

The Taxonomy of Everyday Self-management Strategies (TEDSS): A framework derived from the literature and refined using empirical data

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ABSTRACT

Objective: To extend our understanding of self-management by using original data and a recent concept analysis to propose a unifying framework for self-management strategies.

Methods: Longitudinal interview data with 117 people with neurological conditions were used to test a preliminary framework derived from the literature. Statements from the interviews were sorted according to the predefined categories of the preliminary framework to investigate the fit between the framework and the qualitative data. Data on frequencies of strategies complemented the qualitative analysis.

Results: The Taxonomy of Every Day Self-management Strategies (TEDSS) Framework includes five Goal-oriented Domains (Internal, Social Interaction, Activities, Health Behaviour and Disease Controlling), and two additional Support-oriented Domains (Process and Resource). The Support-oriented Domain strategies (such as information seeking and health navigation) are not, in and of themselves, goal focused. Instead, they underlie and support the Goal-oriented Domain strategies. Together, the seven domains create a comprehensive and unified framework for understanding how people with neurological conditions self-manage all aspects of everyday life.

Conclusions: The resulting TEDSS Framework provides a taxonomy that has potential to resolve conceptual confusion within the field of self-management science.

Practice Implications: The TEDSS Framework may help to guide health service delivery and research.

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1. Introduction

During the last two decades, interest in self-management approaches and interventions for people with long-term conditions has grown substantially [1–5]. Self-management is commonly defined as strategies individuals perform to live well with long-term conditions, including medical, role and emotional management [6]. This definition is grounded in the Corbin and Strauss [7] model of illness-related work, which highlights the pervasive demands placed on individuals who live with a long-term condition. However, in research and practice, self-management is sometimes defined in terms of managing disease and

lifestyle behaviours, while other definitions draw on a broader conceptualization, including all strategies people use to live a good life in spite of a long-term condition [8].

Frameworks serve to standardize terms, guide intervention development, facilitate comparisons in meta-analyses, and form the foundation of measurement tools. Such frameworks are particularly needed within self-management research, which has been critiqued for poorly defined terms and ambiguity across many and varied outcome measures [9–12]. A limited number of self-management frameworks currently exist. Of these, most have been developed to describe the underlying mechanisms of self-management support and interventions [cf. 13–15]. For example, Vernooij and colleagues [13] identified critical components enhancing the effectiveness of self-management interventions, and Pearce et al [15] developed a taxonomy of self-management support to specify components and delivery modes.

This paper, however, focuses on self-management frameworks that categorize the self-management strategies used by people to

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manage their conditions. Existing self-management frameworks of this type [cf. [16,17],] have primarily focused on the needs of people with lifestyle modifiable diseases (e.g., heart failure and diabetes). Riegel et al.'s [16] situation-specific theory to understand heart failure self-care provides an example. The focus on disease-specific, medical and life-style self-management, these frameworks may not capture the complete picture of self-management strategies enacted by people managing complex conditions and/or multi-morbidity. This paper extends our understanding of self-management frameworks by focusing on self-management strategies used by people with conditions that 1) are not substantially modifiable with life-style interventions and have limited or demanding treatment options, 2) have persistent symptoms, like chronic pain or fatigue, that are difficult to mitigate, 3) often lead to functional loss (physical or cognitive), and 4) have a profound impact on every-day life leading to activity and participation restrictions, and/or social isolation. For example, self-management of multi morbidity and conditions with unpredictable trajectories is particularly difficult due to fluctuating symptoms and self-management complicated by difficulty distinguishing symptoms, interaction of treatments [18,19] and the lack of guidelines for care [20]. Schulman-Green and colleagues' meta-synthesis of self-management processes [21] comes closest to a patient-centred understanding of self-management strategies; it describes three broad processes of long-term illness self-management: 1) focusing on illness needs, 2) activating resources, and 3) living with a chronic illness. Born out of work on cancer self-management, this framework is comprehensive and detailed, including 12 specific processes, 20 tasks, and 75 skills. Operationalization of this framework in practice has not yet been reported; however, it has been included in the "Self- and Family-Management Framework" [22]. Although their work [21] has added to our understanding of self-management processes, our goal is to develop a comprehensive framework that captures all aspects of self-management needed to live well with multiple and/or complex conditions, one that will guide both clinical care and research. People with neurological conditions, including those with physical and cognitive limitations and multi-morbidity often experience activity limitations and participation restrictions that demand both role and emotional management [23]. They represent the ever increasing population of high consumers of care, who are often the most difficult for providers to support, and who often experience low levels of well-being and quality of life [24]. While health-care providers acknowledge the effort needed to manage every-day activities, lack of a useful framework means they remain focused on needed life-style changes and medication management [cf. 25]. A framework that details and acknowledges role- and emotional management as well as medical management has the potential to support providers in their patient communication and/or be the foundation for a patient-centered outcome measure.

