

**Effectiveness of the
Chronic Disease Self-Management Program**

Reported Submitted to Pamela Morrison

Aboriginal Diabetes Initiative

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**University
of Victoria**



**Centre
on Aging**

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Executive Summary

In 2009, the University of Victoria - Centre on Aging received a grant to investigate the evidence of the Chronic Disease Self-Management Program (CDSMP) in Aboriginal communities. This project began in mid-June and was completed August 31st. The specific activities of the project were to:

1. recruit up to 100 CDSMP leaders and participants to complete a questionnaire containing sixteen health outcome measures; and
2. conduct in-depth interviews with 35-40 persons who participated in the program during the last 6 - 9 month period to inquire about the knowledge and skills they learned in the program, if they were now engaged in behaviours (e.g., walking) as a result of taking the program, and whether they felt their health had improved.

Two Aboriginal researchers were hired - June Clearsky and Linda Epp. June had worked in the Aboriginal Community in the Vancouver area for the past 20 years in managing budgets and coordinating events and had recently completed a CDSMP Leader-Training workshop. Linda was completing a Bachelor of Tourism Management Degree and had nearly 20 years experience in the field of sales and marketing. June and Linda worked with University of Victoria researchers and coordinators at the Ladner Office.

In total 104 persons were consulted in this research; 42 persons participated in an in-person interview, and 62 persons completed a questionnaire. **Only persons who had personal experience with the Chronic Disease Self-Management Program participated in this study.**

The main findings of the research that used the program questionnaires is that at six-months post-program, participants indicated that they:

- were using more coping strategies to deal with pain or symptoms;
- were communicating more with their physician (preparing written questions, asking questions, discussing problems);
- were spending more time doing aerobic exercise;
- were spending more time doing stretching and strengthening exercises;
- had higher self-efficacy in their ability to manage disease symptoms;
- had higher self-efficacy in their ability to manage their disease;
- were in better health;
- had less disability;
- had fewer social or role limitations;
- were experiencing fewer depressive symptoms;
- had more energy;
- were experiencing less health distress;
- were experiencing less fatigue;
- were experiencing less shortness of breath;
- were experiencing less pain; and
- felt their illness had less intrusiveness in their life.

And, importantly, the study found that **the amount of change that took place from the time before people took the program to six-months later was larger than the amount of change experienced by program participants in the general population of BC.**

The following provides a brief summary of the results of the in-person interviews.

The main reasons why people took the CDSMP were to: learn how to manage their own chronic conditions; learn about chronic conditions; gain new skills and knowledge to help them work with clients; and to pass on skills and knowledge to other persons living in the community. When they took the training people said: they felt nervous; that it was fun; that they enjoyed meeting others; that it was easy to follow and used layman terms; that the four-day training for Leaders was too long; and that they liked the training process.

People said they learned a variety of things, including learning the following: about one's role in managing health, how to access resources, about specific diseases, about the symptom cycle, about taking medication, about pain management, how to set goals and make and action plans, how to problem solve, about relaxation and distraction, and how to deliver the program to others. They were using the information by helping others, and by using the action planning and the problem solving process in their own lives, and by using the skills in working with their clients.

When asked about skills learned in the CDSMP, people responded that they learned how to deliver the program, how to use the action planning and problem solving processes, how to relax and pace themselves, and learned to use the skills in working with their clients. They said they were also applying these skills in their own lives by sharing them with others, by using the goal setting, action planning and problem solving processes, and using the relaxation techniques that they had learned.

People reported that they were making action plans to get them started in doing things and using problem solving when they encountered problems. They started exercising, eating healthier, using the relaxation techniques, and abstaining from alcohol. They also reported that they had a number of tools in their "tool box" on which to draw on when needed. Some respondents were more conscious of being healthy following the training. Others explained that their health was better as a result of taking action and not letting things get worse. Some participants were making an effort to improve their mental health by leaving the home and getting out and being active.

Everyone said they got what they wanted out of the self-management program. Some didn't know what to expect from the training, while other reporting receiving more from the training than they expected, namely: the skills and information to be able to support people both personally and professionally; skills that promote independence in clients; a better understanding of challenges for people living with chronic conditions; the tools that are adaptable to other situations in life; to be responsible for oneself; the group processes that were used (specifically 'peer' interaction); and more self-awareness.

In conclusion, the interview people were asked if there was anything else they wanted to add. They emphasized that: the program was worth taking; they were sharing the information with the community; that the courses should be offered on an on-going basis; that they appreciated the simple and helpful format especially for people with low literacy and being able to adapt the program to meet the needs of people in their community; that there is a need for a Diabetes and the Pain Self-Management Program; and they suggested that there should be more time in the program for people to share their stories.

Project Team

Project Researchers	June Clearsky Linda Epp
Program Coordinators	Rhonda Carriere Karen Hannah Mark Davies Terry Cayer
Associate Researcher	Sherry Lynch
Project Analyst	Jennifer Ramsay
Interview Transcriber	Suzanne Harmandian
Administrative Support	Rita Reeves
Project Director	Patrick McGowan

Effectiveness of the Chronic Disease Self-Management Program in Aboriginal Communities

Final Report – September 18, 2009

Between 2005 and 2009, The University of Victoria – Centre on Aging received four grants from the Aboriginal Diabetes Initiative to implement and refine the Chronic Disease Self-Management Program (CDSMP) to make it appropriate for Aboriginal communities.

In 2009 the Centre on Aging received another grant to obtain evidence on the effectiveness of the CDSMP. This project began in mid-June and was completed August 31st. The specific objectives of this project were:

1. To recruit up to 100 CDSMP leaders or participants to complete a questionnaire containing sixteen health outcome measures. The analysis would:
 - investigate participants' perceived changes between the time before they took the program and six-months later;
 - compare the aggregate pre- and post-program results with the aggregate data of the general population of BC to see whether the scores were similar; and would
 - compare the amount of change that took place pre- and six-months post program to see if it was similar or different to the amount of change that took place in the general BC population that took the program.
2. To conduct in-depth interviews with 35-40 persons who participated in the program during the last 6 - 9 month period to inquire about the knowledge and skills they learned in the program, if they were now engaged in behaviours (e.g., walking) as a result of taking the program , and whether they felt their health had improved.

In total 104 persons were consulted in this research; 42 persons participated in an in-person interview and 62 persons completed a questionnaire. All 104 persons who provided feedback in this research had personal experience with the Chronic Disease Self-Management Program either as a Program Leader who had completed a 4-day training workshop to lead the program, or as a program participant who took the 6-week program when it was delivered in their community.

This report will provide a brief description of the Chronic Disease Self-Management Program. It will then describe how the program was implemented in Aboriginal communities between 2005 and 2009, listing annual program implementation and evaluation objectives and providing data on where it was implemented and the number of persons involved.

The report will then describe how the quantitative study (i.e., using questionnaires) was conducted and provides a summary of the results. Lastly, it will describe the qualitative study (i.e., in-person interviews) and provides a summary of the analysis.

DESCRIPTION OF THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM

The Chronic Disease Self-Management Program (CDSMP) is a lay-led patient education program. This program is led by pairs of trained lay leaders to groups of eight to ten people once each week for 2 1/2 hours for six consecutive weeks. Courses are held in community locations such as recreation centres, community centres, schools and churches. Each leader successfully completes a four-day training workshop where he/she learns to follow a Manual to lead the course. The courses are then delivered in the community. Course participants include persons living with chronic health conditions as well as their families, friends and caregivers.

The program teaches the following content: how to develop an exercise program; using the mind to manage symptoms; healthy eating; breathing exercises; problem solving; communication skills (with family, friends, and health care providers); use of medication; and how to deal with the emotions of chronic illness such as anger and depression.

This program does not take the place of regular and/or traditional education but is complementary to and reinforces such education. In the program people obtain new information, learn new skills and abilities, and develop higher levels of confidence to manage and cope with chronic health conditions. Approximately 75% of participants make plans to exercise and to improve eating habits.

Key features of the self-management program include; it is: led by trained community volunteers; highly interactive; delivered in community settings; provides opportunities for people to learn from each other; teaches practical skills needed to manage and cope with conditions on a day-to-day basis; teaches cognitive techniques; uses 'best practice' interventions; and it encourages the development of individual and community capacity.

2005 – 2009 PROJECT OBJECTIVES

There were specific objectives for each year's project, and each year built upon the previous year's results.

2005-2006 Objectives

1. Arrange and coordinate 5 four-day Leader Training Workshops.
1. Recruit 10-18 people to participate in each workshop.
2. Arrange 5 focus group meetings (one in each community).
3. Conduct the meetings and speak to community leaders
4. Make recommendations for subsequent implementation activity

2006-2007 Objectives

1. Provide ongoing encouragement, support and program materials to leaders trained during 2005-2006.
2. Expand the reach of the CDSMP in the Northeast, Northwest, and Northern Coast by delivering three 4-day Leader-Training Workshops to a minimum of 30 people.
3. Make modifications to the Leader's Manual piloted in 2005/2006, based on feedback received from leaders in the focus group meetings following the trainings.

2007-2008 Objectives

1. Incorporate recommendations of earlier pilots and redesign the Program Charts.
2. Train new Program Leaders in 6 communities determined in conjunction with nursing staff.
3. Provide \$150 training incentives to volunteer leaders.

4. Increase the amount of time for the 6 program sessions from 2 ½ to 3 hours.
5. Provide ongoing encouragement, support and program materials to leaders trained during the previous pilot communities.

2008-2009 Objectives

1. Determine and provide the supports and incentives needed to get the newly trained leaders to deliver the program in their home communities.
2. Employ and train a First Nations Program Coordinator, who will develop expertise in all aspects in the chronic disease self-management program will be the primary contact and support person for the current First Nations Program Leaders.
3. Deliver the four-day leader-training workshops in four communities that express interest.
4. Deliver 4 half-day Self-Management Support training workshops to groups of aboriginal health care professionals (nurses, doctors, medical office assistants and Home Care nurses, CHR's).

Between 2005 and 2009, thirty 4-day Leader-Training Workshops were conducted which trained 330 persons to be certified Program Leaders. The locations and number of persons trained in each location is listed below.

	<u>Location</u>	<u>Number of trained Leaders</u>
2005-2006	Kincolith	15
	Greenville	11
	New Aiyansh (2)	19
	Lillooet	5
	Gold River	10
	Tofino	9
	Keremeos	9
	Port Alberni	6
2006-2007	Squamish	8
	Penticton (2)	53
	Prince George	27
	Bella Bella	9
	Kitkatla	5
	Gitsegukla	15
	Moricetown	2
2007-2008	Wonowon	14
	Port Alberni	6
	Penticton	8
	Mount Currie	15
	Central Saanich	6
	Ki-Low-Na	6
2008-2009	Vancouver	12
	Vancouver	13
	Surrey	9
	Mt Currie	9
	New Aiyansh	4
	Kitimat Village	11
Gitsegukla	14	

The trained Leaders then delivered 42 six-week Chronic Disease Self-Management Programs to 399 participants living in Aboriginal communities. Aboriginal persons living in other locations in British Columbia also took the CDSMP as part of general program implementation but numbers were not recorded.

