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Managing everyday life: Self-management strategies people use to live well with neurological conditions

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ABSTRACT

Objective: This paper uses the Taxonomy of Everyday Self-management Strategies (TEDSS) to provide insight and understanding into the complex and interdependent self-management strategies people with neurological conditions use to manage everyday life.
Methods: As part of a national Canadian study, structured telephone interviews were conducted monthly for eleven months, with 117 people living with one or more neurological conditions. Answers to five open-ended questions were analyzed using qualitative content analysis. A total of 7236 statements were analyzed.
Results: Findings are presented in two overarching patterns: 1) self-management pervades all aspects of life, and 2) self-management is a chain of decisions and behaviours. Participants emphasized management of daily activities and social relationships as important to maintaining meaning in their lives.
Conclusion: Managing everyday life with a neurological condition includes a wide range of diverse strategies that often interact and complement each other. Some people need to intentionally manage every aspect of everyday life.
Practice implications: For people living with neurological conditions, there is a need for health providers and systems to go beyond standard advice for self-management. Self-management support is best tailored to each individual, their life context and the realities of their illness trajectory.
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1. Introduction

Living with neurological conditions often includes experiencing difficult physical symptoms (i.e. fatigue and/or pain), cognitive problems (i.e. poor concentration, executive function or short-term memory loss), physical disability, and/or emotional and social consequences [1]. Adaptation and self-management are often required to control and manage the everyday life consequences of these conditions [2,3]. Evidence shows that peoples' everyday management of their condition and its consequences has a profound impact on their current and future health and well-being [4]. However, research to understand the self-management issues and needs of people living with neurological conditions has received less attention than those of people with other long-term conditions such as diabetes or heart failure.

Knowledge of the depth, extent and diversity of self-management strategies people with neurological conditions use to manage their everyday lives is critical to high quality chronic disease management services. However, research describing what people actually do to manage their neurological condition(s) on a daily basis is limited. What does exist mostly focuses on a single condition or a specific area of self-management such as pain management [5], or managing identity threats [6]. To offer relevant and successful suggestions and ideas to patients, health providers need to understand the complexity, challenges and self-management strategies needed to self-manage every day with a neurological condition.

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The recently developed Taxonomy of Everyday Self-management Strategies (TEDSS) is one of the few self-management frameworks developed from the perspective of people living with neurological conditions [7]. The TEDSS is a comprehensive framework comprised of seven self-management domains, and 26 sub-domains. The framework includes both behavioural strategies (e.g., adapting the home environment or exercising) and cognitive strategies (e.g., positive thinking) [7]. Other models/frameworks touching on self-management of neurological conditions are the *Finding Meaning and Purpose* [8], the *Search for Self-identity* based upon the experiences of people living with epilepsy [9], and *a Conceptual Model of the Path to MS Self-management* [10]. These frameworks differ from TEDSS, focusing on the antecedents influencing self-management development rather than detailing actual day-to-day self-management strategies.

The TEDSS Framework is being used to guide research into self-management support provided by health care teams [11,12], to evaluate the content of self-management interventions [13], to analyze existing measurement tools [14], and as a theoretical model to underpin a new patient reported outcome measure [15]. Although the domains and subdomains of the TEDSS have previously been defined and labeled [7], the labels do not provide sufficient depth to understand the complexity of how people manage neurological conditions in everyday life situations. In order to fill this gap and provide a rich picture of these strategies, this paper delves into the qualitative interview-data used to validate and refine the TEDSS Framework. The aim of this paper is to use the TEDSS Framework to provide a rich description of the strategies people with neurological conditions use to manage everyday life, enabling providers to understand and translate the TEDSS domains into practical advice and examples for patients.

2. Materials and methods

2.1. Design and setting

The TEDSS Framework emerged from the LINC study ('The everyday experience of living with and managing a neurological condition') [16]. The overall aim of the LINC study was to understand the everyday lives of people with neurological conditions. Over 750 people with neurological conditions, primarily recruited through the Neurological Health Charities of Canada, participated in an on-line survey. One hundred and seventeen people who completed the survey were recruited to take part in a prospective cohort study over eleven months. Data analyzed in this paper were collected as part of that cohort study.

