STEP

Stakeholder Training the Prevention of Outcomes

and Education for Pressure Ulcers 2009

UP









Acknowledgements

The Step-Up Project and this final report have been made possible by the following individuals or organizations.

Funding

The Province of Manitoba, Department of Health and Family Services and Housing

Development and Implementation

Pre planning partners:

Canadian Paraplegic Association (CPA)Ron Burky, Executive Director and Darlene Cooper, Director of Services CPA Manitoba

Community Partners

Linda Dando, WRHA Director of Long Term Access Center / Home Care; Shannon Guerreiro; Manager of Patient, HSC Adult Emergency; Nicole Dubois, Nurse Clinician HSC Rehabilitation Hospital; Rick Stevens, Retail Sales Manager, The Stevens Co. Neil MacHutchon, Regional Director, HSC Physiotherapy Services; Kristal Laminman, HSC Director Occupational Therapy and Therapeutic Recreation; Michelle Todoruk-Orchard, WRHA Clinical Nurse Specialist; Bonita Yarjau HSC Nursing; as well as consultations with HSC Physiatrists; Dr. Karen Ethans and Dr. Allen Casey; to gain support for the overall concept prior to the formal proposal.

Cheryl Vines, Susan Garber and Jim Angelo for the contribution of their Consumer Action to Prevent Pressure Sores project material developed and field tested in Arkansas. Thank you for your thoughtful suggestions and support.

Training

Dave Colvin of the Addictions Foundation of Manitoba provided a two day workshop for CPA staff focused on "Stages of Change and Motivational Counselling".

Preliminary Data Analysis

Dr. Kristine Cowley, Research Associate, University of Manitoba, SCI Research Center; provided consultations throughout the development and implementation of the project; as well, she assisted with the data analysis and production of the final report. Dr. Cowley's experience with CPA and her clinical research background was invaluable.

Shannon Howell PHD Psychology completed the statistical analysis of the raw data compiled in the project.

We are grateful for the opportunity to work collaboratively with this outstanding team of professionals.

Finally, the on going support of the CPA Program Committee and our Board of Directors is appreciated.

Final Report Writing and Design

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Project Summary:

The quality and capacity to provide health care education has had profound effects on the quality of life for people living with a spinal cord injury. With this report to the Manitoba Department of Health, the Canadian Paraplegic Association of Manitoba hopes to illustrate that funding the Step-Up project has made a significant change in promoting health for the CPA membership, in particular, the prevention of pressure ulcers for people discharged from a rehabilitation facility within the parameters and timeframe of the program.

The Stakeholder Training and Education for Pressure Ulcer Prevention (Step-Up) has been extremely important in terms of affirming some of CPA's organizational beliefs. It is imperative to provide holistic rehabilitation services in order to achieve the most cost effective and quality of life enhancing results. We must continue to deal with the overall needs of the individual in order to effect health and wellness and, in particular, to prevent skin breakdown leading to the costly secondary condition of pressure ulcers.

Reduction of Economic and Human Costs:

This project was supported with \$100,000.00 over 24 months or \$4167.00/month. None of the 42 participants in this pilot study developed a pressure ulcer while in the study. In contrast, 30% (6/21) of a comparison group which did not participate in the project, developed pressure ulcers during the same time period. This financial cost is minimal when compared to the human cost and of providing medical and surgical services to the non participants of the control group who developed pressure ulcers. For example, the projected costs for addressing the medical needs of just one individual would include the following: the two hour surgical procedure at \$5083.00, the per diem rate for hospital bed occupancy \$1248.00/night, the home intravenous follow up at \$500.00-\$600.00 per day, the additional home care costs to support these individuals post operatively in the community, the expense of HSC SCI Outpatient Clinic follow up, and the cost of purchasing or renting pressure reducing mattresses.

The conservative estimate for treatment of pressure ulcers range from individuals treated without complications (4 weeks in hospital) \$156,068.00 to those with complications (6 months in hospital) \$339,571.00. The maintenance of funding for this project is a cost effective solution.

CPA is one of the provinces preferred service providers. CPA has a proven track record with Family Services and Housing in the provision of services that yield employment outcomes. This specialized health prevention program has been lacking in CPA's service delivery model to date.

