Self-Management from the Perspective of People with Chronic Disease: Initiatives of the Chronic Disease Self-Management Program

Japan Chronic Disease Self-Management Association

Director

Hiroki TAKEDA



Self-Introduction (Hiroki TAKEDA)

- Born with hemophilia and affected by HIV infection, chronic hepatitis, and atrioventricular block (Wenckebach type).
- Discovered in 2020 to have familial heterozygous hypercholesterolemia.
- In 2005, the "Japan Chronic Disease Self-Management Association(J-CDSMA)" was established to introduce the Chronic Disease Self-Management Program (CDSMP) in Japan, and I joined as a staff member.
- In 2007, completed the Master Training (MT) course for the Chronic Disease Self-Management Program at The Stanford Patient Education Research Center.
- As an MT for CDSMP, involved in training CDSMP leaders in Japan and conducted workshops as a CDSMP leader myself

Chronic Disease Self-Management Program

- The Stanford Patient Education Research Center began developing the program in the 1970s and it was officially launched in 1993. It is a program that supports individuals with chronic diseases in acquiring selfmanagement skills. (https://selfmanagementresource.com/about/history/)
- Initially developed as a program for individuals with rheumatoid arthritis, it was found that the challenges faced by people with chronic diseases were similar, leading to the development of a cross-disease program.
- Currently, under a licensing agreement with the Self-Management Resource Center (https://selfmanagementresource.com/), the program is held in various countries worldwide and is available in 19 languages in addition to English.

Arabic, **Chinese (Hong Kong**), Chinese (Taiwan), Creole, Danish, Finnish, French Canadian, Hindi, Hmong, Italian, **Japanese, Korean**, Māori, Portuguese, Russian, **Samoan**, Singapore, **Tongan, Vietnamese**



Chronic Disease Self-Management Program Workshop

- Individuals with chronic disease, regardless of the specific disease, can participate.
- The workshops consist of approximately 8 to 16 participants.
- Participants learn in a workshop format, meeting once a week for 2.5 hours over a total of six weeks.
- At least one of the two facilitators(leaders) is a lay person (nonspecialist) with a chronic illness



Example)

Day 1	6/4 13:30~16:00
Day 2	6/11 13:30~16:00
Day 3	6/18 13:30~16:00
Day 4	6/25 13:30~16:00
Day 5	7/2 13:30~16:00
Day 6	7/9 13:30~16:00

Assumptions of CDSMP

• People with chronic disease, although their specific conditions may differ,

Symptom

/Treatment

Emotion

Life

face similar challenges

•Social roles (work, household chores, parenting, etc.)

•Relationships with friends

Engagement in hobbies and activities

•Dealing with pain, numbness, fatigue, etc.

- •Understanding one's own disease/condition.
- •Communicating one's desires to healthcare professionals.
- •Properly managing medication, diet, exercise, etc.

Anxiety about the disease.

•Frustration with a restricted lifestyle.

•Feeling of helplessness and "why me?"

⇒ The program teaches techniques for self-management to address three key challenges:

Overview of the content learned in CDSMP

Transversal skills

- Problem-solving techniques
- Decision-making
- Action planning

Individualized skills

Self-management of symptoms and treatment

Appropriate exercise for oneself / Proper medication usage / Healthy eating / Collaborating with healthcare professionals / Quality sleep / Weight management / Oral hygiene, etc.

Self-management of daily life

Effective communication skills

Managing fatigue and preparing for emergencies, etc.

Self-management of emotions

Coping with frustration, anger, anxiety, etc.

Positive thinking, etc.



Concept of CDSMP $1/_3$

 Self-management for doing what you want, rather than reluctantly managing it as told by healthcare providers.

Elements of an action plan:

- 1. What you want to do
- 2. What you can do (achievable goals for the week)
- 3. Specific actions (e.g., "stop snacking" instead of "lose weight")
- 4. Answer the following questions:
 - 1. What?
 - 2. How much?
 - 3. When during the day?
 - 4. How many times per week?
- 5. Have a confidence level of 7 or higher in achieving the entire plan.



Concept of CDSMP 2/3

• Individuals should acquire problem-solving skills themselves, instead of someone solving their problems

The program's pillars are:

Action plan / Problem-solving techniques / Decision-making

Steps in problem-solving techniques:

- 1. Calmly identify the actual problem (e.g., "fatigue is the problem" \rightarrow What is causing the fatigue?)
- 2. Generate ideas to solve the problem and try them out one by one.
- 3. Evaluate the results.
- 4. If your own ideas don't solve the problem, seek advice from others or research in books for more ideas.
- 5. Evaluate the results.
- 6. If the problem remains unsolved, accept that it cannot be solved now and revisit it later.

Concept of CDSMP $3/_3$

 Participating in the CDSMP workshop enhances self-efficacy (A. Bandura) and is designed to naturally promote behavioral change.