Quantitative (Questionnaire) Study

The standard way the CDSMP is evaluated in British Columbia is to have participants complete a program questionnaire before they take the program and complete it again six months after they have completed the program. Then a pre- and six-month post-program matched-pairs analysis is conducted. Essentially outcome measures for each person are compared at two time points for each person. Previous studies in BC can be found at www.coag.uvic.ca/cdsmp.

The outcomes measure used in this study are described in Appendix A.

The questionnaires were completed either in person or by telephone. The interviewers asked participants to answer each question in two ways: 1) the way they felt before they took the CDSMP; and 2) the way they felt after they completed the CDSMP.

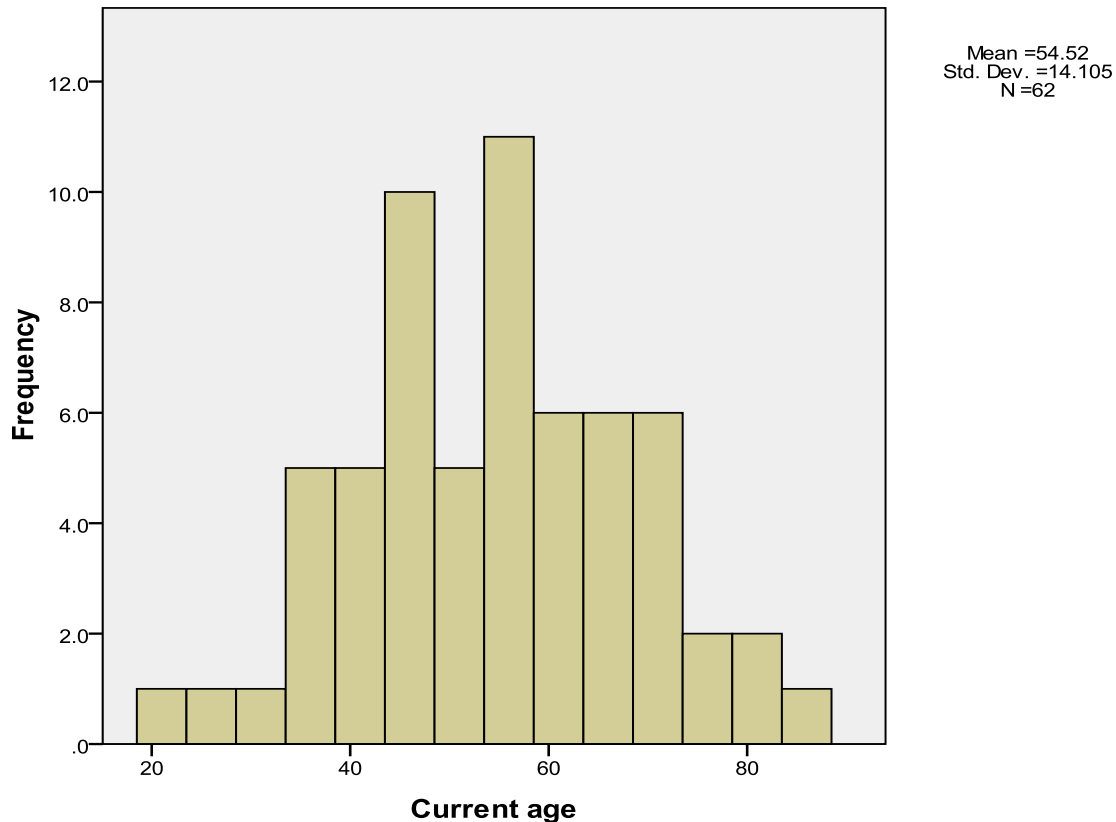
The 62 respondents were from 12 communities where the CDSMP had been implemented. Each person who completed the questionnaire received an honorarium of \$30. Table 1 lists where participants lived and the number of persons who completed the questionnaire.

Table 1 Communities and number of persons who completed the questionnaires

Community	Number of Questionnaires	Community	Number of Questionnaires
Burnaby	2	Mission	1
Chilliwack	9	Mt. Currie	15
Cultus Lake	2	New Aiyansh	1
Duncan	1	Port Alberni	6
Kincolith	1	Surrey	3
Kitimat	1	Ucluelet	3
Lillooet	1	Vancouver	16

Sixty-two participants completed the questionnaire, 42 females and 20 males. The average age was 55 years (SD=14 years). Table 2 shows the distribution of ages in 5-year cohorts.

Table 2 Age of persons who completed the outcome measures questionnaire



The average years of education completed was 11 years (SD=3 Years), and 47 persons (76%) were living with others persons. Five participants reported they did not have a chronic health condition; 35 reported having one condition; 16 reported having two conditions; 4 reported having three conditions; and 2 reported having four or more conditions. The most frequently reported chronic condition was arthritis (18 persons), followed by diabetes (16 persons), heart disease (8 persons), asthma (7 persons), and emphysema and other lung diseases (4 persons).

Results of the Analysis

Health measure scores were computed and compared between the two time periods to calculate whether differences were statistically significant. Table 3 shows the pre- and post-program scores on each measure as well as t-scores and significance levels.

Table 2 Aboriginal Study pre- and post-program scores on CDSMP outcome measures (n=62)

MEASURES	Pre	Post	T	Sig. (2-tailed)
<i>Self-Management Behaviours</i>				
Cognitive symptom management (coping)	1.75	2.08	-3.36	.001
Communication with physician	2.25	2.67	-2.71	.009
Time doing aerobic exercises	.87	1.16	-3.61	.001
Time doing stretching/strengthening	1.29	1.92	-4.37	.000
<i>Self-efficacy Measures</i>				
Self-efficacy to manage disease symptoms	6.12	7.51	-4.82	.000
Self-efficacy to manage the disease	6.10	7.58	-5.25	.000
<i>Health Status</i>				
Self-rated health	3.31	2.76	5.38	.000
Disability	1.31	1.14	2.45	.018
Social/role activities limitations	1.55	1.05	4.42	.000
Depressive symptoms	13.22	10.88	3.72	.000
Energy/fatigue	2.60	3.20	-5.56	.000
Health distress	2.42	1.68	5.67	.000
Fatigue level	5.42	4.06	4.93	.000
Shortness of breath	4.05	3.05	4.20	.000
Pain severity	4.77	3.65	3.91	.000
Illness intrusiveness	49.11	43.26	3.42	.001

Note - A statistically significant change takes place when the Sig. Level (bolded in Table 2) score is less than .05. As seen in this table, there were statistically significant differences in all outcome measures. Note that on some measures (e.g., Self-rated health) lower score indicate improvement.

In summary, the 62 Aboriginal program participants who completed the questionnaire improved on all 16 health outcome measures. At six-months post-program, participants:

1. were using more coping strategies to deal with pain or symptoms;
2. were communicating more with their physician (preparing written questions, asking questions, discussing problems);
3. were spending more time doing aerobic exercise;
4. were spending more time doing stretching and strengthening exercises;
5. had higher self-efficacy in their ability to manage disease symptoms;
6. had higher self-efficacy in their ability to manage their disease;
7. perceived they were in better health;
8. had less disability;
9. had fewer social or role limitations;
10. were experiencing fewer depressive symptoms;
11. had more energy;
12. were experiencing less health distress;
13. were experiencing less fatigue;
14. were experiencing less shortness of breath
15. were experiencing less pain; and
16. felt their illness had less intrusiveness in their life.

Table 3 shows the same outcome measure scores for the 639 persons who took the CDSMP throughout BC during 2003 – 2005.

Table 3 BC Study pre- and six-month post-program scores on CDSMP outcome measures (n=639)

MEASURES	Pre	Post	T	Sig. (2-tailed)
<i>Self-Management Behaviours</i>				
Cognitive symptom management (coping)	1.64	1.90	-7.18	.000
Communication with physician	3.01	3.12	-2.58	.010
Time doing aerobic exercises	.74	.84	-4.11	.000
Time doing stretching/strengthening	1.59	1.58	.182	.856
<i>Self-efficacy Measures</i>				
Self-efficacy to manage disease symptoms	5.70	6.09	-4.46	.000
Self-efficacy to manage the disease	6.40	6.68	-3.04	.002
<i>Health Status</i>				
Self-rated health	3.15	3.06	2.98	.003
Disability	.35	.33	2.08	.038
Social/role activities limitations	1.63	1.47	4.56	.000
Depressive symptoms	11.33	10.13	5.55	.000
Energy/fatigue	2.21	2.38	-4.62	.000
Health distress	2.04	1.77	6.15	.000
Fatigue level	4.97	4.66	3.78	.000
Shortness of breath	2.23	2.17	.62	.537
Pain severity	4.75	4.34	4.54	.000
Illness intrusiveness	39.49	37.56	3.44	.001

A comparison of the PRE outcome measure scores between the two groups (Table 2 and 3) shows that Aboriginal participants had higher cognitive symptom management (i.e., coping) scores, less communication with physicians, spent more time doing aerobic exercise, spent less time doing stretching and strengthening exercise, had higher self-efficacy to manage disease symptoms but lower self-efficacy to manage disease, had lower self-rated health, greater disability, lower social/role activity limitations, more depressive symptoms, less energy, more health distress, greater fatigue, more shortness of breath, higher pain level, and their health conditions caused more intrusiveness in their lives.

However, a comparison of the POST program scores shows that the Aboriginal scores were greater on 11 of the 16 measures.

The next, and most important part of the analysis, was to determine whether the amount of change that took place between the pre- and post-program scores of Aboriginal persons who took the CDSMP were of the same magnitude as the amount of change that took place in the general population of BC.

This was calculated in the following manner:

1. Standard Errors were calculated from the means and the t-stats (SE = Differences in Means (Post minus Pre) divided by the t-stat).
2. Then 95% confidence intervals (CI) were constructed as: (Post Mean minus Pre Mean) +/- 2 SE
3. If the CI includes the Post minus Pre mean from the general BC scores, then the two are considered NOT statistically significantly different.

The analysis found that the amount of change that took place from PRE to POST in the Aboriginal study was greater than the change that took place in the general BC population.

2009 Aboriginal Study	Outcome Measure	Within Confidence Interval?
<i>Sig. Level (2-tailed)</i>	<i>Self-Management Behaviours</i>	
.001	Cognitive symptom management (coping)	NO (change was larger)
.009	Communication with physician	NO (change was larger)
.001	Time doing aerobic exercises	NO (change was larger)
.000	Time doing stretching/strengthening	NO (change was larger)
	<i>Self-efficacy Measures</i>	
.000	Self-efficacy to manage disease symptoms	NO (change was larger)
.000	Self-efficacy to manage the disease	NO (change was larger)
	<i>Health Status</i>	
.000	Self-rated health	NO (change was larger)
.018	Disability	NO (change was larger)
.000	Social/role activities limitations	NO (change was larger)
.000	Depressive symptoms	NO (change was larger)
.000	Energy/fatigue	NO (change was larger)
.000	Health distress	NO (change was larger)
.000	Fatigue level	NO (change was larger)
.000	Shortness of breath	NO (change was larger)
.000	Pain severity	NO (change was larger)
.001	Illness intrusiveness	NO (change was larger)

The amount of change that took place from the time before they took the program to six-months later was larger than the amount of change experienced by program participants in the general population of BC. This finding must be taken with caution however, because respondents in this study completed the questionnaire at one time point (i.e., 6-9 months after the program) but also indicated how they felt before they took the program. In the general population study, respondents completed the questionnaire at two time points – before they took the program and again six-months later. This may partially explain why the amount of change was larger in this study.