Lessons learned:

- The present lack of capacity to provide community follow up in health related topics leaves many people
 with spinal cord injuries vulnerable to serious life threatening health complications that could be avoided.
 Continuation of STEP-UP would be cost effective in providing better health education and keep Manitobans
 with spinal cord injuries healthier.
- This project demonstrated that we have tremendous potential to increase positive health outcomes by the prevention of serious skin breakdown resulting in pressure ulcers and costly pressure ulcer surgery.
- The practical and positive results, demonstrate that of the 42 participants in the 24 month project, there was zero occurrence of pressure ulcers.
- How effectively people are empowered to manage their own health when provided with early one-to-one support and accurate review of health related information. Trends in the occurrence of pressure ulcers include disturbing inequalities for some groups of Manitobans such as new injuries, rural, and Aboriginal communities members. These inequities could worsen unless we invest in greater preventive care for people at high risk (new injuries) of developing pressure ulcers. It is unlikely that patients receive sufficient information while in the hospital relating to their special spinal cord injury-related health care concerns. Indeed, given that it takes physicians, therapists, and others working in the rehabilitation profession, years of training to specialize in spinal cord injury care, it is not surprising that people who have sustained a spinal cord injury would benefit from specialized injury-related health information after discharge from hospital.
- Test results of participants evidenced the lack of retention of hospital training about skin management and how to remain healthy after sustaining a spinal cord injury.
- The **need to reinforce previous learning** received during a very disruptive / traumatic time, while in hospital.

Introduction:

Pressure ulcers are one of the most common secondary conditions experienced by individuals with a spinal cord injury (SCI) and carry significant costs in terms of individual quality of life and health care dollars. Research points to the efficacy of community-based prevention education oriented to enhancing individual protective factors in the areas of nutrition, skin maintenance, appropriately maintained equipment and lifestyle choices.

It is critical to put this in the perspective of the human cost. A person with a pressure ulcer is completely absent of interaction and participation in all life events by bed rest for weeks or months. Given the devastating effects of this secondary condition, CPA has placed an emphasis on addressing pressure ulcers: a condition that impairs ones ability to fully participate in the community after a spinal cord injury. This impacts the individual, their family and the individual's contributions to society.

Prior to this project, a demonstration project to prevent the occurrence of pressure ulcers had not been undertaken. CPA was able to hire a project coordinator with the financial support of the Province of Manitoba to design and implement this project. The details of the successful outcomes are summarized in this report.

Project Development:

CPA obtained permission to replicate a three year project titled "Consumer Action to Prevent Pressure Sores" (CAPPS), which was conducted in Arkansas in 1998. Prevention assessments and interventions were structured around the Stages of Change Model and Motivational Interviewing to encourage clients with SCI to progress through the stages of change and take personal responsibility for participation in pressure sore prevention behaviors. The first aspect of the project was to study the CAPPS project for reference and inclusion in the Step-Up Project.

Cheryl Vines from the Arkansas Spinal Cord Commission was contacted. Cheryl informed us that no statistics were kept from the CAPPS project.

Susan Garber at the Houston Veterans Affairs Medical Center, Baylor College of Medicine, Houston, Texas was also contacted as she published a study on "A Structured Educational Model to Improve Pressure Ulcer Prevention Knowledge in Veterans with Spinal Cord Dysfunction". Demographic and knowledge test forms developed for her study were forwarded to CPA. The Health Locus of Control Scale was used in her study, which classifies a person's perception of being internally or externally controlled. For example, the person believes they control their life versus the environment, some higher power, or other people control their decisions and their life.

Jim Angelo who is associated with the Paralyzed Veterans of America provided us with a copy of their publication "Yes, You Can!". This publication was used as a training resource in the CAPPS project. The two above projects were used to design and develop some of the tests for the pilot Step-Up program. These tests were as follows:

Pressure Sore Behavior Survey
Health Care Questionnaire
Health Locus of Control
(see appendices)

In addition, a 60 question test was developed to assess the participant's knowledge of skin management, nutrition, and healthy living.

A Participants Pressure Ulcer Prevention Education Manual was formatted and copies were made for all potential participants.

A Consent to Access Information form was developed for all participants to sign before starting the project.

Three days of staff training on Stages of Change and Motivational Interviewing was completed. Participant progress tracking sheets were developed for recording visits and test results.

Rick Stephens from the Stevens Home Medical Supply store supplied a blood pressure unit for the project.

