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Characteristics and Components of Self Management Programs for

Spinal Cord Injury

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**Self-Management for Spinal Cord Injury**

# 1.0 Introduction

The onset of a spinal cord injury (SCI) is a life-altering event and often contributes to a wide range of chronic health conditions, such as sensory and motor impairment, impaired bowel and bladder function, pressure ulcers, spasticity, neuropathic and/or musculoskeletal pain, and depression 1. Research has shown that despite the considerable increase in life expectancy among individuals with SCI in recent decades, secondary health conditions stemming from SCI continue to hinder the functional independence and social participation of those living with SCI throughout their life span 2,3. This highlights the need for self-management (SM) interventions to mitigate the long-lasting impact of SCI and its related health conditions on patients’ quality of life.

**1.1 Definitions of Self-Management**

The term *self-management* (SM) was first used in the literature by Creer and colleagues 4 in their work on the rehabilitation of children with asthma. It highlighted the important role of individuals as active participants in the treatment of their own conditions. Currently, there are several widely accepted definitions of SM, with some focusing on the individual components of SM (e.g., Clark et al. 5) and others focusing on the group intervention elements (e.g., Alderson et al. 6). The US Institute of Medicine refers to SM as: “the tasks that individuals must undertake to live with one or more chronic conditions.” According to this definition, SM tasks encompasses the management of medical, emotional, and social role aspects of the individuals’ health conditions. Furthermore, as suggested by Nakagawa-Kogan et al. 7, SM involves the utilization of biological, psychological, as well as social intervention strategies. For the purpose of this chapter, we employ one of the mostly widely accepted definition of SM proposed by Barlow and colleagues 8:

“[...] the individual’s ability to manage the symptoms, treatment, physical, and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious SM encompasses ability to monitor one’s condition and to affect the cognitive, behavioural and emotional consequences necessary to maintain satisfactory quality of life.” (p. 178)

**1.2 Purpose**

This chapter aims to provide an overview of the characteristics of existing SM interventions for SCI and to identify the components involved in those programs. The clinical implications of SM interventions and gaps in the scientific literature will also be discussed. Evaluating the effectiveness of the current SCI SM interventions was outside the scope of this chapter.

**­­­1.3 Literature Search Strategy**

A comprehensive literature search was performed using five scholarly databases: CINAHL, PubMed, EMBASE, MEDLINE, and PsycINFO. The search terms used were related to two constructs: SM and SCI. The literature search included articles published between 1990 and 2020 in English language. Any duplicates were removed. Title and abstract screening and full-text review were conducted by two independent reviewers to assess the relevance of each article, using the following inclusion criteria: (a) detailed an intervention in a primarily SCI population (>50%) and b) described a program plan relevant to SM. Given that self-management is a nebulous concept with several existing definitions, we aimed to examine self-management from multiple dimensions. Not all authors may have described or reported their program as being SM per se; however, if the intervention and outcomes included elements of SM (as described by the Lorig and Holman’s Taxonomy,9 Barlow’s taxonomy,8 and Practical Reviews in Self-Management Support (PRISMS).10) the article was included. Studies were excluded if they were (a) not an intervention applied to a study population, (b) not applicable to SCI or an intervention not for SCI populations, (c) conference abstracts with related texts already included, (d) interventions with fewer than three participants, and (e) interventions not relevant to SM.

**1.4 Data Summarization and Reporting**

The study characteristics were then extracted from included articles, and the intervention descriptions were coded using the Template for Intervention Description and Replication (TIDieR) checklist 11, a commonly used guide for reporting intervention program characteristics and evaluating the descriptions of intervention programs published in the literature (see section 3.0 for the full description of the TIDieR checklist). The self-management components embedded in the interventions were identified using Lorig and Holman’s Taxonomy,9 Barlow’s taxonomy,8 and Practical Reviews in Self-Management Support (PRISMS).10 (see section 4.0 for the full description of the SM component taxonomies).

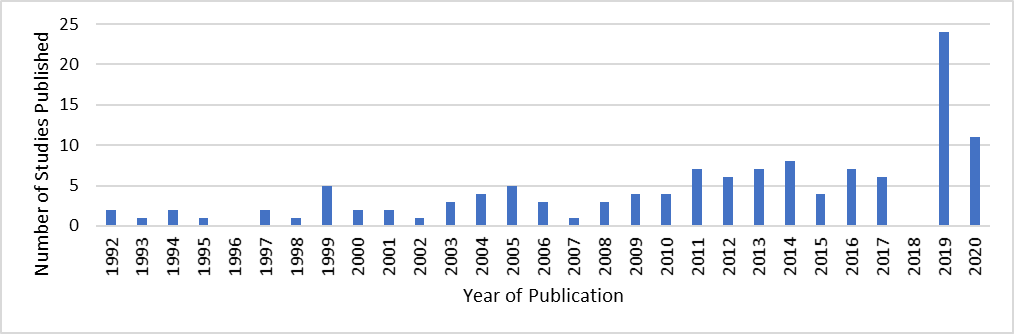
# 2.0 Study Characteristics

## 2.1 Total Studies

A total of 126 studies examining SM programs among individuals with SCI were included (See appendix located after references).