2.2. Ethics

The LINC study received ethical approval from the Health Canada and Public Health Agency of Canada Research Ethics Board and the ethics review boards of 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. Participants gave written, informed consent before participation and because some neurological conditions can cause rapid changes in cognition, each monthly interview began with questions to ensure participants' abilities to give ongoing informed consent.

2.3. Participants and procedure

Data for this analysis were gathered from 117 LINC study participants between the ages of 18 and 65 [16] who gave permission to contact them for continued participation. All had at least one self-reported neurological condition. After giving consent, participants were contacted monthly from February to December 2012 for a 30 to 60-minute phone interview that included administration of standardized questionnaires and open-ended questions related to self-management of their condition(s). Self-management in the LINC study was defined in accordance with the work of Corbin and Strauss [17]: medical, role and emotional management of a long-term condition. Therefore, the open-ended questions asked participants about strategies used in the previous month to: 1) stay healthy, 2) manage day to day activities, 3) maintain relationships with others, and 4) manage emotions. Data were collected by trained research assistants who conducted the interviews and simultaneously entered the responses into an electronic data collection form. Notes were primarily written verbatim but sometimes they were condensed by the interviewer. Not all participants could be reached every month. Baseline demographic and descriptive data were extracted from the full LINC dataset.

2.4. Data analysis

Analysis was conducted according to the principles of qualitative content analysis [18]. Data material (7236 statements in answers to the open-ended questions) were first sorted according to the subdomains of the TEDSS Framework. Open coding was first applied, in which all statements were labeled with one or several codes. The codes and coded text were then brought together, first to form strategies that represented a type of self-management action, and secondly under higher order headings to describe patterns of how self-management was performed across the participants. The data were managed using the software program NVivo 10 (www.qsrinternational.com).

Trustworthiness was enhanced through a number of strategies. Prolonged engagement (11 months) ensured a wide variety of self-management strategies were captured, including those less commonly used or used only seasonally (for example during summer or winter). The large number of participants ensured diversity of neurological conditions and wide variation in the participants' contexts, disease severity and life situations. The analysis was performed by the first author, however, results were iteratively discussed within the team. The authors' differing disciplinary lens' and perspectives' (e.g., nursing, occupational therapy, leisure science, health-care organization) raised questions of pre-understanding and interpretation, thus helping to refine and clarify coding. To enhance authenticity of results, additional quotes are provided in a supplementary file (see Appendix 1).

Table 1
Description of participant scores using select NeuroQoL scales.

Neuro QOL	Severe, (< 30) Frequency (%)	Moderate, (30–39) Frequency (%)	Mild (40–44) Frequency (%)	Normal (> 45) Frequency (%)
Upper Extremity Function (Fine Motor, ADL)	12 (10.3)	36 (30.8)	16 (13.7)	53 (45.3)
Lower Extremity Function (Mobility)	14 (12)	20(17.1)	19 (16.2)	64 (54.7)
Applied Cognition- General Concerns	15 (12.8)	35 (29.9)	23 (19.7)	43 (36.8)
Applied Cognition-Executive Functioning	7 (6)	36 (30.8)	16 (13.7)	58 (49.6)

Table 2
Pervasive everyday self-management strategies categorized by the five TEDSS goal-oriented domains.