Meetings were conducted with the Health Sciences Center Rehabilitation Hospital Director of Physiotherapy - Neil MacHutchon, the Director of Occupational Therapy - Kristal Laminman, to inform them about the project. to A brief meeting with the OT staff followed.

We consulted with a local researcher, Dr. Kristine Cowley, to review the data collection sheets and implementation of the project.

Implementation:

Eligibility:

Participants for the Step-Up program were identified during CPA's weekly team meetings. The participants had to meet the following criterion:

- · discharged from RR5, HSC during project time frame
- a diagnosis of SCI (paraplegic or quadriplegia)
- sufficient cognitive abilities to participate (an ability to participate in a conversation and retain information)
- a desire to prevent pressure ulcers from forming and taking active steps to do so
- live independently in the community (e.g., in own home vs. a nursing home where individuals are not in control of their own care)
- reside within the region of the WRHA boundaries
- · access to and ability to use a telephone

The Coordinator/Health Educator (C/HE) phoned every eligible participant within 10 days of discharge from the Rehabilitation Hospital. A brief explanation of the Step-Up Program was given and potential participants were asked if they would be willing to participate in the voluntary program. If the participant agreed to be a part of the program, an appointment was made for the C/HE to visit them in their home.

Informed Consent:

During the first visit to a participant's home, a detailed explanation of the Step-Up Program was discussed. The participant signed the consent to access information form for the Step Up Program. An individualized Step-Up rehabilitation plan was developed. The participant completed the following tests:

- Pressure Sore Behavior Survey
- Health Care Questionnaire
- Health Locus of Control
- Step-Up Pre-Test Questions

Appendix III defines the above test content.

A Participants Pressure Ulcer Prevention Education Manual was given to the participant. At the end of the session, an appointment for the next visit was scheduled.

Educational Sessions:

The initial home visit was followed by weekly visits to build and reinforce the prevention components that were reviewed with participants while they were in the medical rehabilitation program at the Health Sciences Center, Rehabilitation Hospital. The Participants' Pressure Ulcer Prevention Education Manual was reviewed to offer educational material in such areas as: nutrition, use of appropriate therapeutic cushions, demonstration of safe transfers, demonstration of daily skin inspection or directing of same, maintenance of skin hygiene, regular exercise or range of motion routines, and regular weight shifts. All sessions consisted of supportive measures to enhance the participants quality of life and encourage positive behavior change for health maintenance.

These visits continued until each participant had a good understanding of all of the available material and felt more confident in their community. The participants were also linked to other community resources that fit with and supported their pressure ulcer prevention, such as: peer support linkages, Community Home Care, Health Action Center, volunteer opportunities, and social and recreational opportunities.

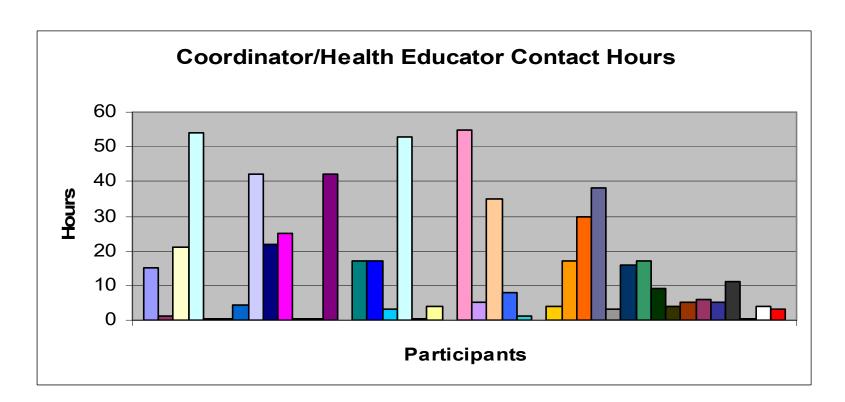
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Monitoring Progress

The monitoring of Step-Up project was conducted by the Coordinator/Health Educator and consisted of:

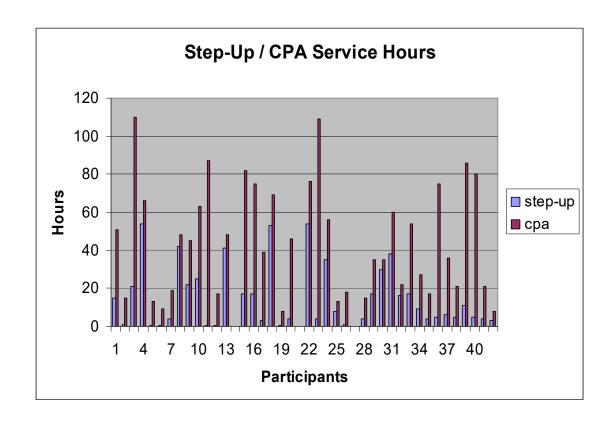
- Participant completion of baseline tests
- •Repeated baseline testing after three months
- •Weekly home visits followed by weekly telephone contact until the participants were confident with the manual material and utilizing the support systems in their community.
- •All tests were repeated at the conclusion of their plan, one year after the initial testing.

The following chart depicts the number of hours the Coordinator spent with participants ranging from .05-55. hours per person. The average time spent per participant was 13.58 hours. This individualized training met each participant's unique learning style and need.



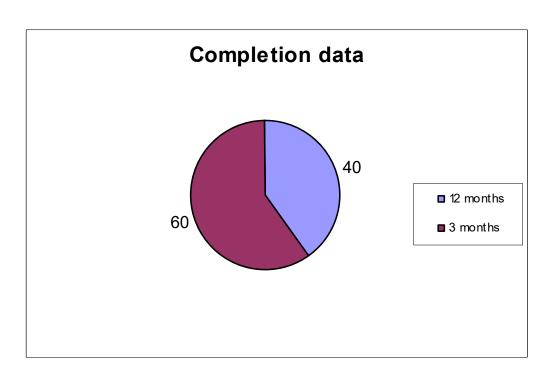
Service Hours:

The Step-Up Project Coordinator / Health Educator met the CPA Manitoba service standards throughout the project. Her time was divided 66% direct client service hours and 33% indirect services for documentation and participation in team meetings.



This indicates a wide range of hours provided by CPA, with some individuals receiving up to 100 hours. The hours shown in purple are the expanded service hours that Step-Up provided. For example; person 4 in the graph received 66 hours of direct client service by CPA staff of which 54 hours through the Step-Up project. The C/HE position provided a specialized health promotion component related to health and wellness. This service support will not be available without the continuation of the Step-Up Project.

Participant Demographics:

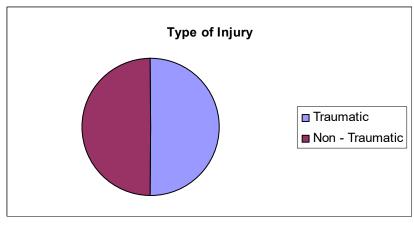


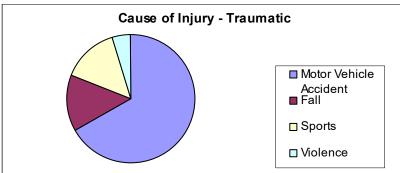
The process was continuous intake and therefore not all participants had the capacity to complete the program in the two years.

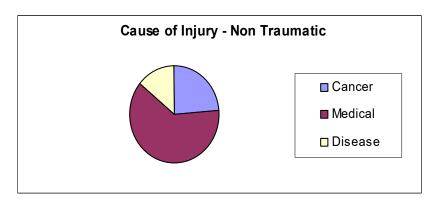
40% or 17 participants completed the twelve month program.

60% or 25 participants completed three months of programming.

Demographics







During the two year project time frame there were 92 new referrals, 14 community referrals and 2 readmissions post pressure ulcer surgery.

Ineligible:

- 37 Outside of projects the geographic boundaries
- 04 Refused to participate
- 05 Deceased
- 04 Lacked language competencies to participate
- 11 Remain in hospital
- 04 Contacted but with no response
- 01 Not spinal cord injured

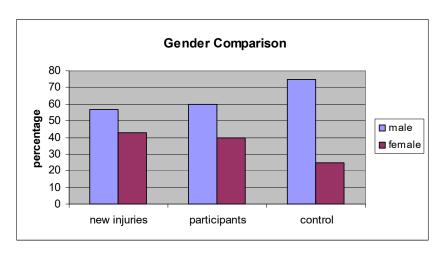
With a total of 42 participants, we exceeded the project goal by two.