## 2.2 Year of Publication

The majority of studies were published between 2010 and 2020 (66.7%; N=84) (Figure 1). Between 2000 and 2010, 28 (22.2%) studies were published and prior to 2000, just 14 (11.1%) studies were published.



**Figure 1.** Number of studies published per year

## 2.3 Country of Affiliation

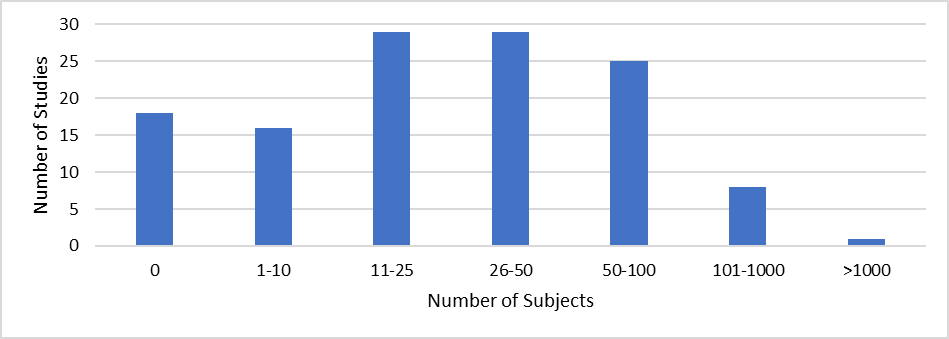
There were 18 unique countries represented; the majority of studies were published in the USA (48.4%; N=61), followed by Canada (16.7%; N=21), and Australia (11.9%; N=15). Among the remaining countries represented, 11 (8.7%) were from Europe, 9 (7.1%) were from Asia, and 1 (0.8%) was from Africa.

## 2.4 Research Design

There were nine different research designs employed in the studies. The majority of research design were either Pre-Post (28.6%; N=36) or Randomized Controlled Trials (25.4%; N=32), followed by Program Descriptions (15.1%; N=19), Observational studies (11.1%; N=14), and Prospective Controlled Trials (7.9%; N=10). The remaining 15 (11.9%) studies were either Case Series, Post-Tests, Cohort or Case Control studies.

## 2.5 Sample Size

There were 17 studies with a sample size of 0 (program description studies). The majority of the remaining studies had a sample size less than 100 subjects or less (78.6%; N=99) (Figure 2).



**Figure 2.** Number of studies publishing with sample sizes in the following groupings: 0, 1-10, 11-25, 26-50, 51-100, 101-1000 and >1000.

# 3.0 Program Characteristics

The TIDieR checklist was used to guide the summary of the program characteristics. The checklist, a commonly used guide for reporting intervention program characteristics and evaluating the descriptions of intervention programs published in the literature, includes 12 items capturing important elements of most intervention programs across disciplines, such as intervention procedure, mode of delivery, and type of providers delivering the intervention 11. In this section, we review the program characteristics of the SM interventions for SCI reported in the included studies by each TIDieR checklist item.

## 3.1 Name

**TIDiers #1: “Brief Name: Provide specific name given to the program.”**

In total, 61 studies named their self-management program, whereas 65 did not have a specific name.

## 3.2 Definition

**TIDiers #2: “Why: Describe any rationale, theory, or goal of the elements essential to the**

**Intervention program.”**

Since the majority of studies included in this chapter did not explicitly frame the intervention programs as SM interventions in the reporting, the rational and theoretical underpinning of the programs are summarized here. We evaluated whether the studies clearly defined the term SM in the program descriptions. Overall, just 17 (13.5%) studies provided a definition of the SM in the body of the manuscript or indicated SM in the title. There was a wide range of topics studied by the SM management programs (Table 1). A significant proportion of the programs focused on a specific secondary impairment or condition(s) (N=50; 40.0%) such as bladder and/or bowel management, nutrition, infection, pain, etc. The two topics most studied were psychological wellbeing (N=19; 15.1%), and pressure ulcer and skin integrity (N=18; 14.3%).

**Table 1.** Topics covered by SM programs, ordered alphabetically.

|  |  |  |
| --- | --- | --- |
| Topic | Citation | # Studies |
| Psychological Wellbeing (e.g., cognitive appraisal, coping, social support, adjustment, hope, QoL) | 12-30 | 19 |
| Pressure Ulcer and Skin Integrity | 31-48 | 18 |
| Physical Activity | 49-61 | 13 |
| Bladder and/or Bowel Management | 3,62-70 | 11 |
| General/Unspecified Self-Management | 71-80 | 10 |
| Pain | 81-90 | 10 |
| Self-Efficacy | 91-100 | 10 |
| Peer-led Mentoring and/or Support | 2,101-108 | 9 |
| Community Reintegration | 109-115 | 7 |
| Secondary Condition Management (e.g., physical activity, bowel and bladder, respiratory, autonomic dysreflexia, skin care, communication, medication, mood) | 116-121 | 6 |
| Diabetes Prevention & Obesity Management & Nutrition | 122-124 | 3 |
| Communication | 125,126 | 2 |
| Goal Planning | 127,128 | 2 |
| Depression | 129 | 1 |
| Vocational Rehabilitation | 130,131 | 2 |
| Medication Management | 132 | 1 |
| Infection Prevention | 133 | 1 |
| Sexual health | 134 | 1 |