Qualitative Study (In-Person Interview)

Two Aboriginal interviewers were hired and received interview training. They worked with the program coordinators to identify persons who had participated in the CDSMP during the previous six to nine month period. They contacted people to make arrangements and then traveled to participants' communities to conduct these interviews. The interview took between 30-60 minutes to complete, and each interviewee received a \$100 honorarium. In total 42 interviews were completed in the following communities.

Community	Number of Interviews
Nuu-Chah-Nulth	6
Katzie First Nations	2
Ladner	1
Cowichan Bay	2
Vernon Okanagan Nation	3
Semiahmoo First Nations	2
Sto:lo First Nations	4
Mt. Currie	7
Vancouver	4
Kitamat	8
New Aiyansh	1
Greenville	2

The main objective of the project was to obtain information on the effectiveness of this program in Aboriginal communities.

A basic principle of obtaining information about people is to ask them directly. This was made clear by Chief Gary Alexcee in an interview conducted by Nadine Caron and Tony Penikett in the Vancouver Sun on February 16. Talking about “Empowerment and Health” Chief Alexcee stated:

How do patients become empowered? It starts by understanding that technology cannot replace a patient’s story. A physician asks questions because only the patient can describe his pain. For a physician to care for a patient (rather than “treat a disease”) the care plan must reflect the input of both but the interests of one - the patient. A person knows more than is realized about her own body, spirit, history, culture and community. Modern health care should not separate these parts of a person.

The interviews were conducted with trained Program Leaders or with persons who had taken the six-week program as a participant. All interviews were conducted in the interviewees’ home community. To obtain information on the effectiveness of the program the questions focused on: why they participated; what information they received and how they used the information; the skills they learned and how they have used these skills; new behaviors they had began as a result of participating in the program; and whether they felt their health or other people’s health had improved. The specific questions are listed:

1. Why did you take the self-management program when it came to your community?
2. Try to remember what it was like - how was it?
3. What information did you learn in the program?
4. How did you use the information that you learned in the self-management program?
5. What skills did you learn? (You need to prompt – remind them about problem solving, making action plans, evaluating treatment options, relaxation...etc).
6. How have you used these skills in your own life?
7. Are you doing any new behaviours now that you have taken the self-management training? Please describe these behaviours?
8. How about your health? Has this self-management training affected your overall health in any way – made it better or worse? Please describe in which ways.
9. How has the course helped others in your community?
10. The first question I first asked you was why you took the self-management course. Now, when you think back, did you get what you initially wanted out of it?
11. Anything else you want to say?

The 42 interviews were taped and later transcribed. A content analysis was conducted to ascertain the major themes. This report provides a rather long analysis of the interviews. This was done purposely in order to accurately report what people were saying rather than trying to provide a brief summary where the substance of what people said would be lost. As well, it respects the integrity of the interviewees' contributions.

Analysis

1. Why did you take the self-management program when it came to your community?

The interviewees included a variety of people who were either taking the four-day leader training or taking the six session workshop as participants. The types of participants included peer counselors, community health representatives, people with chronic conditions, and members of the community who wanted to help their family members or friends living with chronic health conditions. Reasons for taking the program included: a) to learn how to better manage their own chronic conditions; b) to learn about chronic conditions; c) to gain new skills and knowledge for working with clients; and d) to pass on skills and knowledge to other persons living with chronic health conditions. As well, there was a variety of other miscellaneous reasons.

- a) An opportunity to learn to manage their own chronic conditions

I had recently been diagnosed with diabetes and felt very strongly that knowledge is power and that is what I needed

I have arthritis and I have a lot of pain with that – I have taken an arthritis workshop, so I thought I would take this course, learn stuff for my own self

I have severe psoriatic arthritis and I have rheumatoid, a touch of rheumatism and a touch of osteoarthritis. I am on all kinds of medication and sometimes the medication doesn't work so I needed to take it to understand.

I have chronic pain and I am a nurse and have injured my back and now have a herniated disc so any information that I can learn from personally to help me with my pain on a daily basis is a bonus.

Sometimes the pain is so unbearable I have just about go into convulsions so I need something. So when I heard about this course I was there and I was there every day.

I am a diabetic and wanted to find out more about health issues. It is pretty hard going through that because when you first go through it you feel like you are alone but when you start talking to people you find out that everybody goes through that, so I wanted to find out as much as I could about all the other things that people go through.

It was a good time for me to learn to manage my fibromyalgia, chronic fatigue and so it was a good learning experience and we learnt so much from each other, and to know that something could be done other than doctors was good. It was a good pace too – we learned that somebody

else is in pain too, like mine.

I needed to understand more about myself first and learn from other people too, get to know I can do for myself first and then I could be able to give it to other people.

Mainly because even though I am a health worker I find that it helps me in my daily routine and keeping myself, helping myself keep my self esteem and I guess my stamina to stay away from medication because I am pre-diabetic. So I need it for myself.

b) To learn about chronic conditions

not just for me but also for my dad and my son. He has had a chronic heart since he was born. I like to get well informed and I do my own research sometimes. That is why -for my knowledge.

I wanted to learn more about the chronic disease because I am at the age where I see a lot of people with different points of sickness.

c) To gain new skills and knowledge to help me work with clients

Persons employed in the health care field took the training for professional development i.e., to gain skills and knowledge to better support their clients living with chronic conditions. Some were required to take the training.

To tell you the truth about the whole thing, I was instructed by my supervisor to take the course

I took it because part of our work requirements was to take the course so that we can present the workshops and I think if it hadn't been part of my work I would have looked into taking it on my own – it is a great program

It was part of our self management training that we had this self management program we had going here - a requirement that we took the course. I take courses that we have here anyway so whatever is offered I usually end up taking

I thought it would help me a lot in my home support and residential care job

I took it because I am in the health care profession it is my job to help people deal with their pain and not just with medication but with other different avenues as well

I would take it because we help with alcohol and drugs and I thought it would help because we do the meditation work there

Just doing healthy lifestyle nursing in the team it seemed like a really good fit to have another program or tool to kind of bring people in and have people be their own managers

I was working with people who came to our centre who had chronic diseases and felt that this

could be a really good course for them to manage their diseases, whatever disease they had or just in general

I am a community liaison health worker so the people I work with often are in pain, so any tools I can learn to help. I always take workshops concerning health issues and also for myself because I also have health issues

d) To pass on skills and knowledge to other persons living with chronic health conditions

Through the healing centre where I worked it was offered and when we were going over the information it sounded really good to me to take because of not only family, but friends, elders

I thought by being taught I could teach others and it sounded very interesting to me

We were offered the opportunity and thought that I would jump at the chance to learn something new and to be able to reinvest it back into my community – so it was more to probably learn and re-contribute the knowledge and wisdom that we would get

I wanted to help people and saw this as a way and for many years I have been trying to get that kind of a chronic self management program going on the reserve but we never able to tap into it before, you know there were people coming from Kamloops, Kelowna and they really didn't want to come out regularly to the reserve in Vernon, so this is something I have been wanting to do for a long time.

I looked at it and saw the program and how it would benefit not only myself but it was something that I could share in the community.

e) Other reasons for taking the program

I was asked by a friend who had taken the course and she was talking about how great it was and so I signed my name up for it

We were looking for a better way to help people actively self manage diabetes and other chronic conditions and we had heard good reviews about the program

It was offered and I figured it would be a great opportunity to understand more about it

It sounded like something that would be appropriate for everybody, not specific for just one condition – I thought I would give it a try and see if it was something that might work here

It was so easy to get to. It was in the community for one, very convenient. There are so many classes and courses that were outside the community and wouldn't work for me so I came because I want to take it and I want to facilitate it

I have read the book to use prior and I thought this was a really good book

It was an update because I had already taken it once before with the previous nurse that was here

2. Try to remember what it was like - how was it?

All participants provided favorable feedback on the program. Words used to describe the experience included ‘amazing’, ‘informative’, ‘challenging’ ‘interesting’ and ‘fun’. Comments were made about the ease of delivering it in terms of the content and process used by the facilitators.

- It was fun

It was fun – I remember laughing a lot and it was a really positive experience

It was good and a lot of fun. I think everyone was nervous going in because you have to get up in front of a group of people, strangers and talk

- Felt nervous

I was really nervous, I am not used to talking – I am not a very talky person, but I was really glad I took it and I learned a lot – I am glad I took it

I felt nervous like I didn’t know what to expect for one and I didn’t want to be picked on to do anything. But after the introduction of everybody that I know and that are willing to do this kind of thing, it kind of gave me the confidence after all. And then I thought, “Okay, I will do it!”

Just signing up was very scary for me ... I was scared of teachers, presenters because of the abuse that I once knew before, so helping, this helped me to have confidence even though this initial nervousness and fear. After that, there was confidence and I can do this – getting over the fear was the first step – it really helped, it really did

I enjoyed it – for myself because I have chronic conditions and also to be able to hopefully to be able to present to the community even though I am kind of scared to do that

- Enjoyed meeting others

I really enjoyed it – I met people and we really worked well together

I had a great time – formed new relations with non natives from town

Met lots of great people who were doing good work in their community, so it is a very positive experience for me

- Easy to follow (‘user-friendly’ and it used ‘layman terms’)

It was pretty much straight forward. We also had some clients there that took it with us and they were kind of leery about taking it especially when they saw the books. It was pretty much straight forward and very user friendly

Everything was organized and laid out easy and it was easy to follow. The instructions were very good. Everything was clear and precise and it was smooth. It was laid out with the agenda what we were going to be discussing and it was very easy to follow

The outline in general was really easily understood and it was somewhat of a roadmap in place for us to follow

Actually I really like the way the materials were set out, how we had all the tools we needed

It wasn't really highly filled with medical terms or anything like that. It was in layman terms and it was fairly easy to follow along so that anybody could do it

The program is very set. It does not require professional knowledge. People just need to follow the program the way it is

It surprised me – it was laid out in the book. Like it tells you exactly what you need, what to do what to say and I thought that was really good because I don't like talking in front of people that much so you know, when you have it laid out in front of you, you can't really screw up too much and if you do, they wouldn't know anyway

The leader's book is very well presented and easy to follow.

- Length of the workshop

Some participants found the training too long, especially if they haven't taken courses.

- Liked the training process

Having the book and having someone there especially when two people are doing the presentation is awesome. You learn a lot in terms of when there is a group of people who are participating, facilitating. It makes it a lot easier to understand. The interaction is more important for me than reading the books, but I have the book now so I am reading it, studying it

The way it was presented. I really like the presenters. I like the way that they used humor. I liked the way we practiced. I think the course was very well presented and I like it and I think it will be easy to give

The instructor was really empathetic with us and our different levels of learning

Well modeled, well paced, well monitored. I did enjoy the facilitators. They worked well with the agenda and the timeline. I really do appreciate. I am a stickler for remaining on schedules so I appreciate that they were very responsible and honored that we were on a schedule and we have work to do. They were really quite considerate with the group approach. I appreciated that they cared, which meant that with that ingredient in place that I was all the more eager to be there and learn and know that this is pretty important that they were investing that quality of service

The facilitator spoke clearly, slowly which was good for everyone involved in the presentation and she didn't just move through the course material because she had to. She really wanted to take the time. If someone wanted to ask questions, she more than willingly answered all the questions

At the time it was kind of difficult. It was just at the time when my husband had passed away so it was kind of difficult time for me then, but I really enjoyed it. I really enjoyed the whole training session

I enjoyed it. It was well presented. They [facilitators] were really clear in what they were reading to us and they made sure that we understood what they wanted to hear from us. That is what I enjoyed and we weren't rushed into it. We were taking our time and we were given our time to speak. I might have spoken more than others too as well, you know. You will find out I like to talk once I get going!