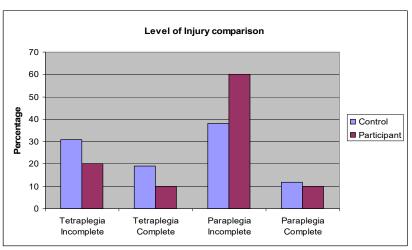
Comparisons of Participant and Control Group:

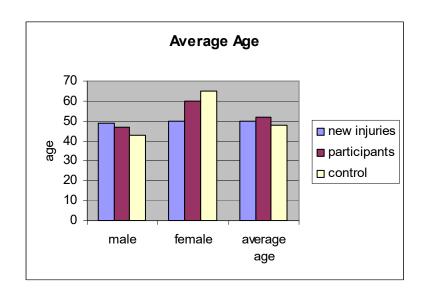
Through the use of CPA's electronic case management system we attempted to match participants of the Step-Up project and other individuals with new injuries who resided outside the regional boundaries and who were eligible for CPA's services. The following criterion was utilized:

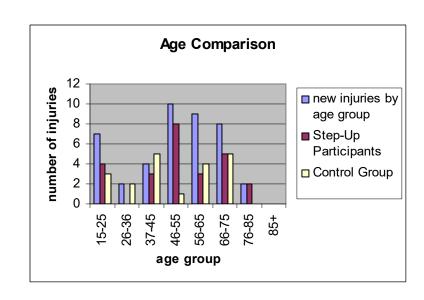
- •Onset dates August 20, 2007- June 8, 2009
- Level of injury
- Severity of injury
- •Gender
- •Age
- Marital status

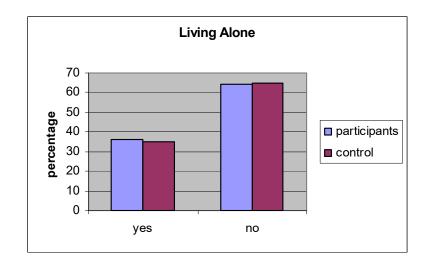
The comparison graphs indicate a high correlation between the two groups. The size of the control group was 50% that of the participant group. This was due to the match criterion sited above.

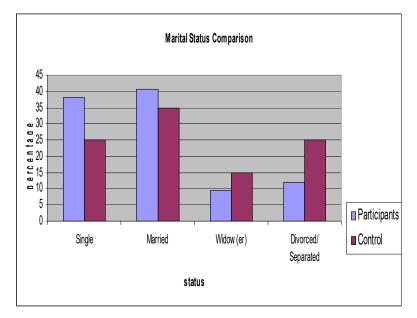












Control Group

For individuals in the control group who sustained pressure ulcers we found a high correlation in the variables such as:

- Age
- Marital status
- Living alone
- Level of injury

It appears that the key determinants may be lack of capacity for community intervention, health locus of control and/or the lack of personal responsibility for skin care.

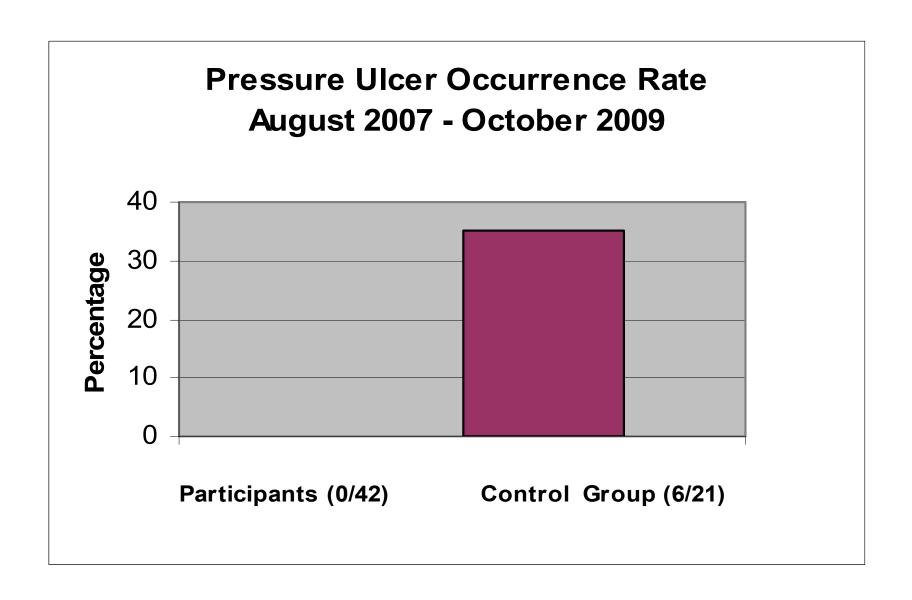
The results of the study show a zero occurrence of pressure ulcers in the participant group. It is apparent that empowering CPA members, to become self reliant in personal routines, results in increased healthy living choices and wellness. Therefore, we conclude that the continuation of these services is an effective and efficient solution that has the potential to improve quality of life, significantly reduce expenditures in health care costs and prevent costly life-threatening pressure ulcers that plague citizens with spinal cord injuries.