## 3.3 Format

**TIDiers #3: “What: Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL).”**

**TIDiers #4: “What: Procedures: Describe each of the procedures, activities, and/or processes used in the intervention including any enabling or support activities.”**

In reference to TIDier items #3 and #4, the included SM programs in this review used different tools, formats, and resources to implement their program. A variety of SM program formats were found, including individual sessions with healthcare providers, audio tapes, telephone, online resources, booklets, lecture/ seminar, exercise/recreation, group sessions, peer mentoring, cognitive behavioral therapy, videos, and counseling (Table 2).The most common format used was group sessions (N=34; 27.0%), followed closely by the use of booklets/handouts (N=28; 22.2%), lecture/seminars (N=24; 19.1%), online/electronic (N=20; 15.9%), and peer mentoring/support (N=20; 15.9%).

**Table 2.** Formats used by SM programs in descending order by total number of studies

|  |  |  |  |
| --- | --- | --- | --- |
| Format | Type | Citation | # Studies |
| Group Session | Only | 18,25-27,78,88,89,92,110,113 | 10 |
| Mixed | 3,12,19,20,23,24,29,43,45,49,51,57,65,66,77,80,83,85,86,95-100,111,112,115,121-124 | 32 |
| Booklet/Hard copy resources | Only | 22,47,50,59,73,133 | 6 |
| Mixed | 3,23,24,29,35,39,43,45,51,52,56,59,61,63,65,66,72,76,81,85-87,115,122,126,129,132 | 27 |
| Online/Electronic (e.g., DVDs) | Only | 14,16,32,33,44,46,48,60-62,69,117,118,125,134 | 15 |
| Mixed | 3,17,56,65,66,74,82,84,100,101,119,129-131 | 14 |
| Individual session w/ HCP | Only | 28,31,40,64,70,90,91,135 | 8 |
| Mixed | 23,24,30,34,35,42,45,49,53,54,59,61,63,80,81,99,111,114,128 | 19 |
| Peer mentoring/support | Only | 2,67,102,104,105,108 | 6 |
| Mixed | 17,21,23,24,34,74-77,93,96,99,101,103,109,111,112,114,115,119,122 | 21 |
| Lecture/seminar | Only | 116 | 1 |
| Mixed | 2,19,37,38,43,45,55,68,72,74,75,77,87,95,96,98,99,122-124,130-132 | 23 |
| Counselling | Only | 13,106,107,127 | 4 |
| Mixed | 12,20,36-39,41,51,52,71,74,75,82,83,94,97,109,126,128 | 19 |
| Telephone | Only | 79 | 1 |
| Mixed | 3,17,21,36,41,42,59,65,66,71,75,103,120 | 13 |
| Exercise/Recreation Session | Only | 58 | 1 |
| Mixed | 53-55,57,72,82-86,98,99 | 12 |
| Videos | Only |  | 0 |
| Mixed | 19,41,43,56,68,76,82,119,120,130-132 | 12 |
| Cognitive Behavioural Therapy | Only | 15,29 | 2 |
| Mixed | 49,8292 | 3 |
| Audio Tapes | Only |  | 0 |
| Mixed | 37,38,76 | 3 |
| Role Playing | Only |  | 0 |
| Mixed | 19,93 | 2 |

\*Only=a program used only one format; Mixed= a program used more than one format

## 3.4 Intervention Providers

**TIDiers #5: “Who Provided: For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.”**

Intervention providers indicate the individual who helped facilitate, run or mentor the individual through the self-management program. Table 3 showed the types of intervention providers used by the SM programs. Among studies that used a mixed tutor approach, the most common types were peers (N=24; 19.0%), followed by nurses (N=20; 15.9%), individuals in psychology (N=15; 11.9%), general, unspecified health professionals (N=14; 11.1%) and physical therapists (N=14; 11.1%). Among studies that only included a single tutor, the most common types were researchers (N=20; 15.9%), other, unspecified individuals (not one of the other types of tutors listed) (N=15; 11.9%), and nurses (N=14; 11.1%),