TEDSS Domain	TEDSS Subdomain	Self-management strategies	Example quotes
Disease Controlling Strategies . . . include reducing the risk of disease-related complications, controlling and/or limiting symptoms.	**Management and prevention of symptoms and complications**	-Detecting risks -Monitoring symptoms -Interpreting symptoms to inform decision making -Taking action to mitigate symptoms -Preventing complications -Creating an emergency plan	"*Preventing accidents or UTIs with good bladder and bowel habits*" (woman, age ~65, dystonia) (Preventing complications)
	Managing medication and treatment plan	-Following prescriptions -Judging the need for and taking on-demand medication -Self-dosing medication -Creating treatment routines	*"I try really hard to take my medication on time. I have a watch with a double alarm on it that helps out with this."* (woman, age ~50, epilepsy) (Following prescriptions & Creating treatment routines)
	Complementary medicine	-Visiting alternative health-providers -Using supplements	*"I use specific herbs to enhance my memory."* (man, age ~56, 3 neurological conditions) (Using supplements)
Healthy Behaviour Strategies . . . are strategies used pro-actively to strengthen and maintain health such as eating a healthy diet, performing physical and mental/cognitive exercise and creating good sleep habits.	**Physical exercise**	-Performing physical activity -Adapting physical activity to one's own ability -Stretching to reduce tension and stiffness -Planning and integrating physical exercise into daily routine	*"[I] walk the length of my driveway and back . . . provided . . . no ice. [I] do it every day to keep moving. Do it with my walker."* (woman, age ~50, MS) (Performing physical activity & Planning and integrating physical exercise into daily routine)
	Mental exercise	-Performing activities that challenges concentration and cognition	*"I try to do a lot of mental exercise. Whether it is reading, being involved in community activities, or doing brain games to keep my mind active."* (man, age ~60, stroke)
	Diet	-Cutting down on or avoiding certain foods -Trying to eat more of certain foods -Eating special food in order to manage symptoms or specific health problems -Using routines to maintain a healthy diet	*"Juicing carrots and apples and ginger . . . . boosts immunity."* (unknown gender, age ~60, Parkinson) (Eating special food in order to manage symptoms or specific health problems)
	Sleep hygiene	-Maintaining a regular sleeping pattern -Managing disruptions in sleep patterns -Being attentive to sleeping position -Using strategies to fall asleep	*"I watch my sleep pattern so I make sure I get enough sleep*" (woman, age ~25, epilepsy, migrane) (Maintaining a regular sleeping pattern)
Internal Strategies . . . are those used to manage negative emotions and stress, accept the situation and 'move forward'.	**Acceptance**	-Focusing on one's ability -Not trying to control the uncontrollable -Controlling one's attitude -Working on inner balance	*"Doing something I can be good at is important especially when everything else goes to shit . . . Cooking is something I am good at and makes me feel successful."* (woman, age ~35, spina bifida) (Focusing on one's ability)
	Staying positive	-Emphasizing the positive -Limiting the negative -Presenting a positive attitude -Making comparisons to gain perspective -Feeling grateful -Finding meaning in life -Living in the moment -Being there for others -Being forgiving to oneself	*"[I] have to give up control . . . [I] have a basic sense of the day and then there's always room for surprise . . . surprise rather than limitation is an outlook that helps."* (woman, age ~35, spina bifida) (Presenting a positive attitude)
	Controlling Stress and Negative Emotions	-Keeping emotions inside -Taking time for myself -Minimizing disturbing thoughts -Avoiding stressful or negative situations -Giving emotions time to settle -Using meditation and/or relaxation technics -Using everyday activities to calm down and relax -Having a treat to keep one's mind off things -Using distraction -Changing one's mindset	*"I try not to be stressed. I use my keyboard and sing a few songs to keep myself from getting down. I have my cries from time to time, but I know I can't be doing that all the time. Music is great therapy for me. It keeps me from being so stressed."* (woman, age ~55, Parkinsons) (Using everyday activities to calm down and relax)
	Allowing time for sadness and grief	-Allowing oneself to be emotional -Venting	*"A good cry helps with anything. Get it out of your system and then move on!"* (woman, age ~50, brain tumor). (Allowing oneself to be emotional)
	Seeking comfort in faith and spirituality	-Taking part in a spiritual community -Praying -Maintaining faith -Reading religious texts	*"[I'm] also fortunate to be involved in a spiritual community. [I] receive encouragement from them as well as giving a lot."* (woman, age ~65, dystonia) (Taking part in a spiritual community)
Activities Strategies . . . focus on enabling participation in everyday activities, despite disability or persisting symptoms.	**Engage in valued activities**	-Engaging in activities to feel value -Persisting	*"Despite emotional challenges. [I] maintain external activities and support church. Go out. Do things. Get involved despite how you feel."* (woman, age ~60,

Table 2 (*Continued*)