The instructor was very, very good. I like that he was hands on and his openness on and making us aware of what was really out there and what a chronic illness is and how much it really affects a lot of people. It is not just come, it is there, it is constant and to deal with it. He taught us how to help the people understand and make the pain lesser. It will always be there and just to help with exercises and stuff and you just don't realize how many are out there, how many chronic illnesses

3. What information did you learn in the program?

The majority of participants reported learning at least one piece of information in the program. Only three of the interviewees felt they had not learned anything new, and of these three, one of the participants noted that the program served as a refresher of the information he had learned in the past.

- As a refresher

I don't know that it was new information, the content was new. I don't think the content itself was new or different information for me

I don't want to say nothing but, I have done a lot of training similar to that so it was more of a refresher for me so I can't think of one thing that I actually learnt but it was just an all around refresher management course. You know, how to handle life basically, chronic disease

There were lots of validating things that I do already for myself and so I thought that was cool that someone else was thinking about that and putting it in a book to help yourself

- Learned about one's role in managing health

Sometimes having to utilize the professionals out there and see ourselves as a professional being that it is up to us to responsibly exercise a new system or a system program with the help of the professionals as well

Making sure you take care of your own health and your own self first because you won't succeed... you can't help anyone else

- Learned how to access resources

A lot of things about the importance of having the 811 number for example, just in case anything went wrong and we don't really necessarily need 911, you can call 811 and then you ask questions about medication, anything health related. They can direct you

Having the personal medical records that you keep with you at all times

- Learned about specific diseases

I was looking at the one for asthma because my brother in law has it and his is bad and I read in the book about all the things about allergies and how asthma can be caused by allergies and that is good to know

I learned actually about some of the different chronic conditions and how to identify what an acute condition is

I found it very interesting information regarding diabetes, cancer, rheumatoid arthritis, hip replacements all kinds of different things in there. I do keep reading. I still have the book that we were given and I refresh on that because I work with elders and disability and it just helps me to understand and be able to cope with them and understand why their days are sometimes not very good

I learned how to manage my asthma. I use the information from the program a lot now. I learned how to manage it and I also use it. I try to use it with my family

I have been working with elders both dancing and for fundraising or whatever so this helps me a lot to understand what kind of illness they are going through and I utilize whatever comes up

The program about chronic pain – some pain like you can go and have an operation and the pain subsides for a while and maybe it is gone but chronic pain comes on slow and lasts forever. And some with other pain you can get operated on and it's finished like the appendicitis or gall

stones but with arthritis or hearts, and diabetes there is no operation so you have to live with the pain and you know make the best of it and try and manage it the best you can

I learned was just sharing the information with other people with different illnesses that in itself, networking is one of the best things that anybody could do and especially in this regard – commonality of illnesses

- Learned about the symptom cycle

I really liked how the symptom cycle - sort of understanding that you have the disease and it affects all areas of our life and causes stress and fatigue and how it all bounces around

I appreciated the different skills within being able to attend the toolbox, the continuum of the cycle that goes along with pain, emotional stress, how everything can be connected and we can create a system that can contribute to either the positive or negative within our chronic illness – how we can jump around on breaking that cycle is an option, on paying attention to some of the principles of personal health and wellness

- Learned about taking medication

I learned what has to be done at certain times, like chronics have to be on time with their medicine at all times

- Learned about pain management

I have learned different ways to handle my pain. Some things I had not thought of in the past necessarily and just learned different ways how to handle my pain, the different emotions that can arise from feeling the pain and so that helps me personally and professionally

- Learned about goal setting and action plans

I guess for people who look outside of themselves for help or answers or someone to do work for them, including I guess myself to a point, of learning those skills of goal setting I think is really, really good and I use it myself. I think it is probably the best tool in the whole program for people to learn if they are writing things down and making small manageable goals and building on them

The most important thing is that my pain is manageable and a wellness action plan is the only thing that stuck with my mind – ACTION PLAN – and I still do it with what we learned through that, through the problem solving I have coordinated right into my daily life. I probably have 2 or 3 action plans now

Well, I think the action plan is a really good tool that you can use with just about anything

- Learned about problem solving

I think that the biggest lesson for me there was learning how to problem solve, to look at a problem I may be experiencing, specifically around my illness, and what could I do instead of throwing my hands up in the air and going “Oh my gosh, now what?” Running to the doctor? Running to the clinic? It made me think, “What can I do first? What can I do to make the situation better and improve the situation for myself?” It really opened the door for me because I have not really thought about solving my own medical problems

- Learned about distraction

It’s not easy to think of two things at the same time in dealing with chronic illness. We have that opportunity to focus our attention on another thought as opposed to the pain and that was interesting to me. I appreciated that

- Learned about relaxation techniques

What stuck with me most was the relaxation and the storing your pain, like putting it on a shelf, saying it’s ok, you know it’s cool or whatever. I don’t have a lot of chronic pain so I am not like some of the people that were there. You can see it and I sympathize with them and I am glad they were there and took the program so that can learn to deal with it

What I learned was using imagery and breathing to relieve pain

- Learned how to deliver the program to others

I was able to learn to how to actually use materials in the book [Leader’s Manual]

It was that when you got something that you have to present, you don’t have to present it in one big chunk. You can break it up and then do it over time and it just kind of makes it easier on yourself and for the people

I was most impressed with how they break it down and make it sound simple and I guess it is, and that anyone can do it. You can show people step by step and in the end how to take control of their own health and how they can help themselves

I learned a lot of different techniques or strategies that I apply in my day to day practice with working with clients out in the field and a lot of strategies to help them work on their conditions and different strategies for them to come up and more putting the ball back into their court and giving them the power

4. How did you use the information that you learned in the self-management program?

Participants who took the Leader Training workshop learned how to deliver the program in their community.

We have been offering the CDSMP twice a year since we took the training, so far we have had good feedback from participants

- **Helping others**

I was teaching my family how to do deep breathing and coughing and I was telling them about drinking lots of water to loosen their phlegm. My husband has emphysema

I applied it to myself. I have also applied to my hubby, my mother, so there are a few other people out there. This is a new program that you actually have to sit down and realize it's a way of teaching that you are accountable. You learn by setting up an action plan. It's yours, you own it. It is what YOU want to do and you follow through with it so it is a good teaching tool

I have made some suggestions to my daughter who does have chronic pain

It was nice that I am given that opportunity to share what I have learned. I think that is where the question is answered, that given the opportunity to exercise the teachings that I received and share the knowledge, wisdom. It will make a difference with the people that we work with within our community

I gave the book to my husband so he can read about it. Sometimes he has swollen joints from arthritis. He loves to read and I know that he will learn something from it.

I practiced what I could, what she taught us and when somebody else is going through pain a lot. I share what I got out of the book. I share with them what I do. My homemaker has lupus and she learns something from me every day. If someone else is having problems, I share what I get from the book

Elders can come to me and I can be their sounding board. They are more comfortable and if they can recollect just part of the conversation about something they can do, they call me up and I can help them

- **Using action plans**

I use it mostly for my own personal fitness and healthy living because I can look week to week and set a goal each week to work towards. And I can be successful at it. And it helps me to build on to longer term goals and it makes me really accountable to myself

I have been using them on myself actually, with my diabetes, even though there wasn't much on diabetes. I am using them within that sense and now walk to work every day from the time that we were doing that to and from work which is a big step for me because I only live just over there

It just motivates you for yourself with the eating and exercise and planning to do something and to actually follow through and if you have a goal and it is rewarding then to get that goal

- Using problem solving

The problem solving was the biggest component for me of the course. I ended up using it daily. It made me look at how I can use it every day with regard to my condition as well as other things that were happening in my life

I like the problem solving. It is most helpful because I have been reading many articles on the fact that we need to learn how to self manage the diabetes disease or condition and this was a helpful tool on how to do that

I used it in other areas of my life. For example, when both my children are having problems I say, "Well, ok. Let's do a little brainstorming around that, okay? Let's do a plan of action." It gave me a tool to work with, not just with regard to disease but in managing your life in general and a good guidance tool

- Used skills with clients

I have used it a lot with my practice out in the field working with clients and trying to come up with different ways for them to deal with difficulties or changes in their condition or adjusting to their condition, working with them and their families helping them to come up with different strategies, different thoughts, different ways of maybe looking at things. I have used brainstorming in my own life

I introduced them to some things that I learned that they could use to stop the stiffness and the pain and we just work from there

I use it all the time. I have three clients and I use a lot of the stuff that I learned in the course. They all have HIV so I use it that way

I also work at the hospital. It lets people who are having pain or whatever it is and they are so focused on that pain that you have to use the distraction and the relaxation and the imagery and just try to get them out of being in so much pain

When you see people that are maybe not being good to themselves in a healthy way, you can maybe make suggestions

5. What skills did you learn?

- Learned to deliver program

I learned a little bit on how to speak in public. I don't really speak very often. I can on my own write it out but I learned how

I think the part I learned was the actual being able to stand up and do kind of presentation because it is not an easy thing to stand up in front of people

I guess the biggest skill I am thinking of is teaching, being able to teach somebody something. I will be able to think of ways to present it

I learned patience and not to have fear of being in front of people. I thought I am ok with it but I needed a little more confidence. They tried to encourage you like in one group to be a heckler you know so we had fun learning different ways of teaching

I think the skill I mostly learned was to be a facilitator and I can see the value in learning something like this because you can use it as a guide to set up any program

I've been a toastmaster for quite a few years. I have given many speech courses and stuff like that. I started toast masters clubs and whatever, but I learned a lot from that program. I learned different techniques for dealing with people in a crowd. I learnt some things about myself that needed to be brought to my attention, my manner of presenting. I learnt from other people that presented, things that they did or didn't do or things that they would like not do or things that I would like to do. So, there was lots of assistance in that regard as to how to actually run the course and get through tricky parts in it

I'm not used to speaking out in front of the group so the practice was a start. Trying to learn how to out to speak out myself too

I learned how to use body language like to face people and not the board when using it

- **Learned Action Planning**

I guess the action plan was new for me, and definitely the action plan is something that I have used for myself as well

No matter where people are starting from they can learn how to build on their starting point. I guess the actions plans are one of the best skills to learn when taking the program

Goal setting - that was huge. I never did that for me before. I didn't stick to it and if I did, I set the bar too high. So the Leader taught us how to effectively attain our goals without letting ourselves down and setting ourselves up for failure. So, that was really good

Yes, action plans is another one you can use on a daily basis too, just setting goals, small steps

The problem solving and making action plans. I use it a lot in my own life because I have a really hard time with my weight and I am always looking at the larger picture where they tell you to take little steps, small goals, so that is really helping me