**Table 3.** Intervention Providers for SM programs in descending order by total number of studies

|  |  |  |  |
| --- | --- | --- | --- |
| Intervention Provider | Type | Citation | # Studies |
| Nurse | Only | 3,18,31,37,38,41,42,59,65,66,70,120,133,135 | 14 |
| Mixed | 2,21,33,39,48,63,67,71,77,78,88,89,92,93,102,112,119,124,126,132 | 20 |
| Researcher | Only | 19,20,22,26,30,35,44,50,60,62,80,82,87,91,94,100,108,109,129,134 | 20 |
| Mixed | 2,15,17,27,46,58,81,102,104,125 | 10 |
| Peer | Only | 76,101,103,105,107 | 5 |
| Mixed | 2,16,17,21,34,36,67,69,71,75,77,92,93,95,98,102,104,106,110,111,114,119,125,132 | 24 |
| Other and/or Unspecified | Only | 14,43,45,47,49,52,53,56,72,116,121-123,127,128 | 15 |
| Mixed | 32,34,48,67,75,78,88,111,112,124-126 | 12 |
| General/unspecified health professional | Only | 23,24,64,97,99,130,131 | 7 |
| Mixed | 28,32,36,67,69,73,81,90,95,98,106,111,114,125 | 14 |
| Field of Psychology (therapist, psychologist) | Only | 13,25,29,79 | 4 |
| Mixed | 12,15-17,27,34,48,51,58,71,85,86,88,89,93 | 15 |
| Physical Therapist | Only | 61,84 | 2 |
| Mixed | 34,48,54,55,57,71,77,83,85,86,88,89,92,117 | 14 |
| Occupational Therapist | Only | 40,113 | 2 |
| Mixed | 12,34,48,54,55,57,67,77,83,88,110,115 | 12 |
| Social Worker | Only |  | 0 |
| Mixed | 34,51,78,83,92,96,106,115,126 | 9 |
| Physician | Only |  | 0 |
| Mixed | 34,48,63,68,71,77,88,89 | 8 |
| Self | Only | 118 | 1 |
| Mixed | 33,39,46,117 | 4 |
| Nurse Practitioner | Only |  | 0 |
| Mixed | 85,86 | 2 |

\*Only=a program used only one type of tutors; Mixed= a program used more than one type of intervention providers

## 3.5 Mode of Delivery

**TIDiers #6: “How: Describe the modes of delivery (e.g., face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.”**

The mode of delivery captures how the self-management program was designed, whether for an individual or group setting, or both (i.e., mixed). About half (N=64; 51.6%) of the programs were presented in an individual mode of delivery, 29.3% (N=37) were delivered as a group, and 19.1% (N=25) was delivered as a mixed mode (individual and group).

## 3.6 Location

**TIDiers #7: “Where: Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.”**

SM programs were delivered in a wide variety of locations (Table 4); if a program was delivered in more than one location, a tally was made in the “mixed” column. Regarding delivery location, The SM programs were most frequently delivered in a hospital setting (N=30; 23.8%), followed by the community (N=28 22.2%), rehabilitation (N=27; 21.4%), and virtually (online/electronic) (N=27; 21.4%).

**Table 4.** Delivery location for SM programs in descending order by total number of studies

|  |  |  |  |
| --- | --- | --- | --- |
| Format | Type | Citation | # Studies |
| Hospital | Only | 12,19,20,25,26,28,30,31,35,39,42,47,64,70,76,78,83,95,97,100,103,111,113,115,132 | 25 |
| Mixed | 23,24,52,81,90 | 5 |
| Community | Only | 22,34,41,50,51,55,57,68,72,77,88,89,93,98,99,105,106,108,109,112,114,116,120,121,131,135 | 26 |
| Mixed | 17,119 | 2 |
| Virtually (online) | Only | 3,15,32,33,62,65,66,69,74,82,101,117,118,125,129 14,16,44,46,48,56,60,130,131 | 24 |
| Mixed | 17,61,119 | 3 |
| Rehabilitation | Only | 2,13,18,29,40,43,45,53,54,67,73,79,80,85-87,94,96,102,104,107,110,123,124,127,128 | 26 |
| Mixed | 58 | 1 |
| Home | Only | 21,36-38,59,61,71,75,91,122 | 10 |
| Mixed | 17,23,24,52,58,61,81,90 | 8 |
| SCI Center | Only | 27,92,126,133,134 | 5 |
| Mixed |  | 0 |
| University | Only | 49 | 1 |
| Mixed |  | 0 |

\*Only= a program used only one delivery location; Mixed= a program used more than one delivery location

## 3.7 Intensity, Dose, Duration

**TIDiers #8: “When and How Much: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.”**

The reporting of the intensity, dose, and duration of the interventions varied across studies. As such, only the total numbers of the intervention sessions across the SM programs are summarized here. Thirty-one (24.6%) studies did not report or specify the total number of the program sessions included (Table 5). Eight (6.3%) SM programs, mainly online-based, provided participants with unlimited access to the intervention services/materials during the intervention period. For the remaining programs, each SM program had, on average, 10.6 sessions in total, and the median total number of sessions included in a program was 8 sessions. More than half (n=49; 56.3%) included 1 to 9 sessions; 26 (20.6%) programs consisted of 10 to 19 sessions, and 12 (9.5%) programs offered between 20 and 49 sessions.