Four elements to enhance self-efficacy:

- 1. Personal success experiences (Experience)
- 2. Observing others' success (Modeling)
- 3. Verbal persuasion and encouragement (Verbal Persuasion)
- 4. Joy and comfort (Psychological Factor)



CDSMP Research Results $1/_3$: US

Stanford University (2001):

- •831 participants
- •Age: 40 or older
- •Diseases: Heart disease, lung disease, stroke, or arthritis
- •Long-term effects of the program were evaluated by comparing data before program participation and 2 years later.
- •Reduction in emergency room visits/outpatient visits (p < 0.05)
- •Decrease in health-related worries (p < 0.05)
- •Increase in self-efficacy (p < 0.05)
- •Notably, despite a worsening disability in the first year, participants maintained or improved in all health indicators and had fewer outpatient visits.

Medical Care, 39(11),1217-1223, November 2001. LorigKR, Ritter PL, Stewart AL, SobelDS, Brown BW, BanduraA, GonzálezVM, Laurent DD, Holman HR. Chronic Disease Self-Management Program: 2-Year Health Status and Health Care Utilization Outcomes.



CDSMP Research Results $2/_3$: Japan

Evaluation study from 2007 to 2010:

- Significant improvements after 6 months: 7 items (
)
- Significant improvement after 1 year: 1 item (■)
- Self-assessment of health status (2007, 2008, 2009)
- Worries about health status (2007, 2008, 2009)
- Cognitive coping with symptoms (2007, 2008, 2009, 2010)
- Communication with physicians (2008)
- Self-efficacy in dealing with health problems (2007, 2008, 2010)
- Satisfaction with daily life (2007, 2008, 2009)
- Stress coping ability (SOC) (2009)
- lacktriangle Increased exercise time (2009; for patients with rheumatic diseases and allergies)

From the report of the research project with the Ministry of Health, Labour and Welfare Science Research Grant, Project Number H17-Immunization-General-013, as well as Project Number H20-Immunization-General-013, "Planning and Evaluation of Future Directions for Immunology Allergy Disease Prevention and Treatment Research" (Research Collaborators: Yoshihiko Yamazaki), conducted in the indicated years.

CDSMP Research Results $3/_3$: Japan

Evaluation study from 2014:

- Results (significant effects in pre- and post-comparison):
 - Low pre-test group:
 - Medication adherence
 - Collaboration with healthcare providers regarding medication
 - Satisfaction and harmony with medication and daily life
- The content of CDSMP, such as "relationship with healthcare providers" and individualized self-management, potentially influenced improvements in actual medication behavior after the workshop, especially in the low pre-test group.

From the report of the research project with the Ministry of Health, Labour and Welfare Science Research Grant, Project Number H23-Immunization-Specified-017, "Planning and Evaluation of Future Directions for Immunology Allergy Disease Prevention and Treatment Research" (Research Collaborator: Fumiko Yasukata), conducted in the year 2014.



Testimonials from Japanese participants of the CDSMP workshop: $1/_3$

Last year, I attended a workshop. Suddenly, I developed conditions such as Graves' disease, valvular heart disease, and Parkinson's disease, and I ended up with multiple diseases and depression. I also quit my job. However, I made a bold decision to dive into the CDSMP workshop. I created an action plan and realized that there were still things I could do for myself. Currently, I'm doing lymphatic stretching, which has helped me regain some energy and stabilize my health condition. This is the result of attending the workshop.

Male, Parkinson's disease, valvular heart disease, Graves' disease



Testimonials from Japanese participants of the CDSMP workshop: $2/_3$

This summer, I was hospitalized due to a deterioration in my health, which made me keenly aware of the importance of self-management. During the workshop, I learned specific ways to handle concerns about my disease and how to effectively communicate with healthcare professionals during consultations. This changed my mindset. By changing my mindset, I noticed changes in my emotional state and behavior. It was a joyful and fulfilling six weeks.

Female, 20s, ulcerative colitis



Testimonials from Japanese participants of the CDSMP workshop: $3/_3$

As I entered the workshop venue and walked to my seat, other participants praised the way I walked. Prior to that, when I answered a phone call from my wife at home, the person on the other end commented that my voice had changed like a different person, and my wife also said, "You've become less prone to falling lately." I realized that the incorporation of rehabilitation into my action plan was showing results. If I hadn't known the term "action plan," I wouldn't have been doing rehabilitation every day. I am grateful, so grateful.

Male, 60s, progressive supranuclear palsy



Summary

- CDSMP aims to solve three common problems (symptoms/treatment, daily life and emotions) for people with chronic illnesses
- CDSMP workshops are open to people with any illness
- CDSMP workshops are facilitated by people with illness and are designed to naturally increase self-efficacy and encourage behavior change
- The aim of self-management is to live better and "to do the things you want to do"
- People are able to solve their own problems, rather than having someone else solve them.
- Research has confirmed its effectiveness