I used the action plan and started out with 15 minutes of walking then after one week, I add five

minutes on to it and then up to an hour. It was pretty good at attaining that goal

The action plans help you to map out something that you really want to do and you can utilize on a daily basis. The action plan was probably the most important aspect of what I got from the program. It is something I could probably utilize more with the people I work with but for now it is just with myself

- Learned skills to work with clients

It helped me to look at the way I was looking at things and helped me to step back and put the control back in to the clients hands as far as managing their conditions

I learned how not to answer questions for people because as a health care worker and as an advocate you learn, I learned that some people don't know how to quite express things. But with this program, they have to learn how to express how they are feeling and what they want to do for themselves. So that was a good part of the program

- Learned problem solving

I learned that you are not alone and that in each group of people the problem solving, we might be brain storming and you realize it can help you as well. It is a safe place where you can speak up, support people and be supportive

I thought problem solving was great. They get confronted with a problem and it becomes all encompassing and they cannot see around it or past it, so it is good to just talk to them about what other ways they might deal with this

Problem solving gives you the idea that you are not in this alone and you can always have a buddy to reach out to. I could phone up and talk to and say, "Hey, listen I have got this problem, let's brainstorm, help me brainstorm, help me get to the bottom of solving this problem". It gives you the sense that people care but you also take your own direction in managing what you need to be managed at the time

The brainstorming part of problem solving was good. Some of it was repetitious but I like the part where even if it was mentioned before they would put a tick beside it or they would re-write just so that they acknowledged you as a person, which I like

- Learning to relax and pace yourself

I learned to look after myself and relax at times. I noticed that it does certainly helps when you take time out for yourself

I am now running a meditation group every Friday night here in the centre. It has done wonders. I have people coming and asking me when the time is every week. It has just turned out wonderful and I never thought it would but I have tried it and it really works. And I don't ever want to stop it because it is bringing in people that I never dreamed would come

I have my CD ready to go with me all the time and for one with having arthritis I find just the breathing exercises are very calming. I am a lot less stressed now by listening to it and the calming voice. There are other different relaxation methods, but I like this one because it only takes 12 minutes and that is good for being busy. We are all busy you know, but just take that time out for you

The relaxation was one thing that I actually had done that before but I kind of had forgotten about or hadn't used. It helps

The relaxation was good because it is good meditation for me, to learn how to relax and it makes you more alive after you meditate. I feel good after meditating

6. How have you used these skills in your own life?

- Shared skills with others

By teaching and sharing because a lot of my family has lupus, knock on wood I don't have lupus so if somebody has something I try to share what I have learned and maybe it won't work for them but it works for me but who knows! They might get something out of it

I use relaxation and the action plans and teach them to my son. I leave pamphlets around from my course so they pick it up and say this looks interesting. I have my husband looking at the books now

I practice these new skills on my husband. It was good just to be conscious of it and I just, refer to some of the charts and even my manual which I use a reference

We let others know that there are things out there that you can do and encourage them to ask for help and learn to use the health centre and doctors and not to be intimidated but to ask questions. We enable and empower them because oppressed people were told no, or we cannot do it right now for you, so we get turned off

If I can make a difference in one person's life, then my job is worthwhile. By giving them the information that I learned and telling them that it helped me, and passing it on to them

The way I use it is I use it with my parents, making sure that they are taking their medication on time and having something to eat, like breakfast, lunch and dinner

I really was so glad when at the first session when we were talking about pain on a scale of 1 to 5, where is your pain level at. One of the ladies said that her pain level was at a 5... so we did a meditation exercise where you think outside of the pain and so when we went around the circle, she said her level was at a zero or one. I was so surprised and I thought, "Wow you know, it is amazing how powerful our minds are!" What we concentrated on is what is repeated and yet if you concentrate on something different and don't ignore the pain because you know if it is getting worse then you should see a doctor. Also, _____, her arthritis was really bothering her. It started at a four or something and it went down to zero or one. It felt really good that you could help

people in like real ways.

- Used goal setting and action plans in their own lives

I have been using the action plans to accomplish my goals. I'll make myself an action plan for the week and try to stick to it

Setting up a cycle of being able to succeed instead of setting up a cycle that I won't succeed at so reinforcing the negative. I can't do that. I'll never be able to do that. I can do this little bit today. I can do that little bit tomorrow and do more the next time so setting up a cycle to be successful instead of non-success

I learned that even when life hands you something you say, "You know what?" You break it up so that it is easier to digest and handle and it doesn't get so chaotic and overwhelming. That goes for many things from planning a weekend to how you are going to approach your child

- Used problem solving

When I see a problem now, instead of throwing my hands up in the air going "Oh my gosh!" and getting into a panic, I revert back to the class believe it or not and go. "What would we do in the class?" We would do the steps, look at the problem, analyze the problem and go forward. It is hard to explain but I became more analytical. I analyze my problems more now. It is like almost nothing is insurmountable. There is an answer somewhere. There is an answer, be it very small or the total answer but there is an answer, I have learnt that

I talk to friends online and help them deal with problems they have with chronic disease. I tell them to do a brainstorm, make a list of all the pros and cons of this situation and they decide the best course of action. A lot of my friends really value me as a friend and even more because of this skill that I have. And I didn't really do anything except listen to them. They have their own ideas. I just extracted it from what I learned.

I used them when confronting different things coming up in my life. I have just moved in with a new partner and then my daughter is off at school - different things happening and it is just "Ok, what are some ways we can deal with this?"

- Used relaxation techniques

I go into the waterfall one. I love that one where you go through a meadow and then all of a sudden you are at this lake and it is just beautiful

The idea that you cannot focus on two things at the time same time

I use the visualization of walking down a road, and you come across a toolbox where you can put your stresses and worries for now, as opposed to just getting caught up in the experience of that initial experience of the pain

7. Are you doing any new behaviours now that you have taken the self-management training?

The program was mostly a refresher for me but I do use the book once in a while, which I didn't have before. It is nice to have it in writing to show somebody when you are doing counseling

I like to leave what I have learned out on the table so my family will pick it up and read it

The brain storming is now a big part of working with conditions and difficulties the clients face and even in our work. We use brainstorming in our organization to deal with changing policies and constraints

Again it's come back to the problem solving which was huge for me and I apply it in my daily life and it is not a panacea for everything. I am not saying it is but for most things for me, for things that I would throw my hands up in the air about and lose hope and lose faith, I can now sit down and work through it a whole lot better and it is thanks to that course

- Personally using 'taking action' following the program

I feel more motivated. I used to be very sluggish and not wanting to do anything because I have skin cancer and I am not allowed out in the sun very much and sort of isolated myself before I started understanding and this course helped me understand my own – like it is all right and to reach for it instead of staying stuck. If you stay stuck, you are just going to stay miserable.

After suffering a long time, it might take me less time now to do something for myself. Now I don't let things go. I don't let me hips hurt forever and ever and my back hurting forever and ever I will do things about it, hot baths, sea salts and just take care of me

Trying to be a little more, what is the word? I have always tried to eat well and exercise. It has got me a lot more, what is the word... more COMMITTED to make sure that I actually do it rather than once in a blue moon

- Using the techniques in the tool box to draw upon for managing chronic conditions

I guess just acknowledging that I do have a chronic condition and that there are tools to help. I know there are things there like if I am feeling "Oh, how am I going to cope with this?" I know that I've got something I can go back on and something to use and then I know that I have somewhere to look and to find something to help

- Started exercise

I try to walk a lot and I have got my son helping me on my exercise regimen you know and I fall off every once in a while, he kind of helps me. He says "Let's go for a walk," and then we just go for a simple walk and that is what we do

I go out walking more and I am more consistent with my walking

I am doing my stretches and exercises more

I go to the gym. I started this in the program and we gave ourselves expectations to be met on our own behalf to contribute to our wellbeing. I have given myself two times a week at least to go to the gym. It is painful. I really like to be honest with you that I don't like it, but I change my thinking and attitude around that. I've refocused my attention on positive affirmation as opposed to getting caught up in that negative self talk monologue, dialogue, so that is something that I am currently doing. I feel better

- Abstaining from alcohol

I am staying away from the alcohol as well too. I am learning these management things, thinking about myself so this gave me the go ahead and to keep on going and it has given me strength

- Started using relaxation

Probably the biggest one is the breathing technique, the relaxation and also just trying to put that in to your daily life. I think that this is the most important thing for anyone

I now do relaxation and visualization. I sit and close my eyes and go from my toes up, that kind of thing. I am actually getting it because at the last session the other week we did it and I just about fell asleep. That is how relaxed I got. I also use it when I have a hard time falling asleep.

- Eating healthier

I am really watching what I eat. I am going into healthy eating and yesterday I started a cleansing diet so I am cutting off the caffeine. I am only having 2 cups a day whereas I used to have about between anywhere from 8 to 10 cups a day

Yes. I have incorporated two more action plans. We started out with one, but now I have done two – applied more healthy eating and drinking my water, you know, just little changes that to some are just small but like with someone with arthritis, it is a big milestone

I am more aware of what I eat. I have started juicing and things like that. I have had a juicer for years and years and never used it. I have started making smoothies so thinking of getting my vitamins and nourishment from alternative sort of sources rather than just eating. Bit of a good habit to be eating in different areas, you know, like getting carrots, so it will help with eating my vegetables because I have a hard time of getting in the habit of doing it but drinks, everybody counts drinks

I found that eating breakfast really made me feel different. It speeds up my metabolism and not only that, I found out that I have more energy. I am being a lot more active. Doing fish, smoking fish, gardening, picking berries, stuff like that, and being outside. I have been picking berries a lot. I think we have 10 gallons so far. I found out that since I have been more active my

family has become more active. My daughter and my sons and my husband are even out there picking berries

8. How about your health? Has this self-management training affected your overall health in any way – made it better or worse?

Most participants reported that their overall health was made better by participating in the self-management training. Those reporting that the training had not affected their overall health were already maintaining their health prior to the training, and the training served as a reminder to continue making healthy lifestyle choices.

I think my health has stayed pretty much the same since I took the workshop, but I have the awareness and the tools and it is applying them and that is what it is and practicing it

I think I was pretty healthy before and I still am - but it is a good reminder about how to take care of yourself, but I wouldn't say that my health has improved after the course

The training affected me. I am thinking more about my choices, whether it is nutrition or self care kind of things, pain management. My partner has diabetes so I try to get him on the band wagon as well. I also want to be healthy because I don't want to go into the community and talk about lifestyle choices, nutrition and exercise when I am not following it myself when I am not making those healthy choices

Other participants were more conscious of being healthy following the training.

Well it has made me really think about my life longevity and you know how I can stop these diseases from coming in my simple things as eating, exercise and proper sleep. All these things that are emphasized – they are simple things really but you know some people need to be reminded and I am one of those people – I am very conscious of that now

I feel good about my health now that I understand and read about heart disease and the chronic part of it. It has helped me. I have to do more exercise, because if I don't do anything I would probably have another one and it could be a fatal one. So, I am more aware that I need to do this walking and running or whatever exercise I need to do

Participants explained that their health was better as a result of taking action and not letting things get worse. Some participants were making an effort to improve their mental health by leaving the home and getting out and being active.