**Table 5. Total Number of Sessions for SM Programs**

|  |  |  |
| --- | --- | --- |
| Total # Sessions | Citation | # Studies |
| 1-9 | 2,12-14,19,20,22,25,28,29,31-36,49-51,62,63,67,68,73,76-79,81-84,91,92,98-102,109,110,122-124,126,127,130,131,133 | 49 |
| 10-19 | 18,21,23,24,26,27,37-39,48,52,64,71,72,74,75,85,86,93,103,104,116-118,121,128 | 26 |
| 20-49 | 15,40,53,54,87,94,105,108,111,119,129,132 | 12 |
| Unlimited | 47,60,61,96,97,107,115,134 | 8 |
| Not Reported | 3,16,17,30,41-46,55-59,65,66,69,70,80,88-90,95,106,112-114,120,125,135 | 31 |

## 3.8 Tailoring, Modifications and How Well

**TIDiers #9: “Tailoring: If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.”**

**TIDiers #10: “Modifications: If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).”**

**TIDiers #11: “How Well: Planned: If the intervention adherence or fidelity was assessed, describe how and by whom, and it any strategies were used to maintain or improve fidelity, describe them.”**

**TIDiers #12: “How Well: Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.”**

Tailoring (TIDiers #9) describes how the intervention was individually planned and tailored to the participant’s specific needs. Modifications (TIDiers #10) capture if any changes were made to the intervention during the study. The How Well (Planned) (TIDiers #11) item describes if intervention adherence was assessed and maintained and how that occurred. Lastly, the How Well (Actual) (TIDiers #12) item is concerned with whether intervention adherence (or fidelity) was assessed and the degree to which the intervention was delivered as planned 11. Studies included in this chapter either did not report and did not provide sufficient information regarding TIDiers items #9-#12 described above; therefore, the program characteristics related to these items could not be summarized here.

# 4.0 Program Taxonomy Components

Taxonomies of SM program components are established tools for classifying the essential components involved in SM programs for various chronic health conditions 10. In this section, Lorig’s 9 taxonomy, Barlow’s 8 taxonomy, and the PRISMS taxonomy 10 are used to guide the summary of the diverse components utilized in the SCI SM programs.

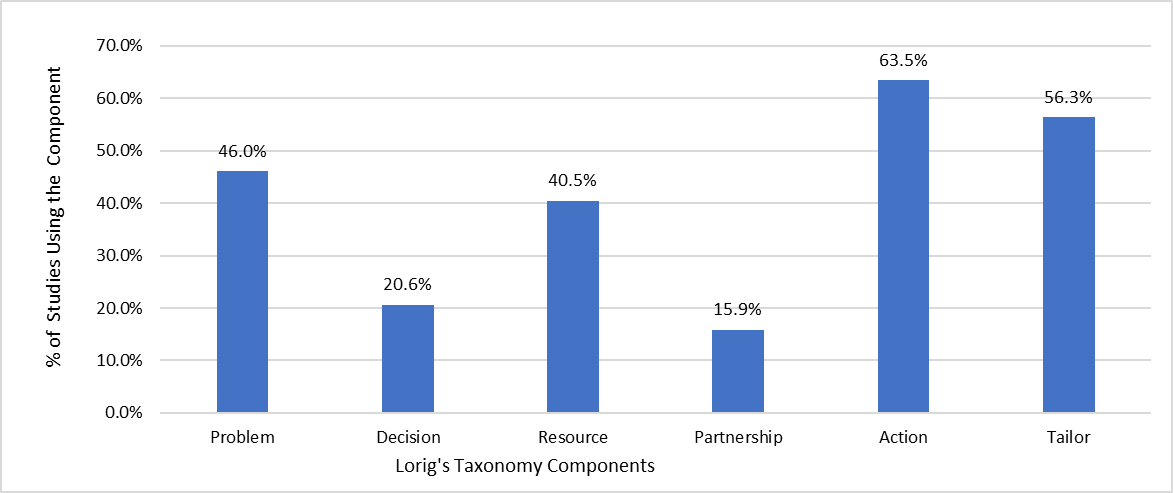
## 4.1 Lorig Taxonomy

Based on their clinical experiences and review of the literature, Lorig and colleagues 9 identified six core components of SM: *problem-solving*, *decision-making*, *resource utilization*, *taking action*, and *self-tailoring*. Each component is described in detail in Table 6.

**Table 6.** Lorig 9 Taxonomy Components

|  |  |  |
| --- | --- | --- |
| Abbreviated Code | Code | Description |
| Problem | Problem solving | Program participants are taught basic problem-solving skills, such as problem definition, generation of possible solutions (e.g., solicitating suggestions from friends and health care professionals), solution implementation, and evaluation of results. |
| Decision | Decision-making | Program participants are provided with necessary information and knowledge that facilitate their everyday decision-making about the management of their conditions (e.g., determining whether a particular symptom needs medical attention). |
| Resource | Resource utilization | Program participants are taught how to gather and utilize resources, such as phone books, internet, and community resource guide. |
| Partnership | Forming patient-health care provider partnership | Program participants are taught skills that help them form partnerships with their health care providers, such as accurately reporting their symptoms and discussing treatment options with their providers. |
| Action | Taking action | Program participants are taught how to make and a carry out realistic and doable action plans that enable them to achieve behavioural change. |
| Tailor | Self-tailoring | Self-tailored SM interventions are individualized based on the patient’s characteristics (e.g., readiness to learn, health beliefs, the nature of their condition), and is done by the patient though learning the principles for behavioural change and SM skills. |

Figure 3 shows the percentage of studies included in this review using each of the components from Lorig’s taxonomy. Under Lorig’s Taxonomy of SM program components, *taking action* is the most prevalent component in the SM programs for SCI reviewed in this chapter, utilized in 63.5 % of the program. In addition, more than half (53.6%) of the programs involved the *self-tailoring* component. While the management of secondary health conditions post SCI often requires the collaboration between patients and healthcare providers, *forming patient-healthcare provider* *partnership* was the least frequent used component, only present in 15.9% of the SM programs.