As part of a concept analysis of self-management, adaptation and coping (three ambiguous, interrelated concepts) in the context of living with a neurological condition our team developed a preliminary framework [8]. Seventy-seven research articles were identified and analyzed. *Characteristics* [cf. 26] of coping strategies, adaptive tasks, and self-management behaviors were sorted into eight broad strategy groups and 68 specific strategy types, to facilitate comparisons between the concepts. Even though each concept was identified by a unique, identifiable core, considerable overlap existed between them. The eight strategy groups thus became the genesis of a new framework (the 'Preliminary Framework') to understand peoples' everyday management of long-term conditions (Table 1 provides an overview). This Preliminary Framework [8] is similar to that

described by Schulman-Green et al. [21] in that it shares a broad definition of self-management and an emphasis on every-day life activities. However, differences exist in how the strategies for living with a long-term illness are categorized. The absence, in Schulman-Green et al.'s work, of strategies to facilitate and maintain social participation is a notable difference. Regardless of similarities and differences, both highlight the need for an organizing framework upon which to build comprehensive, integrated, and tailored self-management support services and systems.

Conceptual work, such as creation of taxonomies, are typically developed through qualitative analysis [27] or by synthesizing existing research [28]. When concept development is based on qualitative data, specific contextual factors may be missed or too heavily weighted because of the limited number of respondents or contexts [29]. In contrast, when theory is developed solely based on research literature, the author may lack the detailed understanding that emerges through examination of primary data. To overcome these methodological shortcomings, we used original data to refine and validate the Preliminary Framework. The aim of this paper, therefore, is to refine and validate our preliminary framework for everyday self-management strategies, grounded in the experiences of people with neurological conditions. This includes, describing domains and sub-domains within the framework by 1) confirming their relevance, content, and definitions, and 2) describing the commonality of use (reported as proportions) of the domains and sub-domains.

2. Methods

Data were drawn from the study 'The Everyday Experience of Living with and Managing a Neurological Condition' (the LINC study) [30]. Qualitative data reported in this analysis were collected in a prospective cohort study that followed participants with neurological conditions monthly for up to 11 months. Participant demographic data were drawn from the LINC online survey (a national survey which preceded the cohort study). Qualitative data were used to test our interpretation of the literature and the resultant Preliminary Framework.

2.1. Ethics

Ethical approval for the LINC study was received from the Health Canada and Public Health Agency of Canada Research Ethics Board as well as the appropriate ethics review boards at Dalhousie University, Queens University, the University of Manitoba, and the University of Prince Edward Island. Data collection in Newfoundland and Labrador was acknowledged by the provincial Health Research Ethics Authority. All participants gave written, informed consent before participation.

2.2. Procedure

Data were collected by trained research assistants from February to December 2012 via monthly phone interviews, although not every participant was available every month. Participants answered both open-ended questions and standardized questionnaires. For this study, responses to four open-ended questions about strategies used to manage life with a neurological condition, and a final question concerning other issues of importance, were analyzed (Table 2). The four questions were built on self-management theories [cf. 6, 7], and answers were typed into a database by trained research assistants. Some text was recorded in "first person" (I/me) while other text was recorded in "third person" (he/she).

Table 1

An overview of the Preliminary Framework, each Strategy group includes a number of Strategy types [8].

Strategy Group	Strategy Types
1: Internal Strategies Definition: Mental or cognitive strategies used to manage or overcome a demand or challenge with the specific aim to control stress or emotions.	-Finding help in religious beliefs -Putting responsibility somewhere else -Living one day at a time -Managing emotions -Avoidance thinking -Denial -Rationalization -Acceptance -Humour -Proactive orientation -Assimilation -Using medication
2: Disease-controlling Strategies Definition: Strategies to control symptoms, limit complications and/or disease progression.	-Using complementary medicines -Participation in rehabilitation -Healthcare consultations -Adopting healthy behaviours -Exercising -Healthy diet -Substance use
3: Healthy Behaviours Definitions: Behaviours enacted to enhance health and limit the risk of lifestyle related illness.	-Risk avoidance -Detecting/avoiding symptom triggers -Symptom management -Stress management -Quitting or controlling smoking -Rest or relaxation -Sleep hygiene
4: Substance Use Definition: Using drugs	
5: Activity Related Definition: Strategies to facilitate activities (leisure activities, work activities, household chores) and participation.	-Maintain regular activities -Plan and pace -Distraction -Withdrawal -Generativity
6: Process Strategies Definition: Strategies that are used to increase one's skills or abilities to make good decisions or enact management strategies.	-Problem-solving -Decision-making -Body listening
7: Resource Utilization Definition: Seeking out or managing different types of formal or informal support.	-Tangible support -Interacting with peers -Controlling support structures -Reciprocal interacting relationships
8: Social Strategies Definition: Strategies enacted either to be able to continue to be socially active or to manage social situations, for example, embarrassment.	-Avoid contact with peers -Avoiding showing emotion -Social participation

2.3. Participants

Participants in the LINC study were primarily recruited through the Neurological Health Charities of Canada [30]. All had one or more self-reported neurological condition(s). Participants in the cohort study were adults age 17–65, living in Manitoba, Ontario, or Atlantic Canada, and were sequentially drawn from participants in the online survey, based on interest to participate.