The information that I have learned is a positive thing and I will definitely not let things go on for so long. I will get on and start doing things a lot sooner than later. I think I look after myself way better than I have ever had

I think it has made it better in a lot of ways because now I am going out. If there is

anything happening in the community, the van picks me up and I am out there. I am busy. I go to meetings. I am an elder spokesperson. Anything happening out there, they never leave me out. They always pick me up. When I am home I am reading, I am writing, I am breathing. I keep busy – whereas I was bed ridden for 5 months I couldn't do anything. I did not like that the nurse had to come comb my hair, bath me, brush my teeth, put my medicine on, and feed me. I took the program. I can do more for myself and everyone is saying you are walking better, well great to see you down the road. I would take it again because I sit and read my book and get more out of each time. I highlight everything I think is important. I then read it again and I still did more highlighting and each time I highlight I use a different colour, and even then I still take notes. I have a small blue container and I have flash cards, I go to a dictionary. I find out what a word means. People are saying it is so good, you are looking good, what are you taking – give me some!

I like the way it motivated me and I am not sluggish anymore. I do go out and before I would just stay inside on days like this but now I can go to the beach and sit under a tree – you know it is just as hot, it has shade but still it is nice out there

I think it has made it better because I try to watch how I eat and try and cut back on my salt. I used to have lots of pop so I have cut down on that. That is how I gained a lot of weight before

Absolutely made it better with the understanding of nutrition and stress management, again those are big components of that program and that certainly has a benefit on my sugar or glucose numbers

With the smoking, if this had been six months or a year ago, I would wheeze so bad it wasn't funny. I haven't used my puffer since the beginning of the year almost so that has cut down because of the smoking and walking

It has made it better by learning these techniques, relaxation which creates less stress which has made me relax and stretch out muscles. I should have been stretching every day. It has made me a lot better person

I exercise all the time now. I did have high blood pressure and now it is normal. Yes, that surprised me – so it actually works, my blood pressure goes down. You think after a month or two you would see that it wouldn't do anything, but I have been working hard since December and it actually did. That surprised me. It is nice to have a visual or something concrete that shows for all the work you have done. It is one thing to say I feel so much better but it is totally objective. It could be a state of mind you know what I mean, you feel as good as you want to but to have a concrete data or whatever to show that it is actually doing something

My overall health has been great, knock on wood...my overall health I think is pretty good. I am looking at exercising more, going for walks and my spouse, he, we went for a walk last night and my daughter came with us and we took the dog. He says, "You know what? I have never been a walker and you know look at me!" I am walking, just getting out, even if it is only half an hour. Last night we went for an hour

It has made it better. I know I have arthritis and of course with arthritis you are going to feel

pain. It doesn't matter what you do. You don't know when the pain is going to hit you. But I have a lot of good days since I have been exercising; it has helped with the pain, since I started doing the light weights with my arms. I don't feel pain in my shoulders any more. I am not saying it is not there, but the exercise is helping

I would say foremost mentally, because I have learned how to deal with my pain on an emotional level. I can now do some things to help me with pain. I apply them daily

I think it helped me a lot, because after I was diagnosed, I never used to like to talk about it before but now I talk to other people and they tell me what they are going through and we talk about our problems. It is true what they say that what you share with other people can make it lighter. That helped me out a lot

It has made it a lot better, a lot better especially my asthma. I never used to take my puffers at all and I figured I am a nurse but I am thinking that I would get addicted to it, but that is not the case. If I am going to go for a really long walk, I would take a puffer before whereas I never used to. I would wait until it happens whereas I prevent it now before I have an asthma attack. It has really helped me and I think it will help me with my overall health

I use action plans and now I am taking my vitamins

I think better by not trying to do too much at once but to factor in 'time out'. I now give responsibility back to other people instead of taking care of everybody in the family myself. I am being more of a director than a person doing these things for them all the time

9. How has the course helped others in your community?

I think it helped a lot of people to set goals and set manageable goals. I think that is good and the goal setting and learning a few new skills, like the muscle relaxation

I have seen a lot of people use the book and action plans. The training and stuff that we got with the action plans was I think probably the most helpful part

I think people really enjoyed coming together and hearing from other people who have other chronic conditions and realizing that they are all in the same position and relating to each other even though their chronic condition is different. I think it helps people to come together and relate to each other

I think there are real positive changes in the people that have come to the groups. When you see them later and talk to them. They will bring up something that came up in the course, how it helped them or they have connected with someone. They are actually keeping in touch with each other so that they can reinforce what they learned. I think people are generally supporting each other and not staying isolated

I think it has helped them open up I noticed and be more open to other people

I think we learned to trust each other. One thing we learned was that if we don't trust the outside, who can we learn to trust? We are there for each other. Like now when we do graveyard cleaning, we are there with our aches and pains. We can share our laughs and our good times and we don't hide too much. We are out there and helping each other. I think having gone to residential school where we were all sectioned off. We could not talk to our brothers and our older sisters. It is one of the healing areas without even realizing it, that you learn to communicate and relate and trust. The biggest thing is being able to trust in a good, safe environment

We have been able to tell the rest of the community about the things we learned in the course

It obviously directly affected the people that were in the course, but the elders learned to sit around with their tea at the elders centre and anything new in their life they like to pass it on. So, even without knowing it, they are passing on the information to their friends who pass it on to a family member. So again, pay it forward

Other people have been informed about the course. I told them that we can bring our charming upbeat personalities and that there are people out there who are interested

People are interested to take the course because I participated in it. They ask how come you are going to it, you are healthy? I say I look healthy at times but most of the time inside I need to do something, maybe my eating, maybe exercise, maybe the way I think or maybe the way I breathe so it kind of opens them up – “Can I check it out?” I say yes and I have the book and read it

Well within the work place, I have the fortune of having had to attend the course with a couple of my co-workers, a couple of other co-workers wound up saying, “I don't need this.” It really is quite a shame because this professional community - we do have a duty to learn, grow and teach and this was a perfect example of those principles being offered to us and really being able to teach the teachers, the minds, the clients that will be sitting there as clients eventually will be contagious. It is really important to me that I have this gift to be able to share for something that is as important as health and wellness

We have done four workshops in different communities and I think in every community there are at least one or two that are so enthused and excited about the tools they are getting from the workshops - whether it is the action planning or to see little things like freezing small meals ahead for the days when you are too tired and in too much pain to cook and asking family or friends for help and different ways of communicating. I think we may not reach the whole group but if there are 1 or 2 in each group it is wonderful. They are very grateful and excited.

I think it has helped a lot. The emails comment on the things that they have learned so much and when I see clients around, there was this one lady and I looked at her and she just smiled and said yes, I am drinking lots of water, she was one that didn't drink at all, so she got to drinking water and got to learn about the diabetes and the medications so she was really happy about it. Her husband has diabetes too so they learned a lot. I have a number of other people commenting on the course and they keep telling us to come back, that they would take it over

again in the community

I think that the people that I know that have taken that course I see more exercising, I see more doing than complaining, just the ladies that I know personally. I was talking with one actually this morning and you know they are riding their bikes more. She talked about the course and was laughing about the course and also I see her continuing on with her exercise program and she seems a little bit more upbeat. There are people that did take the course but there are people who haven't taken the course and hear about it and want to take the course and so they are asking, "When you are going to run a course?"

Through this workshop, and by talking to others who have taken it in the past with me, they said that basically it gave them an awareness, it gave them coping skills and kind of really gave them that push to start trying to incorporate those little steps in order to become more healthy and be more aware. I have seen some of them. They have started walking around the loop on the lava

I see a big difference in even the ones that had actually taken the program the first time around because their outlook is better. They have some tools. They have this as their reference book and we can talk about that, something that you know like it is a term now that we use, oh you know – oh yes so that person has a chronic illness, that is just like our program that we took that can help them. It is planting that seed. People look forward to our sessions when we have them and I think it will help the community in that us as front line workers can say, oh you know, like I am seeing more people that could use that program so let's get going and set up a session

We have been able to talk more freely about their conditions and what they can do to help themselves. The thing I did take out of the course, how to help themselves, how to become more vocal about it and I've seen Currie. He has been more active, he has been walking – you never used to see him around, he has spent a lot of time in hospital and he is now looking way better. He is a real inspiration, I tell you. I have got a lot of inspiration from him, how he has changed his attitude about himself and what he wants to do to improve his health

We have added to the sessions it has really helped people because there are times when they don't really understand their condition. We added the holistic approach which is more a spiritual like mental emotional spiritual. We added that and I think that helps a lot of people to realise that everything is connected. We also have an elder who talks about your health as aboriginal person. That is something I think that people really enjoy – talking about all these old things that they still do traditionally. I also talk about traditional methods a lot at my program. In my position, I talk about how everything is connected. If you are depressed you get fatigued you know, there is a whole symptom cycle so those are the things for us in our program that have helped

10. The first question I asked was why you took the self-management program. Now, when you think back, did you get what you initially wanted out of it?

All participants reported that they did get what they initially wanted out of the self-management course. Some did not know what to expect from the training, while other reporting receiving more from the training than they expected.

- Didn't know what they wanted out of the program before taking it

I didn't really know what I wanted out of it but I knew I was going to learn something about health. It is right what they say you learn something new every day. It was good and I really enjoyed it.

Definitely! Going into it I didn't know what to expect as far as what the course was really all about and how much it encompassed but I think I got more out of it then I definitely expected and I am able to use it

I think I got more because I didn't really know what to expect ...

- To get skills and information to be able to support people both personally and professionally

Yes I think I did. It is a very good program and I think it's helping the community, helping individuals and I think it is exactly what we're looking for and we will continue to offer it

Yes. The intention of why I took the course was to help the aboriginal community strive ahead with health and to make better decisions and do it for the whole family starting from the when they are small, so it is an overall thing. And it is a really, really good course that I would recommend to anybody and to recommend anybody to take it because it would help them in their lives, their children lives and their parents and grandparents all down the line and make our people a healthier stronger nation

It certainly helped me out. And things later on in after the course you figure out – did this help me or didn't it? Like I said it pretty much helped me out like in day to day life looking after my parents and sharing information like I said networking is one of the best things that anybody can do so that is what I will do with family or friends with whatever illness that they have. You constantly share information. Yeah, that is pretty much the reason why I am interested in personally is because I enjoy helping other people out in that regard

More than I expected. I was really scared to... oh my god getting that opportunity to sit and to be in a room say as a teacher. I have never had that offered to me before. And now the prospect of sharing on this level as you know I mean people looking to us to coming to this program with a standard and we have a standard to meet ... you have something to teach here, you have something to share and that standard is really nice to have to be put in that position which is really important for self esteem.