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**Figure 3.** Percentage of studies using each of the components from Lorig’s taxonomy

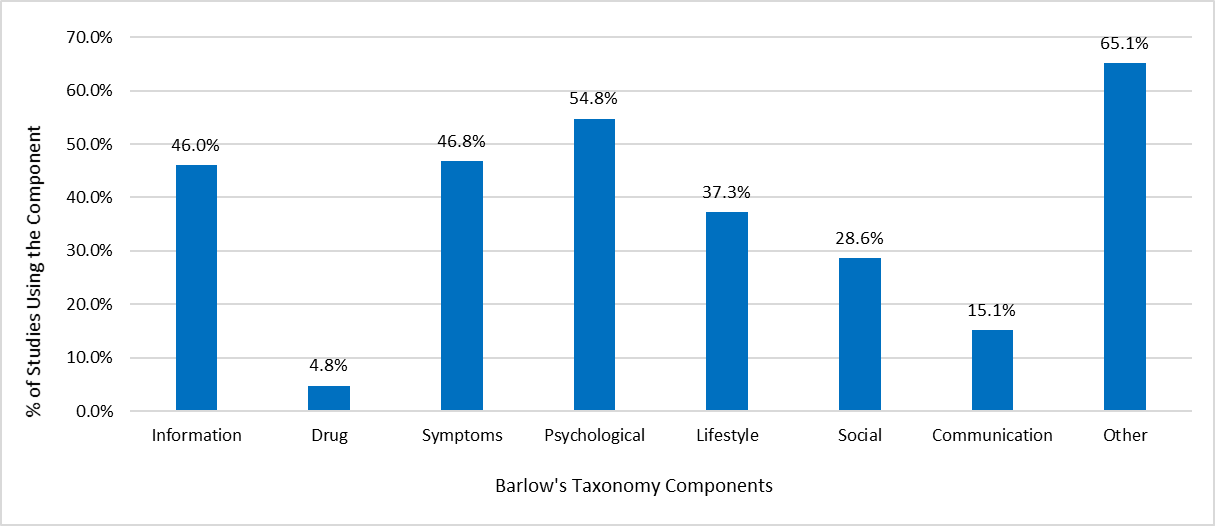
## 4.2 Barlow Taxonomy

Barlow’s 8 taxonomy is derived from a review of SM approaches reported in 145 studies on SM for a diverse range of chronic health conditions. The taxonomy consisted of eight components, which are presented in Table 7:

**Table 7. Barlow’s8 Taxonomy Components**

|  |  |  |
| --- | --- | --- |
| Abbreviated Code | Code | Description |
| Information | Information about condition treatment | Provision of information about the nature of specific conditions and treatment options from credible sources (e.g., information booklet). |
| Drug | Drug management | Training on drug management strategies (e.g., fieldtrip to practice taking medication, overcoming barriers to drug adherence) |
| Symptom | Symptom management | SM training on managing specific symptoms of the disease (e.g., pain management, fatigue management, relaxation techniques). |
| Psychological | Management of psychological consequences | Mitigating psychological consequences associated with the conditions (e.g., anger management, management of depression and stress, disease acceptance). |
| Lifestyle | Lifestyle (including exercise) | Managing conditions through lifestyle changes (e.g., leisure activities, nutrition and diet, overcoming barriers to exercise adherence). |
| Social | Social support | Alleviating the impact of the health conditions by strengthening patients’ connections with their social support network (e.g., family, friends, and peers). |
| Communication | Communication | Enhancing patients’ ability to effectively communicate with health and social service providers (e.g., assertiveness and communication strategy training). |
| Other | Other | Other SM strategies such as career planning, goal setting, and accessing support services. |

Figure 4 shows the percentage of studies included in this review using each of the components from Barlow’s taxonomy. Interestingly, 65.1 % of the programs used components that would be categorized as *other* under Barlow’s taxonomy, making up the largest category. This is followed by *management of psychological consequences* (54.8%), *symptom management* (46.8%), and *information about condition treatment* (46.0%). Drug management was the least popular SM program component among the reviewed studies defined in Barlow’s Taxonomy, with only 4.8% of the programs using it.

****

**Figure 4.** Percentage of studies using each of the components from Barlow’s taxonomy

## 4.3 PRISMS Taxonomy

The PRISMS taxonomy is a classification system for components of SM support developed by Pearce and colleagues 10; it is commonly used as a framework for the design and description of SM interventions, synthesis of evidence, and development of health care with long-term conditions. The taxonomy consists of 14 components, which are described in detail in Table 8.