A total of 117 participants (Table 3) were included in this analysis. The most commonly reported neurological conditions were: migraine, multiple sclerosis, brain injury, epilepsy and Parkinson's disease. Almost half of the participants reported multi-morbidities (41.9%); for example, 22% of participants reported having migraine but no participants reported having only

migraines. In total, 7236 statements were analyzed (each statement included description of at least one self-management strategy), resulting in a mean of 59.74 statements per participant (SD = 33.99).

2.4. Data analysis

Deductive content analysis, supplemented with descriptive quantitative analysis, was used. Deductive content analysis is recommended when a theory/model is tested in relation to a new population, or to identify areas within a theory that require development [31–33]. In deductive content analysis, an existing model is used as a lens for organizing and sorting the data. In this study, the Preliminary Framework [8] was used. In the preparation

Table 2

Interview questions. Interviewers asked for up to five statements per question, giving that one participants could provide a maximum of 25 statements per interview.

The open ended questions from the structured interviews
<ul style="list-style-type: none"> • In the past month, because of your condition, were there things that you did to stay healthy? For example, did you pay specific attention to your diet and/or exercise? Checked your skin for pressure sores? Took your medications as directed? Tell me about those strategies. • In the past month, because of your condition, have you used any deliberate strategies to manage your day to day activities at home, at work or in the community? For example, you took frequent rests? Planned your days? Asked for help? Shortened your work hours? Worked from home? Tell me about those strategies. • In the past month, because of your condition, have you used any deliberate strategies to manage your relationships with others (e.g. your spouse, children, parents, other family members, friends or co-workers)? For example you did not disclose your condition to people at work? Involved family members in treatment decisions? Prioritized your time with your family or friends? Chose your friends carefully? Tell me about those strategies. • In the past month, because of your condition, did you experience any emotional consequences? (YES/NO) Please detail the strategies you used to deal with the emotional consequences of your condition, and how often you used them. For example, did you speak to your religious leader? Did something nice for yourself? Talked to a friend? Wrote in a journal? Tell me about those strategies. • Is there anything else you want to tell us about living with a neurological condition?

Table 3
Participant Demographic Profile.

Variable	n	%
Age		
25 years or younger	6	5.1
26–35	13	11.1
36–45	20	17.1
46–55	38	32.5
56–65	40	34.2
Sex		
Male	39	33.3
Female	77	65.8
Unknown	1	0.9
Marital status		
Married or living together	71	60.7
Divorced	21	17.9
Single, never married	25	21.4
Employment status in past 3 months		
Working	49	41.9
Not working due to health	47	40.2
Not working due to other reasons	19	16.2
Unknown	2	1.7
Highest level of education		
Some post-sec, secondary or less	25	21.4
Post secondary graduation	90	76.9
Unknown	2	1.7
Neurological conditions¹		
Migraine	26	22.2
Multiple sclerosis	25	21.4
Brain Injury	24	20.4
Epilepsy	22	18.8
Parkinson's disease	18	15.4
Dystonia	10	8.5
Stroke	7	6.1
Spinal cord injury	7	6.1
Spina bifida	6	5.1
Muscular dystrophy	6	5.1
Other neurological conditions ²	19	16.3
Comorbidities		
More than one reported diagnosis	49	41.9
Heart conditions	27	23.1
Depression	27	23.1
Diabetes	4	3.4

¹ Total exceeds number of participants because many participants had multiple conditions.

² Hydrocephalus, Huntington's disease, ALS/Lou Gehrig's disease, brain or spinal tumor, Tourette's syndrome, cerebral palsy.

stage, the transcribed text was entered into NVivo 10. Because the brief statements were not sufficiently detailed to be interpreted in depth, this analysis was predominantly manifest (e.g., descriptive) [cf. 33].

To move from the Preliminary Framework to a confirmed framework, we first conceptualized each strategy group in the Preliminary Framework as a self-management domain, and the listed strategy types as subdomains. Therefore, each domain was composed of subdomains considered to be similar, or to share a common goal.

The text was read several times, then deductively organized according to the Preliminary Framework, with data sorted into the sub-domains. Data not matched to an existing sub-domain were analyzed separately using principles of inductive content analysis [31]. The majority of the statements were coded within only one subdomain; however, where statements included elements of several sub-domains, they were coded within all relevant subdomains. The categorized data were used to create definitions for each sub-domain. Sub-domains were then arranged according to the eight domains of the Preliminary Framework. Analysis was conducted by one researcher with extensive qualitative analysis experience (ÅÅ), however the analytical steps, definitions and preliminary results were discussed and developed in collaboration with the whole team.