Yes, yes, I got skills that I can help other people with. it helped my job and it helped myself too through the action plans

I got what I wanted and more. I got a lot more from what I was expecting. I was expecting just like a workshop you know and there is no follow- up or anything in a lot of the workshops but this one I am looking forward to pursuing it further and helping people to explain the chronic pain management that they can do

It gives me a tool to say maybe you should take a look at living healthy with chronic conditions. It

will show you how to exercise. It will show you that eating healthy would be a little be different, maybe be a little difficult but you can do it, and exercise. People say they can't exercise and I will show them in the book that they can exercise sitting down. I didn't know what to expect when I first signed up and the more I looked online about this, I was really interested so I got what I expected and more in doing the workshop

Yes, I thought I got a lot of information from the facilitators that do the course. They understand about chronic disease and about the medication that we take so there was a lot of information for us to use and good to use it for the public awareness

- Skills that promote independence in clients

Yes, because now I can facilitate and that was the biggest thing because I really wanted to be able to help people who were having issues or similar issues with this. There is so much that goes on in the community where I now see they are dependent on us as employees of the band, whether it is healthy lifestyle coordinator or any of the other programs that are going on, and I think you know what? It is time to start looking out for your own self

- About the book

One thing I was really happy to hear that like there were eight clients sitting there who were kind of leery about this big thick book but it is really user friendly and I was totally happy that was their comment

- Better understanding of challenges for people living with chronic conditions

Yes because in my profession as a long term care worker, it helps me like I said to understand where they are coming from and why and you have to be respectful and patient because they are not going to be able to move around as fast and as much as they used to and it gets to them as well

- Tools adaptable to other situations in life

Yeah I did, like I said it is quite helpful and when you learn something new you can adapt those skills to basically anything and everything – that is the way it has helped.

- Being responsible for oneself

Self management put me in this chronic way of my health so I am the only one who can take me out of it. This gives me the tools as well

- The program was practical and understandable

I believe this because I kind of was aware of what it was about. And I was pleasantly surprised that it provided me with information, awareness, tools, things that I could apply and use and things are in everyday language and I felt it was something that wasn't going to be at a university level, but for someone with maybe a lower level of education and we actually emphasize that you don't have to read everything because it only your reference book.

It was exciting and challenging and fun thing to do, yet it was so simple and everything is by the book and that is the another thing that helped us learn too because it is so readily understandable or whatever the words are, they are not great big huge fancy words, it is the kind of words you can use

- Enjoyed the group process used, specifically the ‘peer’ interaction

I got more than I expected. I learned to realize that there were others out there that suffered the same who were higher up in the food chain I guess you know, in academic stuff and they were just, you know, while we were in that room they were the same as me. They were normal people with normal lives that may have to deal with their own chronic condition. It was a good group and we learned team workmanship, we had to operate together as a team and everybody’s ideas and thoughts and statements were kept confidential and we had fun with each other, so you know a variety of people in the group and you get all different people from all different walks of life so it was really great good interaction

I got more out of it because at first I wasn’t sure exactly. It didn’t sound like a very exciting kind of workshop when you hear about chronic this and how to deal with it. You think gosh not another one of those boring kind of things where you sit back and listen. But it is much more dynamic than that and much more organic. It is more like a living kind of thing that everybody is a part of and it is really good. I would say that I got definitely more than what I thought I would get out of it. You stand there and talk about things and stuff like that and you feel so alone sometimes when you are facilitating because you are way up in the front you know and everybody else is sitting back listening but this one is really pro-active and everybody is part of the team, we are all doing it together which is really a way better approach

- More self-awareness

You know it is strange. You think about the name of the course, self management, I thought OK we are going to teach people how to look after themselves and not think about ourselves. I was thinking of how we were going to fix them and make it better for them but going through the course and the course content itself, helps you focus on yourself as an individual and helps you listen and learn how to listen to other people when they are talking about what they need for themselves. You just allow them to own their conditions and learn how to manage it without depending on too much medication. And you have to learn to listen to your body. That is what this program taught me - how to listen to my body

11. Anything else you want to say?

- The program was worth taking

It is an awesome course. Hats off to whoever else takes it. It well worth the three or four days we had. I say TAKE IT!

I wish more people would take the course just for information. It would be great. I know that there are other members who could do a refresher and someone else who might want to do it too.

The facilitators were great and I really like the follow up too as they show the caring for the community and kind of curious about the others areas that the university has to offer too because I think our community is in need in other areas too. I think this is a start

*If there is a workshop here I want to put my name down, like, I would rather do this for me and my family because I got a big family and it is a lot of fun
Well actually, just dealing with the people from this program I found you all to be very very positive, very helpful. I think that this is a fantastic program and I am really happy that the government is supporting it and that UVIC is doing it. I just think it is absolutely great and it will be very good for people*

I would like to see the course come up here more often instead of once a year. It is really a lot of good information that our elders need and I need it too because of helping out a bit. It is good for the public to know about this and this is just the start for us

I enjoyed it. I am glad you came up because it makes me feel that the program is worth everything that it stands for and the people that have written a book, or organized the program whatever it took to do it, I think it is important for them to know that it is working.

For some people it won't. Some people come thinking that they are going to get fixed and find answers and criticize but you are going to have one in every class. It is a different concept, when you are not used to looking after yourself and you can tell that by the habits people have... but we all live and learn, I am living to see another day so I must be doing something right

- **Sharing the information**

I look forward to presenting my own presentation with my partners and I know that the elders are looking forward to the presentation that we are going to present at the elders centre, if not at other places. Me and the ladies are going to do it together We have already been conversing about it and are anxious. Our goal is to do it after the summer because so many people are here now we want a good audience so it can target as many people as possible

I would encourage others to take this and I am looking forward to teaching it. I am really excited about it. We have such a wide variety of people on this reserve. There are about 1800 residents or band members, but I figure about 800 on reserve and about 500 of them are children so there are about 300 adults and if you take a look at it about one, two or three percent who are sick, so you at least look at 30 so there are at least 30 clients you know people who have disabilities or chronic pain. Why not bring them in get them to check out their health centre and this new program

*Yeah, I just want to say that I am really appreciative of taking this program and I believe it is going to be a benefit and I look forward as a front line worker to seeing how we can actually get the sessions going in the community and through the health centre here
It is really useful in this community and it is what I do personally is I network and I tell other community members about what I went through in these workshops and how it would benefit their*

life or people around them. And the next time it does come up I do suggest that they do fit in with each program that comes around and like there are a couple of them that are waiting

- Having courses on an ongoing basis

Well I think it is an excellent, excellent course to be a leader of and to be a participant of and I think that it would be really good if you could get a group of people to take the course and maybe take the course over again in six months and do it more than just once, like an ongoing basis. You tend to forget or let it slide, so if you could come back into it again I think it would reinforce what was learned

- Were able to adapt the program to meet the needs of their community

I think it is a great program and within our program we kind of taken the CDSMP workshop and added to it and kind of tailored it to our three day workshop so it is flexible and we can move things around and it is a great program

I am sure that they already know but usually you get training and then come back here to do the sessions for 6 weeks, which we have done since last fall have we actually, instead of 6 weeks it condenses into four days, and then into 3 days, so we do the whole thing in 3 full days. That is something we have changed also. I think that if you can get the people there for those few days it is great, but the 6 weeks could be quite difficult. I think it is worthwhile. We have had sessions on the West Coast in the community of Port Alberni. We haven't done any in the North yet but are hoping to get up there and do sessions

I am not sure how to adapt it, maybe make longer or shorter days or maybe one day extra, or make it into a week, like five days instead of three just that you know I found that we started out with a large group and you ended up with a small group. You know, it could be that they have got something planned, or something comes up like a doctor's appointment or something. So if you take three days and break it up into half days and extend it into a five day, that leaves them time to do what they need to do in the afternoon or make it in the afternoons until about 5.00. Just to give people time you know during the week we know that people have appointments they have to be at or you know a function so I think that if you make it a little bit longer and maybe half days instead of full days, that would kind of keep people in it from beginning to end.

- A need for a Diabetes and/or Pain Self-Management Program

I am looking forward to the other workshops. I did the pain management workshop and I am excited to do that one again. If there is a diabetes one I would like to do that one too, it seems like a good thing to bring back into our community

I was very happy to hear that they are going to be including information specifically for diabetics, or diabetes and I don't know whether you have heard the statistics on First Nations having a very high rate of diabetes in the community and ours is one of them

There are no services in Surrey for Aboriginal people or people with diabetes with things like

that to eventually I would like to do some work and deliver the self-management program and teach others

There needs to be more teachings and courses about diabetes and self care and information about sugars and juices and things like that

I would love to go to the diabetes self management course just because diabetes is so much information, like _____ was saying – it's huge! It's huge and there is so much information that I wish everybody knew both in young and elderly. There are so many other factors and things that WILL happen if they don't take control of it

The fact that we all have diabetes in the group we can say well, hey this worked for me it might work for you, because there is not very many chances for us to get together with other people that have the same problems, health problems or issues – it is just a thought. Because once the course was over, it is like now what? Now I don't see anybody who has diabetes. I don't talk to anybody and I don't want to bug my doctor, so having that opportunity I think would have been great and I know it might be difficult for a group

I would like everybody to take chronic pain management if they have a chance because it is a great help. People say, what are you on, you are looking good, walking good, what are you doing, give me some. I say chronic pain management. If the chronic pain self-management course comes again I will take it. Whenever it is I would love to take it again everything is possible because I already have a certificate. Every time I open the book I get more out of it. I am happy to have the book at home I can read and highlight what she didn't share with us, so I hope if anybody has the chance by golly take the opportunity - it has helped me a lot

- Appreciated the format – simple is helpful, especially for people with low literacy

I think that the program will help anybody even on a level good physical health. I really like the way the program was running. It is not something that you want to go in a book, you know, flipping a page and read it from cover to cover and so a lot of people who I know who struggle with reading that would turn them off - don't have to do it like that. I like the way that it was laid out and the facilitators were awesome

- Wanting more time to share

I think it would be good to have a period during each segment where people could speak about their own challenges. People did this a little bit but I think it could have been a bit longer. If we were allowed 15 minutes maybe, 25 minutes in a group of talking about challenges because we then bounce ideas off one another and that in itself becomes helpful to one another, even if the presenters perhaps don't have the information.

If they want to reach the native people, they have to leave more time in each session so that people can really share their stories. It is a little bit different if they are not native people. If you want the native people to get more involved they have to get their story. They are more into telling everything that has happened. If you sit and listen then you will have the whole story you will have what you are looking for. If you allow them to finish their story then there won't be too much stories in between.

APPENDIX 1 – Description of Outcome Measures

When participants take the Chronic Disease Self-management Program they complete a questionnaire before they begin the 6-week program and again six months later. A pre- and six-month post-program matched group analysis is conducted to see if participants made statistically significant improvements. The questionnaire contains the following outcome measures which are described below.

1. SELF-RATED HEALTH

Description: This single-item scale score measures general health perception (self-rated health). Scores range from 1 (excellent health) to 5 (poor health).

In general, would you say your health is?

<i>Excellent</i>	1
<i>Very Good</i>	2
<i>Good</i>	3
<i>Fair</i>	4
<i>Poor</i>	5

Source:

National Center for Health Statistics. (1991). *The National Health Interview Survey*. Hyattsville, MD: Author.

Ware, J.E., Nelson, E.C., Shelbourne, C.D., & Stewart, A.L. (1992). Preliminary tests of a 6-item general health survey: A patient application. In A.L. Stewart & J. E., Ware, Jr. (Eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 291-303). Durham, NC: Duke University Press.