Authored by:

Val Reith Darlene Cooper

Health Educator Director of Rehabilitation Services

Step – Up Project Coordinator CPA Manitoba Inc.



Conclusions:

Val and I have reviewed the project evidence and conclude that through Community Engagement, CPA and the Department of Health have made the first step in reducing illness in a vulnerable, high risk population of people with spinal cord injuries. To build on this momentum, we strongly encourage the funders to endorse and continue to fund the enhanced practice for structured community education follow up. This program will provide appropriate and accessible knowledge delivered within the context of CPA's holistic services model. Additional observations are noted in Appendix I "Outstanding Health Issues Summary".

We visited with four participants who were emotionally distressed to learn that this program was ending. One individual wrote on a thank you note to the C/HE stating: "Many thanks for your visits, for your tender care and friendship. You made your visits a time for me to look forward to, and a time of healing which I greatly appreciate". The writer / participant verbally expressed not having any contact with the coordinator "felt like a death in the family". These comments came from an individual well connected in a shared religious community; one can only guess the devastating impact felt by an individual with little or no family or community support. It was a touching and powerful experience for me to have these participants openly share their thoughts regarding the Step-Up Project and, more importantly, how, and by whom it was delivered.

The Project Coordinator/Health Educator, Val Reith (B.PT), deserves special acknowledgement. Val is a great mentor, communicator and creative thinker with the tenacity to see the project to completion.

The observations I made in meeting these four participants convinced me that this C/HE developed trusting relationships over this short period of time and was a valued resource and confidante. Without sustainable funding for a Health Education position, CPA has no way to match these service hours within our present service delivery framework.

We believe we have evidenced the efficiency and efficacy of the Canadian Paraplegic Association to provide health promotion and pressure ulcer prevention for people with spinal cord injuries in Manitoba.

Darlene Cooper
Director of Rehabilitation Services

Appendix I: Outstanding Health Issue Summary

Participants had many health issues during their involvement of the Step-Up program. Issues that were addressed in this target group included:

- Participant was having a very difficult time in transferring from the commode to a shower bench seat. A successful variation was demonstrated using a towel.
- Participant did not think that it was necessary to wear his long leg brace every time he tried walking.
 Safety precautions were discussed and reinforced.
- Participant who had an incomplete spinal cord injury did not know that it was safe enough for the wheelchair arms and legs to be removed in order that wheelchair mobility would be easier.
- Participant did not know how to fold up her new walker. After a demonstration, the participant was successful.
- Participant did not know that her walker could be adjusted to a proper height or how to do it. Education regarding adjustability was immediately provided.
- Participant did not realize that the anti tipping devices on her wheelchair could be turned upside down
 or removed to allow the person pushing the wheelchair more foot room and thus preventing them from
 tripping.
- Participant required continual reminders to stay off of a pressure sore. Continual education and reinforcement was necessary.
- Participant wanted to go on a vacation but was worried about her ability for self- catheterization while away. Options were discussed and a solution was reached.
- C/HE advocated for respite for the family of a participant and was successful.
- C/HE advocated for an increase in home care for safety reasons and was successful.
- C/HE advocated for the successful repair of a wheelchair lift.
- C/HE advocated for removing a wheelchair lift when the participant was able to negotiate the stairs independently.
- C/HE advocated for a meeting for medication education with the community health care nurse and a participant.
- Participant would not walk outside of her house because she did not think that she could. After a
 demonstration, the participant was willing to leave the house.
- C/HE provided interpretation of process to have driver's license re-instated.
- C/HE advocated for a referral to a physiatrist from his general practitioner for bowel management. 18

Appendix I continued:

- Participant never left the house due to being very nervous about loss of balance and the
 possibility of falling. Following support and education, the participant not only was able to leave
 her home but also took her young child with her.
- Participant was encouraged to take vocational testing to discover his interests and pursue educational desires. This was successful.
- Participant was encouraged to see a doctor for his bladder incontinence. After support and encouragement, he complied.
- Participant was shown different ways to position himself in bed and in his wheelchair to decrease his spasticity.
- Participant was shown a different transfer to allow showering to be easier.
- Participant with increased spasticity was shown to change the height of his foot pedals to aid in the decrease of his spasticity.
- C/HE advocated between a participant and Crimes Compensation and was successful.
- C/HE helped a participant get a referral to a family doctor because of recurrent bladder infections.
- C/HE met with a participant weekly to help prevent pressure sores from recurring.
- C/HE assisted a participant to find housing which he lacked.
- C/HE advocated between a participant and a doctor on bladder management and came to a mutual agreement.
- Participant was shown how to safely negotiate a ramp while walking.
- C/HE visited a participant in the hospital for support before she had open heart surgery.
- C/HE visited a participant in the hospital with respiratory complications for support.
- C/HE visited a participant in the hospital following abdominal surgery for support.
- C/HE advocated with CMHC on behalf of a participant in regards to forgiving a mortgage penalty due to health issues and was successful.
- C/HE advocated between a participant and CPA in the acquisition of a donated van. The
 participant received the van.
- C/HE submitted an application to Manitoba Paraplegic Foundation for funding for a new set of front steps to a participant's house due to safety reasons. The application was approved.
- Participant's comment: "I get more support from you than all of the members in this household put together. I look forward to your visits."

Appendix II:

Narrative

My name is Val Reith and I am a Rehabilitation Counsellor with the Canadian Paraplegic Association. I have been involved in a project for the past 2 years which seeks to better understand the role of health education with the well-being of adults with spinal cord injuries to help decrease their risk of developing pressure ulcers. The project was limited to the city of Winnipeg. We are now investigating the possibility of expanding the program to rural areas and are wondering if you would be willing to assist us by answering a few questions. It is entirely up to you as to whether or not you want to participate, and your decision will have no effect of any kind on any services or benefits that you might receive from CPA or from any other source.

It will take 10-15 minutes of your time and benefit our members greatly.

First, I would like to review some information: (cross-referenced with electronic case management system for accuracy).

- 1. Level of Injury incomplete/complete
- 2. Traumatic MVA, falls, sport, violence vs. non-traumatic cancer, medical, disease
- 3. Marital status
- 4. Living alone
- 5. Address
- 6. Have you had a pressure ulcer since discharge? Yes / no
 - if you have is it healed or not healed?
 - have you had surgery for the ulcer?
 - have you been admitted to a hospital for the ulcer?
 - have you received home care for the ulcer?
- 7. Description of pressure ulcer:
- -a pressure ulcer is any skin lesion resulting from pressure, friction and/or shear
- Stage 1- non-blanchable reddened areas that do not return to a normal color after 30 minutes.
- Stage 2 shallow, superficial areas of damage involving the epidermis and/or the dermis.
- Stage 3 tissue damage that extends through the epidermis and dermis into the subcutaneous tissue.
- Stage 4 extensive destruction of the skin extending into muscle, tendons and/or bones
- Stage X unobservable due to eschar or slough

Thank you for your time, may we contact you if we require additional information?

Appendix III:

TESTS

Four tests were administered to all participants in the Step-Up program. These tests focused on:

- 1. Pressure Sore Behavior Survey
- 2. Health Care Questionnaire
- 3. Health Locus of Control
- 4. Step Up Pre-Test/Post-Test Questions

1.Pressure Sore Behavior Survey

The first test to be completed by participants is the "Pressure Sore Behavior Survey".

This survey contains questions on the knowledge of pressure sores post spinal cord injury. The questions are designed to discover whether an individual with a spinal cord injury has any idea of how unrelieved pressure can cause an ulcer. Individuals are adapting to life with a spinal cord injury and with the practitioners' guidance and adequate supports they can implement protective behaviors and new routines that will lower the likelihood of skin breakdown or pressure ulcer development.

This survey contains questions to monitor behavioral change. We recognize that consistent lifelong behavior change is difficult and a gradual process which is comprised of the stages based on the "Stages of Change Model". These stages are:

- 1. Pre-contemplation not thinking about change, may be resigned, and/or may not view current behavior as a problem.
- 2. Contemplation weighing benefits and costs of proposed behavior change.
- 3. Preparation experimenting with small changes.
- 4. Action engaged in change activities.
- 5. Maintenance maintenance of new behavior over time.