**Table 8.** **PRISMS 10 Taxonomy Components**

|  |  |  |
| --- | --- | --- |
| Abbreviated Code | Code | Description |
| Condition | Information about condition and/or its management | Providing patients with information about their conditions or about the essential aspects and principles of managing their conditions (e.g., information sessions on medication management). |
| Resources | Information about available resources | Provision of written, verbal, or visual information on available social service and healthcare resources (e.g., advice on how to access financial assistance and accessible transportation). |
| Plan | Provision of/agreement on specific clinical action plans and/or rescue medication | Individualized written instructions prepared by a health-care professional that enable patients to manage their conditions (e.g., action plan on how to recognize certain symptoms and what actions to take). |
| Review | Regular clinical review | A regular and scheduled review conducted by a healthcare professional, on the patient, their condition, and SM (e.g., regular clinical visits conducted by health professionals). |
| Monitoring | Monitoring of condition with feedback | Monitoring symptoms, behaviours or objective measures related to the patient’s condition, done by the patient or others; the patient receives the results of the monitoring and take actions accordingly, sometimes with the guidance from health professionals (e.g., the completion of daily log to monitor symptoms). |
| Adherence | Practical support with adherence (medication or behavioural) | Providing patients with practical help to improve adherence to medication or behaviour change activities (e.g., reminder phone calls for taking medication). |
| Equipment | Provision of equipment | Providing patients with equipment to enable, assist or promote SM and/or self-monitoring of their condition (e.g., the provision of assistive technology that enables people with SCI to use computers). |
| Advice | Provision of easy access to advice or support when needed \*\*Safety Netting | Provision of access to health services and advice from health professionals when urgent or non-urgent concerns arise (e.g., providing contact information of a specialist nurse helpline). |
| Professionals | Training/rehearsal to communicate with health-care professionals | Helping patients build and practise necessary skills that enable them effectively communicate their needs and collaborate with health professionals (e.g., advocacy skill training workshop). |
| Everyday | Training/rehearsal for everyday activities \*\*ADLs | Enabling patients to build and/or practice skills that support everyday activities (e.g., OT activities such as washing and dressing practice). |
| Practical | Training/ rehearsal for practical self-management activities | Teaching patients practical skills that help them manage their conditions and/or providing patients with opportunities to practise those skills (e.g., home exercise for pressure ulcer management). |
| Psychological | Training/ rehearsal for psychological strategies | Provision of psychological strategies training that help mitigate the impact of the health conditions and/or providing patients with the opportunity to practice the skills they have learned (e.g., cognitive restructuring). |
| Social | Social support | Helping patients build and/or strengthen the connection with their social support network (e.g., peer support groups). |
| Lifestyle | Lifestyle advice and support | Providing patients with advice and support related to health and lifestyle (e.g., advice on physical activity and diet). |

Figure 5 shows the percentage of studies included in this review using each of the components from PRISMS taxonomy. The focus on information provision and psychosocial interventions in the existing SM programs for SCI is also evident in the percentage distribution under each PRISMS taxonomy component. *Information about condition and /or its management* was the most widely utilized component and was used in more than three quarters (79.4%) of the programs, followed by *training/ rehearsal for psychological strategies* (54.8%), *lifestyle advice and support* (45.2%), and *social support* (42.1%). The least used program components were *provision of equipment* (4.0%), *training/rehearsal to communicate with health-care professionals* (4.0%), and *regular clinical review* (2.4%).

**Figure 5.** Percentage of studies using each of the components from PRISMS taxonomy

# 5.0 Clinical Implications

This overview of the literature captures the key characteristics of the existing intervention programs for SM post SCI. Program topic wise, it is worth noting that 40% of SCI SM programs focused on only one specific secondary condition. This may reflect the underlying complexity and challenges of managing multiple secondary health complications in the SCI population 136. Although some SM skills, such as identifying issues, setting goals, and measuring achievement, may be transferrable across different secondary health conditions, certain behavioural skills required to may vary depending on the type and nature of the health condition.

As identified in the previous sections, SCI SM programs were often delivered by peers and healthcare professionals, such as nurses, psychologists, and, occupational therapists. The benefits of peer involvement in SCI SM interventions have been well-documented in the literature. The lived experiences of and social support from those with similar conditions can be especially empowering for program participants 103, and have been shown to enhance self-esteem, improve vocational outcomes, and reduce hospital readmission in individuals with SCI 102,137. The active engagement of clinicians and other healthcare professionals is also a key contributor of the success of many SCI SM interventions. It should be noted that when delivering SM programs, it is crucial for healthcare professionals to appropriately position their role and find a delicate balance between exercising control and providing patients with autonomy to take control over the management of their own conditions 138.