2. HEALTH DISTRESS

Description: This scale is composed of 4 items (the amount of time in past 2 weeks that one felt discouraged, worried, fearful, and frustrated). Uses a Likert scale with scores ranging from 0 (none of the time) to 5 (all of the time). The score is the mean of these four items. If more than one item is missing, set the value of the score for this scale to missing. Higher scores mean more distress. The source is MOS (Medical Outcome Study) health distress modified slightly (Stewart, Hays, & Ware, 1992a, 4 of 6 items); with changes from *afraid because of your health* to *fearful about your future health*, and *frustrated about your health* to *frustrated about your health problems*.

How much during the past 2 weeks

- a) *Were you discouraged by your health problems?*
- b) *Were you fearful about your future health?*
- c) *Was your health a worry in your life?*
- d) *Were your frustrated by your health problems?*

Source:

Stewart, A.L., Hays, R.D., & Ware, J.E., Jr. (1992). Health perceptions, energy/fatigue, and health distress measures. In A.L. Stewart & J.E. Wares (Eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 143-172). Durham, NC: Duke University Press.

3. ENERGY/FATIGUE

Description: This scale is composed of 5 items (the amount of time in past 2 weeks that one felt full of pep, energetic, worn out, tired, had enough energy to do the things one wanted to do). Uses Likert scale with scores ranging from 0 (none of the time) to 5 (all of the time). Higher scores mean more energy and 2 items (worn out and full of pep) are recorded. The source is MOS energy/fatigue (Stewart, Hays, & Ware, 1992a) but note that their time frame is 4 weeks. Items 1 and 3 are reversed as indicated below:

How much during the past 2 weeks

- a) *Did you feel worn out?*
- b) *Did you have a lot of energy?*
- c) *Did you feel tired?*
- d) *Did you feel full of pep?*
- e) *Did you have enough energy to do the things you wanted to do?*

Source:

Stewart, A.L., Hays, R.D., & Ware, J.E., Jr. (1992). Health perceptions, energy/fatigue, and health distress measures. In A.L. Stewart & J.E. Wares (Eds.), *Measuring functioning and well-being: The Medical Outcomes Study approach* (pp. 143-172). Durham, NC: Duke University Press. MOS energy/fatigue.

4. FATIGUE LEVEL

Description: This item uses a visual analogue scale that rates whether or not one is affected by fatigue on a scale from 0 (no fatigue) to 10 (severe fatigue).

5. SHORTNESS OF BREATH

Description: This item uses a visual analogue scale that rates whether or not one is affected by shortness of breath on a scale from 0 (no shortness of breath) to 10 (severe shortness of breath).

6. PAIN SEVERITY

Description: This item uses a visual analogue scale that rates whether or not one is affected by pain on a scale from 0 (no pain) to 10 (severe pain).

7. AMOUNT OF TIME DOING STRETCHING/STRENGTHENING EXERCISES

Description: This single item ranges from 0 (none) to 4 (more than 3 hrs/week). A higher score means more time spent doing stretching/strengthening exercises. Uses an ordinal scale converted into minutes spent. This is a new measure.

During the past week, even if it was not a typical week, how much total time (for the entire week) did you spend on each of the following?

- a) *Stretching or strengthening exercises (range of motion, using weights, etc.)*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

8. AMOUNT OF TIME DOING AEROBIC EXERCISES

Description: This scale is composed of 5 items for the amount of time spent doing walking for exercise, swimming or aquatic exercise, bicycling or stationary bike, aerobic exercise equipment, other aerobic exercise. Scores from each item range from 0 (none) to 4 (more than 3 hrs/week). A higher score means more time spent doing aerobic exercises. Uses the sum of ordinal scales converted to minutes spent. This is a new measure.

*During the past week, even if it was not a typical week, how much **total** time (for the entire week) did you spend on each of the following?*

- a) *Walk for exercise*
- b) *Swimming or aquatic exercise*
- c) *Bicycling (including stationary exercise bikes)*
- d) *Other aerobic exercise equipment (stairmaster, skiing, healthrider, etc.)*
- e) *Other aerobic exercise*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

9. AMOUNT OF TIME TRYING COGNITIVE SYMPTOM MANAGEMENT

Description: This scale is on the frequency of trying various cognitive strategies when feeling bad or having pain or symptoms (e.g., trying to feel distant from the discomfort, talking to self in positive ways, practicing visualization). This score is the mean of 6 items. Scores for each item range from 0 (never) to 5 (always) with a higher score indicating more practice of these techniques. If more than two items are missing answers, set the value of the score for this scale to missing. This is a new measure.

When you are feeling down in the dumps, feeling pain or having other unpleasant symptoms, how often do you

- a) *Try to feel distant from the discomfort and pretend that it is not part of your body*
- b) *Don't think of it as discomfort but as some other sensation, like a warm, numb feeling*
- c) *Play mental games or sing songs to keep your mind off the discomfort*
- d) *Practice progressive muscle relaxation*
- e) *Practice visualization or guided imagery, such as picturing yourself somewhere else*
- f) *Talk to yourself in positive ways*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

10. DISABILITY

Description: This scale asks about the ability to do dressing, arising, eating, walking, hygiene, reaching, gripping and activities. This 8 question scale asks about the ability at this moment, and scores range from 0 (without any difficulty) to 3 (unable to do) and higher scores mean more disability. The source is the Stanford Health Assessment Questionnaire (HAQ), disability scale, modified (Fries et al., 1980; Ramey et al., 1992). Score each item independently so that the score is the mean of 8 items.

At this moment, are you able to:

- a) *Dress yourself, including tying shoelaces and doing buttons?*

- b) *Get in and out of bed?*
- c) *Lift a full cup of glass to your mouth?*
- d) *Walk outdoors on flat ground?*
- e) *Wash and dry your entire body?*
- f) *Bend down and pick up clothing from the floor?*
- g) *Turn faucets on and off?*
- h) *Get in and out of a car?*

Source:

Stanford Health Assessment Questionnaire, disability scale, modified
 Fries, J.F., Spitz, P., Kraines, R.G., & Holman, H.R. (1980). Measurement of patient outcome in arthritis. *Arthritis and Rheumatism*, 23, 137-145.

Ramey, D.R., Raynauld, J.P., & Fries, J.F. (1992). The Health Assessment Questionnaire 1992: Status and review. *Arthritis Care and Research*, 5, 119-129.

11. ILLNESS INTRUSIVENESS

Description: The Illness Intrusiveness Scale has five subscales:

- 1. Physical Well-Being and Diet (questions 1 & 2);
- 2. Work and Finances (questions 3 & 6)
- 3. Marital, Sexual, and Family Relations (questions 7, 8, & 9)
- 4. Recreation and Social Relations (questions 4, 5, & 10); and
- 5. Other Aspects of Life (questions 11, 12 & 13).

There are a total of 13 items within these 5 subscales. Uses a Likert Scale of 8 categories of items. The scores range from 1 (not very much) to 7 (very much) or not applicable and are rated in the context of the current life situation. A higher score means that illness has a negative impact on one's life. The source is Devins (1981). Average the item scores within each subscale for subscale scores, then average the subscale scores to correct for differences in the numbers of items combined. You may also sum the individual items to generate a total Perceived Intrusiveness Score.

The following items ask about how much your illness(es) and/or its treatment interfere with your life. Please circle the one number that best describes your current life situation. If an item is not applicable, please check the box to indicate that this aspect of your life is not affected. Please do not leave any item unanswered.

How much does your illness(es) and/or its treatment interfere with:

- a) *Your feeling of being healthy*
- b) *The things you eat and drink*
- c) *Your work, including your job, house work, chores, or errands*
- d) *Playing sports, gardening, or other physical recreation or hobbies*
- e) *Quiet recreation or hobbies, such as reading, TV, music, knitting, etc.*
- f) *Your financial situation*
- g) *Your relationship with your spouse or domestic partner*
- h) *Your sex life*
- i) *Your relationship and social activities with your family*
- j) *Social activities with your friends, neighbours, or groups*
- k) *Your religious or spiritual activities*
- l) *Your involvement in community or civic activities*
- m) *Your self-improvement or self-expression activities*

Source:

Devins, G.M., & Orme, C.M. (1985). Center for Epidemiologic Studies Depression Scale. In D.J. Keyser & R.C. Sweetland (Eds.), *Test critiques* (Vol. 2, pp. 144-160). Kansas City, MO: Test Corporation of America.

12. SELF-EFFICACY TO MANAGE SYMPTOMS

Description: This score is the mean of 3 items. Scores range from 1 (not at all confident) to 10 (totally confident). Higher scores mean greater self-efficacy. This is a new measure. (Note: originally 5 items)

How confident are you that you can...

- a) *keep the fatigue caused by your disease from interfering with the things you want to do?*
- b) *Keep the physical discomfort or pain of your disease from interfering with the things you want to do?*
- c) *Keep other symptoms or health problems you have from interfering with the things you want to do?*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

13. SELF-EFFICACY TO MANAGE THE DISEASE IN GENERAL

Description: This score is the mean of 3 items. Scores range from 1 (not at all confident) to 10 (totally confident). Higher scores mean greater self-efficacy. This is a new measure. (Note: originally 5 items)

How confident are you that you can...

- a) *Keep the emotional distress caused by your disease from interfering with the things you want to do?*
- b) *Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?*
- c) *Do things other than just taking medication to reduce how much your illness affects your everyday life?*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

14. DEPRESSIVE SYMPTOMS

Description: Asks questions about depressive symptoms experienced over the past week. This scale has been summarized from the original scale that has 20 items. The score is the sum of 10 item weights. Uses a Likert Scale and the scores for each item range from 0 (rarely or none of the time/less than one day) to 3 (all of the time/5 to 7 days). Using the 10 items, the possible range of scores is 0 to 30. A score of 8 or more is considered depressed.

*Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **past week**:*

During the past week...

- g) I was bothered by things that usually don't bother me*
- h) I had trouble keeping my mind on what I was doing*
- i) I felt depressed*
- j) I felt that everything I did was an effort*
- k) I felt hopeful about the future*
- l) I felt fearful*
- m) My sleep was restless*
- n) I was happy*
- o) I felt lonely*
- p) I could not "get going"*

Source:

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measures, 1*, 385-401.

15. SOCIAL/ROLE ACTIVITIES LIMITATIONS

Description: The score is the mean of 4 items that ask about the extent to which health has interfered with social and recreational activities, chores, errands and shopping over the past 4 weeks. Uses a Likert Scale with scores ranging from 0 (not at all) to 4 (almost totally) with a higher score indicating greater limitation in activities. If more than one item is missing, set the value of the score for this scale to missing. This is a new measure.

During the past week, how much has your health interfered with...

- a) your normal social activities with family, friends, neighbours or groups?*
- b) Your hobbies or recreational activities?*
- c) Your household chores?*
- d) Your errands and shopping?*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.

16. COMMUNICATION WITH PHYSICIAN

Description: This score is the mean of 3 items. The items ask that when visiting the physician, frequency of preparing list of questions, asking questions about things one doesn't know /understand, and discussing personal problems related to illness. Uses a Likert Scale and the scores for each item range from 0 (Never) to 5 (Always). The higher scores mean better communication with the physician.

When you visit your doctor, how often do you do the following:

- a) prepare a list of questions for your doctor;*
- b) ask questions about the things you want to know and things you don't understand; and*
- c) discuss any personal problems that may be related to your illness.*

Source:

Lorig, K. Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., & Lynch, J. Outcome measures for health education and other health care interventions. 1996. Sage Publications: Thousand Oaks, CA.