag from requesting the service and having it activated could take 3 month or longer.

The number of individuals who have benefitted (directly and indirectly) from TOP-related equipment or resources since the beginning of the project

| | End Users | Other Beneficiaries |
|----------------------------------|-----------|---------------------|
| Number in human service settings | 100 | 0 |
| Number in cultural settings | 0 | 0 |
| Number in government agencies | 0 | 20 |
| Number in public safety settings | 0 | 0 |
| Number in educational settings | 40 | 0 |
| Number in health care settings | 3575 | 1000 |
| Other end users/other (specify): | 0 | 0 |

Total number of direct and indirect beneficiaries

3715

1020

Section C: Project Expansion

Information on the expansion of the project

Has the project expanded to serve additional end users in locations or organizations beyond those targeted in the TOP proposal: Yes

A description of the (1) scope of the expansion; (2) the number/characteristics of additional end users being served; (3) the funding sources for their expansion; and (4) the approximate dollar amount or value of any additional equipment or resources that were leveraged by your project as part of the expansion.

Expansion has occurred both within the same location/organization and to additional rehabilitation settings serving people with catastrophic brain and spinal cord injuries and the persons served by these settings. Through the generosity of the Marcus Foundation, the telerehab program has been extended to all patients served over an eight year period. In providing access to the basic Learning Connections materials free of charge to anyone over the Internet, we have expanded access of this resource to a much broader group of persons served. Although the exact number and location of these end users is not known we have a general idea that perhaps as many 2,500 users outside of Shepherd Center's network may be benefiting from this resource.

Section D: Spin-Off Activities

Information on spin-off activities from the project

Has the TOP project generated any spin-off activities? Yes

A description of any spin-off activities and the additional services that are being provided.

The most exciting and potentially relevant spin-off activities of the TIAP project have been the continued growth of our on-line instructional and resource materials. Based on the early success of Learning Connections, we have developed an additional line of instructional materials that can be used to provide on-line continuing education courses to rehabilitation professionals, rehabilitation case managers, home health agency personnel. We are in the process of developing similar training and support materials for trauma center staff pertaining to the emergent care needs of individuals with catastrophic spinal cord and brain injuries, and to the primary care physicians to whom these patients are referred upon return to the community.

Section E: Partnerships

Information on project partners

Describe how your project partnership worked?

Some partnerships have worked extremely well and others less so. For example, our primary research and development partner was the Biomedical Interactive Technology Center at Georgia Tech and this partnership has been extremely productive, leading to additional collaborations efforts. Our partnerships with industry partners were not as successful on the whole. For example, our partnership with Cyber-Care was successful in that they readily contributed the technology platforms units for use in providing telerehab services to patients and our testbed was useful in helping them resolve many of the security issues associated with providing healthcare services over the Internet. On the other hand, there were a number of software glitches associated with their systems that required quite a bit of troubleshooting. Our relationship with Earthlink was also less than successful in that they were simply not able to provide high-speed internet services for our patients in a timely manner. Earthlink was at a bit of a disadvantage because they had to purchase their service from Bellsouth and were at their mercy in scheduling new service hook-ups. We ultimately had to go directly to Bellsouth to purchase DSL service for our patients, which we were able to do so at a discount because we provide so much business to Bellsouth already. A third partnership with Siemens Corporate Research was useful in that they provided a cash contribution to the project (used as part of the nonfederal cost-share commitment) and, in return, were able to learn quite a bit from our experiences. It may also result in a second collaborative effort to test internet-based therapy services that Siemens has in development.

Section F: Lessons Learned

Information on the lessons learned from the project

The most significant barrier or obstacle that the project had to overcome

Clearly the most significant barrier was the limited access to high-speed internet services. To overcome this problem, we were forced to revise the schedule for completing our intervention phase, recruit an additional ISP partner in Bellsouth, and pay for the service ourselves rather than rely on contributions from Earthlink or Bellsouth (although we were able to negotiate a reduced rate for the service from Bellsouth).

A description of any lessons that the project has learned that would be of use to future TOP projects

The most important lesson we learned relates to the big disparity between feasibility and actual application of technology (e.g., between advertised and actual availability of high-speed internet service, between promised and actual performance of networking software).

A recommendation that future projects replicate/adapt the TOP-related approach used by your project (YES/NO)

Yes

A description of any lessons or advice that you would pass on to projects that are replicating/adapting this approach

Starting with a test-bed application is very useful for resolving technical issues noted in Lessons Learned 2 above.

Section G: Impact of the TOP Grant

Impact of the grant on the organization and community(s) served

The most likely outcome of the project if it did not received Federal funds through the TOP

program

The activity probably would have been implemented using alternative sources.

How the absence of TOP funding would have affected the range of services offered by the project

The range of services offered by the project would have suffered minor reductions.

How the absence of TOP funding would have affected the scale of the project

The project would have reached significantly fewer people.

How the absence of TOP funding would have affected the implementation schedule of your project

The project would have been slightly delayed.

Specific examples of how the support provided through the TOP program impacted the scope, scale, and success of your project

The most important impact was in expanding the scope and scale of our Learning Connections resource. We would not have had the resources to tackle this project, particularly as an Internet-based resource, without funding from TIIAP. Moreover, as result of providing it over the Internet, we were able to reach a much broader audience and expand the content beyond the originally intended audience of patients and families.

Section H: Future Plans***Information on future plans for project*****The current status of the project**

In full operation.

Factors

Mechanical obsolescence (equipment became inoperable, unreliable, worn out)

Technological obsolescence (faster, more accurate, better alternatives became available)

Personnel changes (project staff who were most interested are no longer involved)

Insufficient funding available for maintenance of project-related activities

Loss of partners or failure of partnerships

Lack of community support

Too costly to maintain/sustain

Policy barriers (specify): *False*

The future plans are envisioned for the project

Our biggest plans for the future pertain to continued expansion and refinement of Learning Connections to provide a more comprehensive and pervasive resource for support of community reintegration of people who sustain catastrophic brain and spinal cord injuries. We have already noted how on-line instruction will be database of information about local resources to support community reintegration. Partial funding for this effort will be provided by our Marcus Community Bridge grant but we are also pursuing additional sources of private and public funding.

Section I: Other

Additional topics or areas not previously addressed

Additional information about program impact is provided in the program evaluation report, which has been submitted in hard copy.

[Top of Page](#)

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