All categorized statements were given corresponding codes, then exported from NVivo to SPSS (version24), in order to calculate frequency of use. Descriptive statistics were used to tabulate demographic information, calculate proportions of participants using each sub-domain and at least one sub-domain per domain. Use of a sub-domain was defined as having reported its use at least once during the data collection period

3. Results

3.1. The Taxonomy of Everyday Self-Management Strategies: TEDSS framework

The interview data from people with neurological conditions, confirmed the use of 26 everyday self-management strategy sub-domains within seven domains, a reduction from the eight strategy groups and 68 strategy types of the Preliminary Framework. The confirmed domains and sub-domains create the Taxonomy of Everyday Self-management Strategies (TEDSS) Framework (Fig. 1), defined in Table 4 with quotes supporting the domains and sub-domains presented in Table 5. The following sections describe the differences between the TEDSS Framework and the Preliminary Framework, and the rationale for changes.

3.2. Evidence for and description of domains

Seven of eight domains in the Preliminary Framework were strongly represented with sufficient description and frequency to demonstrate relevance to people living with complex long-term conditions. The last domain, Substance Use, was removed. In the empirical material, there were only two relevant statements; both described using marijuana in order to manage pain. These statements were coded within the Disease Controlling Strategies Domain, which included other strategies for controlling pain. Data did not indicate the need for any additional domains. Because the first-voice, patient data provided deeper insight into the domains

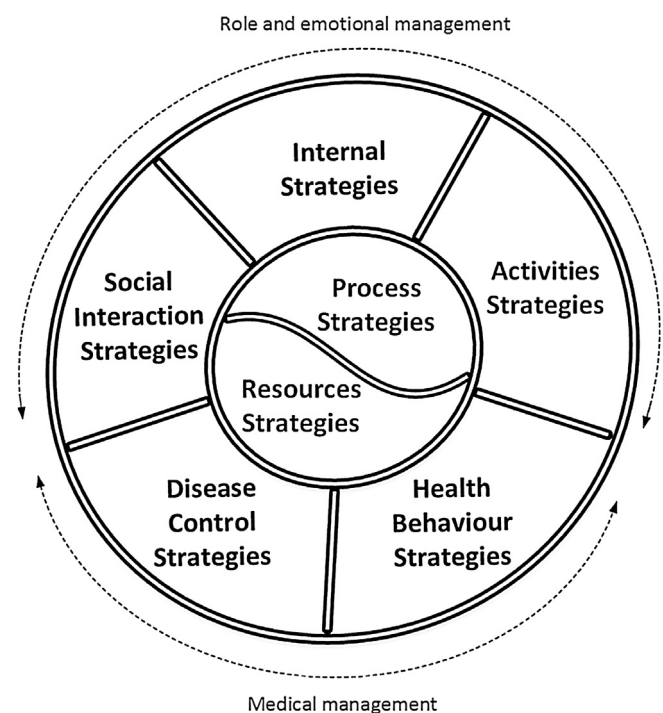


Fig. 1. Illustrates the domains of the TEDSS Framework in relation to role- and emotional and medical management.

Table 4
Definition and frequency of use by Strategy Domain and Sub-domain.