In terms of location of program delivery, besides traditional settings such as rehabilitation hospitals, rehabilitation centres, and community, a significant percentage of SCI SM intervention programs, especially the more recent ones,56,74,130 were delivered virtually via the Internet. In fact, this wide utilization of virtual delivery methods in the implementation of SM programs aligns with the preferences of many patients with SCI. In a qualitative study examining participants’ views on SM program delivery conducted with 99 Canadians with traumatic SCI, the Internet was considered as the preferred method of program delivery by 40% of the participants 139. Virtual delivery methods may be especially ideal for individuals with SCI who experience significant limitations in mobility, and should continue to be utilized in future SCI SM program delivery to improve program accessibility and patient engagement. At the same time, it is worth noting that participating in virtual SM programs often requires participants to have access to newer models of electronic devices and certain level of e-health literacy, which may pose financial and technological challenges for some individuals with SCI, especially those from lower socioeconomic background and older adults. Therefore, in-person SCI SM programs should not be replaced by online-based programs completely in the near future.

Regarding the utilization of established components of SM across interventions, while some SM components were embedded in the intervention programs more frequently than others, all components from each of the three taxonomies were utilized by at least one program. The distribution of utilization of the SM components from Barlow and colleagues’ 8 taxonomy and the PRISMS taxonomy10 reveals that the existing SM interventions for SCI were primarily concerned with providing patients with information about condition and symptom management and psychological training, which were often achieved through the use of information booklets as well as group and/or individual education sessions.. These foci are consistent with SM programs’ traditional emphasis on facilitating symptom management and behavioural changes through education.8,9

From the perspectives of individuals with SCI and their caregivers, facilitators of SM include physical and emotional support from caregivers, support and feedback from peers, acceptance of one’s condition and positive outlook towards the future, and the ability to maintain independence and control over ones own care.140 Barriers of SM consist of caregiver burnout, inadequate funding and associated policies that promote quality of life post SCI, physical limitations resulted from SCI and its secondary health conditions, lack of accessibility, and challenges related to psychosocial adaptation.140 These findings suggest that successful SM interventions for SCI should not only promote self-care skills and lifestyle changes, but also place emphasis on self-advocacy skills and coping skills. Further, they should integrate a wider range of components of SM to achieve the best outcomes.1 In order to maximize the facilitators of SM and address the barriers, SM program developers and implementation teams should engage diverse stakeholders, including but not limited to individuals with SCI, caregivers, and health and social service providers in the development, and/or delivery SCI SM interventions 1.

# 6.0 Gaps in the Evidence

This review of the literature on SCI SM interventions reveals several gaps in the current scientific evidence which carries implications for future research. First, it is worth noting that only a small proportion of studies reviewed in this chapter provided a definition of the term SM in their reporting of the intervention programs. Given the variability in the conceptualization of SM and the complex nature of SCI SM interventions, to assist the future evaluation and uptake of evidence, it is important for researchers to clearly define key terms, such as SM, in their work 10.

In addition, although SM programs were varied in topics, there was a dearth of studies on sexual health and vocational rehabilitation. Despite being central to an individual’s wellbeing, sexual health post-SCI is often a neglected area of care. As such, more programming related to sexual health is warranted. Similarly, employment post-SCI remains low, and further work exploring how SM may support return-to-work strategies is strongly recommended. Furthermore, within the body of work on SM, difficulties in accessing needed medical and social services and financial assistance have been identified as a major barrier in the management of various chronic conditions, including SCI 140-142. To address this challenge, SM interventions for SCI need to move beyond information provision on available resources and services and place focus on teaching program participants how to effectively communicate with service providers and to advocate for a more accessible environment. However, as indicated in our findings, this aspect of SM was rarely dealt with in the existing intervention studies on the management of SCI. This is reflected in the low frequency of utilization of the *forming patient-health care provider partnership* component defined in Lorig’s taxonomy, the *training/rehearsal to communicate with healthcare professionals* component defined in the PRISMS taxonomy and the *communication* component defined in Barlow’s taxonomy. This discrepancy between patient needs and current program provision calls for more research on SM interventions integrating self-advocacy and communication skill training in the future.

Finally, the clinical and demographic characteristics vary considerably across patients with SCI, and each individual is likely to respond differently to the same SM intervention program;143 thus, a one-size-fit-all approach to SM interventions is not likely to result in success. More comparative studies and in-depth qualitative studies are needed to assist researchers and practitioners in better understanding how to tailor intervention programs to meet specific subgroups and individuals’ unique needs.

**7.0 Conclusion**

The importance of SM for individuals with SCI is evident through the widespread implementation of structured programs in diverse settings. SM programs provides the skills for individuals to co-manage their own care in various spheres and in real time as experts of their own lived experiences. Common program characteristics were identified in this chapter using the TIDiers checklist with Lorig, Barlow’s and PRISMS taxonomy further refining core components. They include focusing on the provision of information and support for symptom management, enhancing coping skills including psychological support. This was achieved through more tradition methods such as printed form and group interactions although virtual care was identified as a useful approach. Moving forward, there is a need for consensus on how to define SM and what taxonomies are well-suited for advancing work in this domain related to health and well-being of those with SCI. Doing so will help to identify appropriate outcome measures to assess what underlying variables may change as a result of participating in a SM program. Lastly, sexual health, vocational rehabilitation, as well as advocacy skills by providers were identified as an important area of future research on the topic of SM post SCI.

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# 9.0 Appendix