Appendix III continued

- A central premise of explaining this approach is, when practitioners understand the stages that
 individuals move through in their efforts to change behavior, they are able to tailor their supportive
 approach and interventions more effectively.
- Motivational Interviewing (MI) is a therapeutic style used with the Stages of Change Model. MI
 accepts that ambivalence is a normal part of behavior change and that lack of motivation, rather
 than being a character flaw, is a result of ambivalence. MI is a client-centered approach that
 believes in clients' ability to make decisions and changes in their lives.
- The practitioner's role is to help individuals to explore and resolve ambivalence regarding making changes in their lives and to assist them in discovering their own reasons for needing and wanting to change. Within this frame of reference, the goal is to assist individuals to move through the stages of change toward action (Stage 4) and maintenance (Stage 5).
- Within this framework, relapse is not viewed as failure or an end point, but as part of the ongoing process of change that will be followed by re-engagement (Zimmerman et al, 2000).
- Another component of the survey includes a home evaluation and supports for independence:
 - accommodation
 - personal or household gross annual income before tax
 - personal care
 - employment/education
 - social activities
 - health
 - lifestyle
- These survey components allow demographic information to be captured in order to evaluate and compare statistics related to this unique stakeholder group.

Appendix III continued

2. Health Care Questionnaire

The Health Care Questionnaire was to be completed by hospital members of the Spinal Cord Injury Team. The team members included the Outpatient Clinic Nurse, a physiotherapist, an occupational therapist and a physiatrist. However, due to time constraints, availability, and personnel changes in management positions and varying strategic priorities, they were unable to be involved with the testing. Therefore, the Coordinator/Health Educator completed all of the testing. The questionnaire included:

- medical history
- pressure sore history
- mobility
- bed positioning
- wheelchair condition and fit
- pressure relief technique
- transfer ability
- wheelchair cushion evaluation
- weight perception

There is prevalence within the first year post-spinal cord injury for individuals to be at a high risk for the development of pressure ulcers. Frequently they lack knowledge and/or practice about how to be healthy with a spinal cord injury. A baseline of comprehensive information is mandatory to be able to develop and provide an individual plan to support them in their personal surroundings in the community. This information is part of the educational process during rehabilitation. Many people with new spinal cord injuries do not retain this newly acquired knowledge or cannot put the techniques into practice.

Appendix III continued

3. Health Locus of Control

Studies in health communication have shown that individually tailored health education materials are more effective than traditional or generic materials in producing changes in health-related behaviors. However, tailored materials have not been equally effective for all individuals. Because locus of control affects behavioral outcomes in other self-change interventions, its effect on individuals' responses to tailored messages was of interest. The construct of locus of control of reinforcement refers to the extent to which an individual believes that their behaviors are casually related to their resulting outcomes (internal), or they believe that their outcomes are determined by external factors such as luck, powerful others or fate (external), (Rotter,1966). The Multidimensional Health Locus of Control scale is a measure of beliefs, and beliefs can, and do change over time, depending on a myriad of factors, among which are intervening experiences. Therefore, all participants completed form A of the Multidimensional Health Locus of Control.

4. Step Up Pre-Test/Post-Test Knowledge Questionnaire

Research points out that, during their stay in the hospital, individuals with a spinal cord injury (SCI) are focused on adjusting to their injury and coping with fear, depression and anxiety. Grieving their loss impacts on their ability to focus, attend, retain and recall verbal information. These are primary learning functions that can be altered during or immediately following traumatic exposure and for some continue unrecognized for long periods. Although participation in the rehabilitation program is mandatory for all SCI clients, health advocates today understand how difficult it is for a patient to process information while in an anxious (arousal) state following major trauma and may not be adequately absorbed (McIlraith, 2000). It is also recognized that individuals are better able to apply knowledge once they are back in their personal surroundings and can readily implement changes. A lack of knowledge is shown to be one of the contributing factors for individuals to experience their first pressure ulcer.

A pre-test/post-test questionnaire was developed to assess the participants' level of knowledge in 3 areas:

- skin management
- nutrition
- healthy living 24



Canadian Association
Paraplegic canadienne des
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(Manitoba) Inc.