Strategy Domain (% using > 1)	Strategy Sub-domain	Number and proportion reporting use (n) (%)	
Process Strategies (Support-oriented Domain) (n = 56, 47.9% used > 1) Strategies used to be well informed and to make good decisions. Often used to support use of other, non-process strategies.	Awareness and Problem-solving: Proactive strategies to become aware of choices and consequences of disease related problems in everyday life, trying to find alternative solutions and making informed decisions.	48	41.0
	Information-seeking: Researching and seeking information regarding, for example, one's disease, symptoms and treatment, living with illness, health, social service and insurance systems	18	15.4
Resource Strategies (Support-oriented Domain) (n = 100, 85.5% used > 1) Proactively seeking, pursuing and/or managing needed formal or informal supports and resources.	Self-advocating: Actively pursuing access to health-care providers, social systems, and legal rights. Speaking out against discrimination.	33	28.2
	Seeking and Managing Everyday Support: Judging the need for support, asking for support, planning support, and keeping a sense of autonomy despite receiving support. Seeking and Managing Health/Social-care Needs and Paid Support: Navigating and managing the formal support health-care systems (health, social, financial) in order to receive treatment, referral, equipment, etc. Includes seeking health care, attending appointments and preparing oneself for consultations.	94	80.3
Activities Strategies (Goal-oriented Domain) (n = 114, 97.4% used > 1) Finding ways to participate in everyday activities (leisure activities, work activities, household chores) despite problems such as fatigue, pain, memory loss or disability.	Pace, Plan and Prioritize: Using time wisely, planning the day, resting to conserve energy, adapting activities to current functional level and making important activities a priority.	108	92.3
	Organizing Routines and Systems: Using tables, charts, lists, reminders, tracking systems and routines to organize information, items and equipment and to carry out activities.	59	50.4
	Aids and Physical Adaptations: Using aids (e.g., canes, mug with straw), adapting environments (e.g., rearranging furniture to ease movement, ramps) and adapting behaviors (e.g., having a hand on the wall while moving around) to facilitate activities.	40	34.2
	Engage in Valued Activities: Making time to do the activities that are important and bring meaning and value to the individual. For example being with family, taking a walk, painting, attending a concert.	87	74.4
Internal Strategies (Goal-oriented Domain) (n = 85, 72.6% used > 1) Preventing and managing stress, negative emotions and internal distress; creating inner calm.	Acceptance: Accepting issues and conditions judged to be out of one's control and gaining inner peace with unchangeable circumstances.	40	34.2
	Staying Positive: Deliberately adopting a positive attitude to limit negative feelings and generate positivity. Reevaluating one's situation, finding meaning and perspective in life, sometimes to fight depression.	49	41.9
	Controlling Stress and Negative Emotions: Controlling emotions in order to remain calm, reduce anxiety and/or prevent being overwhelmed by emotions. Using techniques like meditation, breathing techniques and relaxation, or deliberately avoiding thinking about problems, symptoms or future risks by focusing on other activities or thoughts.	57	48.7
	Allowing Time for Sadness and Grief: Expressing feelings (e.g., crying or venting) with the intention to feel better afterwards.	17	14.5
Social Interaction Strategies (Goal-oriented Domain) (n = 90, 76.9% used > 1) Managing social interactions and relationships to be able to participate without exposure to negative reactions.	Seeking Comfort in Faith and Spirituality: Praying, talking with religious leaders or reading spiritual texts, in order to feel inner comfort.	13	11.1
	Disclose Condition: Deciding to whom to disclose information about condition, including what and how much information is given to each person.	56	47.9
	Choosing Social Relationships and Situations: Prioritizing and investing in selected interpersonal relationships. Avoiding emotionally demanding or discriminating interactions; ensuring a sense of control.	51	43.6
	Stay in Contact: Staying in contact with family or friends using traditional and new methods of connecting, sometimes to overcome cognitive or mobility problems (e.g., using social media when home bound).	26	22.2
	Optimize Social Interactions: Facilitating interactions (talking slowly, rephrasing sentences, explaining needs). Controlling misunderstood symptoms (e.g., spasms or drooling), or emotions (e.g., anger or anxiety).	56	47.9
	Use Humor: Using humor or laughter to de-dramatize a situation.	10	8.5
Health Behavior Strategies (Goal-oriented Domain) (n = 114, 97.4% used > 1) Maintaining a healthy lifestyle in order to enhance health and limit the risk of lifestyle related illness.	Physical Exercise: Being physical active (e.g., sports, gym exercise, walking, therapeutic stretching, or swimming) within level of functional ability.	104	88.9
	Mental Exercise: Keeping mentally fit (e.g., brain teasers, games, puzzles, committee membership or volunteering).	14	12.0
	Diet: Maintaining healthy eating habits. Eating more healthy foods (e.g., vegetables, fruit, protein, water consumption, vitamins) and avoiding unhealthy foods (e.g., sweets, deserts, processed foods).	103	88.0
	Sleep Hygiene: Creating a healthy sleep routine, including regular bedtime, calm activities before sleeping, attention to mattress and pillow, and use of needed, routine daily naps.	54	46.2
Disease Controlling Strategies (Goal-oriented Domain) (n = 112, 95.7% used > 1) Preventing, controlling and limiting symptoms, complications and/or disease progression.	Manage Medication and Treatments: Taking prescribed medication and/or over the counter medication. Completing treatments at home.	100	85.5
	Prevent Symptoms and Complications: Accommodating and controlling symptoms and disease related complications (limiting the risk of falling, having an annual flu shot, avoiding seizure triggers) and controlling/limiting existing symptoms (stretching, wound care, hot packs to limit pain).	56	47.9
	Use Complementary Medicine: Using supplements (e.g., herbal remedies, probiotics etc.) and complementary strategies (massage, conductive education).	42	35.9

Table 5
Examples of participant quotes for each strategy domain.

Strategy Domain	Quotes (sub-domain)
Process Strategies	I've had to learn to not put myself under pressure to make decisions, and give myself time to process information and make proper decisions. (<i>Awareness and Problem-solving</i>) Seeking information about my condition, treatment . . . being aware, the less I'm afraid of it . . . makes me feel empowered. (<i>Information-seeking</i>)
Resource Strategies	Also he believes you have to be proactive/advocate for his own health. Will pursue or ask about certain referrals and treatments. You have to find a doctor that is interested in learning more at the very least. If they don't already know. But individuals also have to learn and educate themselves about their own conditions. You need to be able to work with your doctor. (<i>Self-advocating</i>) Every night [I] compile a list of things to do for the following day care provider. (<i>Seeking and Managing Health/Social-care Needs and Paid Support also Organizing Routines and Systems</i>)
Activities Strategies	I ask for help for tasks that are difficult. My husband sets up my medications because I have some cognitive difficulties related to side effects from my epilepsy. (<i>Seeking and Managing Everyday Support also Manage Medication and Treatments</i>) So I carefully plan my days to get as much done as possible, when I have the energy to do it. (<i>Pace, Plan and Prioritize</i>) Listening to my body, when I've done too much my body tells me and I rest. (<i>Pace, Plan and Prioritize</i>) Keeps a list and sends herself emails/phone messages. She also leaves visual reminders on her fridge and at the front door. [She] has people instructed to remind her of certain things. [She] always carries a calendar. (<i>Organizing Routines and Systems also Seeking and Managing Everyday Support</i>)
Internal Strategies	[You] try to concentrate on what you are doing physically. If you concentrate on how you used to do things it can be counterproductive . . . [You] can't live in fear . . . need to keep aware of your present situation. (<i>Acceptance</i>) I talk a lot with my wonderful partner about everything but my condition. I think it's important to focus on bad things to the extent that you need to, but no more than you need to. Whether it's the Tour de France, photos from trips you've been on . . . even if it's Daily Mail UK . . . do whatever can take your mind away from thinking about your bad condition all the time. Don't wallow in it. (<i>Controlling Stress and Negative Emotions also Seeking and Managing Everyday Support</i>) Making the most out of every situation and moment . . . also not too waste time. (<i>Staying Positive</i>) I deliberately choose happy people to be around. People who are negative bring me down. (<i>Choosing Social Relationships and Situations</i>)
Social Interaction Strategies	[I] also try to look as best as I can. I don't dress how I feel. I feel tired all the time with Parkinson's . . . but need to dress how you want to show yourself to others. (<i>Optimize Social Interactions</i>) [I'm] thoughtful about disclosure [of disease status] at work particularly with new people. (<i>Disclose Condition</i>)
Health Behavior Strategies	Exercise three times a week. Walk with assistance. Short distances. Exercise bands for my arms. [He] exercise in the morning. He has a daily routine. (<i>Physical Exercise</i>) [I] keep mentally fit. I keep active and go in the afternoons to do volunteering committee work. In the computer [I] do brain games and puzzles. (<i>Mental Exercise</i>)
Disease Controlling Strategies	[I] make sure my sleep patterns are regular. I make sure I go to bed at the same time every night. (<i>Sleep Hygiene</i>) [I] bring medication with me in case I need it. (<i>Manage Medication and Treatments</i>) [I'm] checking for sores and making sure to always keep my feet clean and dry. I go to a podiatrist every two months who checks my feet for shear callouses. (<i>Prevent Symptoms and Complications</i>) The heat in the summer really bothers my health. Then I feel sicker than usual. I try to find somewhere cold, hydrate, drink. (<i>Prevent Symptoms and Complications</i>)

than available in the original published material, domain definitions were improved with small word changes (see supplementary file for additional detail).

Of the resulting seven domains, five (Internal, Social Interaction, Activities, Health Behaviour and Disease Controlling Strategies Domains) were linked to participants' individual every-day lives and goals, and were therefore labeled Goal-oriented Domains. For example, in the Activities Strategies Domain, descriptions were linked to the goal of facilitating everyday activities: "[I] use [a] scooter to get to astronomy class for safety and to conserve energy". Text describing strategies in Goal-oriented domains suggests that goals are often multi-tiered. For example, participants described strategies to pace and plan, which allowed them to achieve the goal of participating in activities. Participation in turn facilitated well-being.

The five Goal-oriented Domains are aligned with traditional definitions of self-management that include role, emotional and medical management. The Activities Strategies (facilitating activities in everyday life), Social Interaction Strategies (promoting social interaction and limited exposure to negative reactions), and Internal Strategies (supporting inner calmness) focus on role and emotional management, emphasizing areas important in peoples' everyday life. The domains of Disease Controlling Strategies (controlling disease progression and symptoms) and Health Behaviour Strategies (strengthening one's body functioning and fitness) may be thought of as medical management.

Strategies in the two remaining domains (i.e., Process and Resource Strategies Domains) were described differently by

participants than the Goal-oriented Domain strategies and were thus, labelled Support-oriented Domains. Support-oriented Domain strategies were described as strategies that underlie and/or support strategies in the Goal-oriented Domains. They were described in two ways. Some statements described how the participants were deliberate in their use of a Support-oriented strategy, such as information seeking or problem solving. In other statements, Support-oriented strategies were described together with a specific example of how strategies were connected with one or several Goal-oriented Domain strategies. For example, a total of 766 statements were coded in the Resource Strategies Domain. Approximately 70% referred to how participants sought and managed their support systems. The other 30% referred to specific situations where the participants had used resources in relation to other domains, for example talking to a physiotherapist to get exercise advice or asking a neighbor for a ride to the mall (see supplementary file for more detail).

3.3. Evidence for and description of sub-domains

Data supported most strategy sub-domains named in the Preliminary Framework. However, the data showed that in real life, strategies were often intertwined with each other making them less distinguishable than described in the academic literature. Where appropriate, strategy types were therefore collapsed into broader sub-domains (see supplementary file for detail). For example, while many instances of seeking support were found, the overlap between *Instrumental Support* and *Emotional Support* was

more evident than the differences; these were therefore collapsed into *Seeking and Managing Everyday Support*. Other strategies were only briefly described by one or two participants (e.g., *Goal Setting* was described by one participant as part of problem-solving), with insufficient data for retention as unique sub-domains.

Only eight of the strategy types in the Preliminary Framework were not found in the empiric data (e.g., *Confrontational Coping*, *Negative Appraisals*, *Assimilation*, *Rationalization*, *Denial*, *Restraint Coping*, *Tangible Support*, *Quitting or Controlling Smoking*). Six of these were specific to the coping literature in the concept review by Audulv et al. [8]. However, individuals in this study did not describe such strategies. Therefore, these sub-domains were not included in the final TEDSS Framework. Three additional sub-domains, not described in the Preliminary Framework were identified in the data; *Mental Exercise* (Health Behaviour Strategies Domain), *Organizing Routines and Systems* (Activities Strategies Domain), and *Staying in Contact* (Social Interaction Strategies Domain).

3.4. Frequency and commonality of strategy domains and sub-domains

Commonality of use across participants was assessed by calculating the proportion of participants using each domain and sub-domain (Table 4). Between 47.9% and 97.4% of participants reported use of each domain (defined as description of at least one sub-domain per domain at some time during the data collection period). A third of the participants (n=39) reported using strategies from every domain.

On average participants described using 12.17 (SD 4.77) different sub-domains. Interestingly, the five most prevalent sub-domain strategies (*Pace*, *Plan and Prioritize*, *Physical Exercise*, *Diet*, *Managing Medication and Treatments*, *Seeking and Managing Everyday Support*) represent four different domains, illustrating that people self-manage by using many and varied strategies.

4. Discussion and conclusion

4.1. Discussion

The TEDSS framework further refines the Preliminary Framework, developed by our team, by 1) simplifying domains and sub-domains and 2) confirming relevance to patients with complex neurological conditions. The Preliminary Framework was simplified in three ways. First, the proposed Substance Use Domain (with little supporting data) was removed. Second, eight strategy sub-domains, identified during the literature review, were removed during the data analysis due to insufficient evidence within the data. Third, many strategy types in the Preliminary Framework were collapsed into broader sub-domains. These changes reflect participants descriptions of complex real life situations. Relevance was confirmed by a high proportion of participants reporting use of strategies in most of the domains (Activities 97.4%, Internal 72.6%, Social Interaction 76.9%, Health Behaviour 97.4%, Disease Controlling 95.7%, Resource 85.5%) and a third of the participants reported using at least one sub-domain strategy in every single domain.

A unique feature of the TEDSS Framework is the conceptualization of self-management strategies as integrated parts of a complex whole. Understood as connected parts, the Framework resolves apparent contradictions in how self-management is defined. As previously noted, self-management is defined differently, often depending on context, health provider and/or client group [8,9]. The five Goal-oriented Domains of the TEDSS Framework accommodate the different conceptualizations of self-management frequently reported. Results support the importance of medical and health behaviour management, for people

with and without modifiable conditions; preventing and delaying decline in conditions through management of treatments and health behaviours was described as important by people with advanced and complex neurological conditions. The high proportion of people who reported use of strategies within the Activities, Social Interaction and Internal Strategies Domains underscores patients' emphasis on everyday self-management strategies. While the importance of "role and emotional management" is often acknowledged [18], how these are enacted by people living with chronic conditions, or supported by health professionals, is not comprehensively described as medical and health behaviour management.

While the Goal-oriented Domains address areas of importance to patients, competency in the form of information seeking, problem-solving, and health navigation are frequently included in self-management interventions [3,4]. Participants in this study demonstrated deliberate use of strategies in two Support-oriented Domains. These strategies have been previously described, but researchers are at odds about where they fit into the self-management decision-making processes. Lorig & Holman [34] described such strategies as skills and abilities influencing self-management performance, but not as self-management strategies per se. Schulman-Green et al.'s model [21] identified problem-solving and information-seeking as self-management strategies, but linked these strategies specifically to disease management. According to the participants in the current study, *Information Seeking* and *Problem-solving* are used to achieve many goals, including learning about treatments, facilitating activities and managing social interactions. The TEDSS Framework purports that Support-oriented Domains facilitate other self-management strategies. Interventions designed to encourage their deliberate use are therefore likely to lead to positive outcomes. In summary, conceptualizing self-management strategies as both Goal-oriented and Support-oriented resolves conceptual confusion by addressing patient priorities and explaining the composition of many intervention programs. Further qualitative research would be valuable to describe the connection between Support-oriented and Goal-oriented strategies in more depth.

A useful framework should also inform patient care, system reform, and drive research endeavors. Uptake of the TEDSS Framework by members of interdisciplinary chronic disease teams has provided preliminary evidence of value for clinical practice [35]. They indicated that the TEDSS Framework enhances communication within teams by providing a common nomenclature to ensure that all areas of importance to patients are addressed. For example, the TEDSS Framework provides a deliberate and structured way to identify patients' needs for self-management support and to tailor care appropriately. This application is consistent with recent reports that confirm that self-management needs differ depending on each individual's life situation and condition, and that needs likely change over time [36–38]. At the system level, the TEDSS Framework could be used to understand the needs of specific patient populations, evaluate the nature and completeness of self-management support provided, and to determine team composition.

The TEDSS Framework also has the potential to guide future research. Lack of agreement on, and deficiencies in, the conceptualization of self-management have been identified as key issues [10,14] limiting providers' and researchers' ability to describe what is and is not a self-management intervention, and what works for whom under what conditions [14]. We suggest that the TEDSS Framework, could be used to identify and compare content of self-management interventions, thereby evaluating mechanisms for change. To support research and clinical work, a patient reported outcome measure, designed to assess and quantify the components of the TEDSS Domains is now underway.

As with all studies, results should be viewed with a critical lens. Providing examples in the interview questions may have affected participants' responses, potentially increasing the reported frequency of certain strategy domains. Strategies not mentioned as examples or integrated into daily routines may have been underreported. Process strategies are, by their nature, often integrated in every-day life tasks; this may explain why strategies in the Process Strategies Domain were less frequently reported. It may also be argued that some domains are aligned with the focus of the interview questions (e.g., staying healthy, managing everyday activities, relationships with others and emotional issues). However, the open-ended questions were strongly influenced by the widely accepted work of Corbin and Strauss [7]. Finally, the descriptive statistics were based on self-reported strategies, and likely under-estimate use. To further understand frequency of use, survey methodology might provide a useful next step.

Two strengths of the study were the sample size and the collection of data over an eleven-month period. With repeated data on a sample of 117 people, the likelihood of identifying rarely used strategies is increased beyond that in smaller scale qualitative studies, as was the capture of strategies related to infrequent or seasonal events (e.g., managing summer heat and seizure risk). Two limitations should be noted. First, data captured was accomplished by research assistants who manually recorded statements of the participants during the interviews. Recorded interviews transcribed verbatim would have been a more rigorous way of capturing data. Second, data analysis was primarily conducted by one person, the first author. However, the analysis was supported by discussions within the research team regarding meaning of the data, alternative classification, and definitions. The research team has various cultural roots (e.g., Canada, US, Sweden and Iran) and different disciplinary lenses (e.g., nursing, occupational therapy, epidemiology and sociology) helping researchers to challenge their pre-understanding and interpretations.

Participants in this study were recruited on the basis of a neurological diagnosis, giving rise to the question of applicability of the taxonomy beyond neurological conditions. Data collection with this population was motivated by the lack of research and the need to understand self-management from their perspective [39], and because people with neurological conditions live with varied constellations of symptoms and problems that impact everyday life. While this made them an ideal group to inform the strategies used to manage all aspects of every-day life, it is possible that they may use a higher number of self-management strategies than people with other conditions. Three arguments support the transferability of the TEDSS Framework to other people with complex long-term conditions. First, the four open-ended questions that focused on different aspects of self-management were not specifically related to neurological conditions or related symptoms, and have relevance to anyone living with a long-term condition. Secondly, strategies reported were described in relation to everyday life challenges applicable across many types of diagnoses. Finally, almost half of the participants had co-morbid conditions, and a quarter of the sample had a heart condition, diabetes or depression. They reported strategies related to how they managed life as a whole and not just those specific to their neurological condition. However, empirical testing of the TEDSS Framework in the form of surveys or additional qualitative work may help to confirm applicability to additional populations. Surveys would also shed light on differential use or importance of the domains by age, diagnosis, time with the condition, multi-morbidity etc.

4.2. Conclusion

In this paper we propose a comprehensive self-management framework which categorizes self-management strategies

important to patients. A Preliminary Framework, developed first through an extensive concept review was refined using data material gathered in a large sample of patients with neurological conditions over eleven months. The resulting TEDSS Framework suggests a unifying taxonomy that might resolve conceptual confusion within the field of self-management science. TEDSS has potential to guide health service delivery and research. Used as a measurement framework, may help to guide and tailor care.

4.3. Practice implications

Health-care providers typically emphasize strategies in the Disease Controlling and Health Behaviour Strategies Domains when providing self-management support [cf. 40,41,]. These are, of course important, but need to be balanced in relation to strategies in the Social Interaction, Activities, and Internal Strategies Domains, especially for people living with complex conditions and pervasive impacts on everyday life. The TEDSS Framework can assist health-care providers to understand and identify the many issues of self-management relevant to their patients at any point in time and over time. Health-care teams could use the TEDSS Framework to assess the comprehensiveness of their service, to match team members' scopes of practice to different strategy domains, or to determine the need for referrals.

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Conflicts of interests

A patient reported outcome measure, based on this framework is currently under construction.

Availability of data and material

The dataset generated and analyzed during the current study are not publicly available because participant consent included restrictions on use of the data due to patients' privacy concerns. Limited availability is possible. Researchers wishing information should contact Prof. Tanya Packer (tanya.packer@dal.ca).

Authors' contributions

TP was co-principal investigator on the LINC study, leading the study design and data collection. ÅÅ performed most of the qualitative analysis, with support from TP, GW and GK. SG performed the statistical analysis. All authors contributed in discussions to finalize the framework. ÅÅ and TP drafted the manuscript. All authors took part in revising and completing the manuscript.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2018.08.034>.

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