TEDSS Domain	TEDSS Subdomain	Self-management strategies	Example quotes
			stroke) (Engaging in activities to feel value)
	Pace, plan and prioritize	-Prioritizing activities that are considered important -Doing activities at the time of day when one has most capacity -Performing taxing activities for shorter time or less often -Adapting activities -Dividing chores into smaller pieces -Planning rest periods around activities -Resting during the day -Monitoring and acting on symptoms as they occur -Prioritizing and saying "no"	*"[I] pace my days. Work better in the morning . . . appointments, gym or volunteering. [I] set alarm and naps right after lunch, in order to be awake when husband comes home"* (woman, age ~50, brain inj) (Doing activities at the time of day when one has most capacity & Planning rest periods around activities)
	Organizing routines and systems	-Using systems to plan everyday life -Taking notes -Organizing everyday life according to routine -Focusing upon the task	*"[My mobile device] I cannot live without that. It's a thing that helps you remember things. It's like what used to be in the brain is now on [my mobile device]".* (woman, age ~40, epilepsy, brain inj) (Using systems to plan everyday life)
	Aids and physical adaptations	-Paying attention to clothing and dressing -Using aids to move around -Planning and checking accessibility -Arranging and managing physical surroundings -Making home adaptations -Adjusting light -Using cognitive aids -Choosing everyday life aids	*"[I] use a drawstring laundry bag to place laundry in. Then I throw it down the stairway to the laundry room, so I don't have to carry the clothing when going upstairs, I only have to use one hand to carry a drawstring bag. This frees my other hand to hold the rail."* (woman, age ~65, spina bifida, brain inj, migraine) (Choosing everyday life aids)
Social Interaction Strategies . . . are those that maintain social relationships and manage awkward or embarrassing situations.	**Disclosing condition**	-Telling people about one's condition -Being private about condition -Making deliberate decisions about whom to tell -Judging how and what to tell different people -Choosing what aspects of one's condition to disclose	*"I'm upfront, without complaining. I tell people about my situation so they won't be surprised by something inappropriate that I might do."* (man, age ~60, 3 neurological condition) (Telling people about one's condition)
	Use humor	-Finding humor in the situation	"*I`m known as quite a smartass at work. I joke about my condition, which encourages people to joke around with me rather than tip-toing around the situation."* (man, age ~35, neuromuscular)
	Stay in contact	-Initiating contact -Finding feasible ways of staying in contact	"*I prefer emailing rather than speaking to someone, because it is more likely that I will remember everything and I have more time to ensure that my message is clear.*" (man, age ~60, Huntington) (Finding feasible ways of staying in contact)
	Choosing social relationships and situations	-Limiting social contacts -Making deliberate choices about relationships -Preparing oneself for social contacts -Managing social responses	*"I choose my time with friends very carefully to monitor my energy levels. I try not to spend too much time with friends who are energy zappers."* (woman, age ~55, MS) (Making deliberate choices about relationships)

3. Results

A total of 117 people participated: 39 men, 77 women, one unknown. The majority were married (52 %) and had completed university (77 %). Only 42 % were employed; 40 % reported not working due to their neurological condition(s). People reported many neurological conditions; most prevalent were MS, brain injury, epilepsy, migraine, and Parkinson's disease. Multi-morbidity was high (41.9 %), with migraine, ischemic heart disease and depression being common (approximately 20 % each). The Neuro QOL [19] is a set of validated scales that measure domains of importance to people with neurological conditions. The proportion of participants with scores in the severe, moderate, mild and within normal ranges provide an indication of the severity of participants' conditions (see Table 1).

3.1. Self-management pervades all aspects of life

Self-management strategies were used throughout all aspects of everyday life. A total of 90 different self-management strategies were identified and linked to the five goal-oriented TEDSS domains (see Table 2). Self-management strategies differed in their level of impact and consequence. Many involved small scale everyday decisions: "*I make sure the dishwasher is full before I run it because bending over to empty it is difficult.*" (woman, age ~65, 3 neurological conditions). Participants also described large, life changing decisions. For example, one participant described the need to weigh the consequence of losing her support network against the benefits of a new job for her spouse in another city:

My husband wants to get back into his career . . . brings up issues . . . I'm linked to where I live, my psychiatrist, physician .

. . these people I have been seeing for almost 20 years, they know me very well . . . . the thought of leaving this area or the province gets stressful . . . he's aware of the possible consequence for me but he wants to be happy too . . . (woman, age ~50, MS)

3.1.1. Disease controlling strategies

Participants commonly followed a treatment regimen. Those with complicated treatment regimens or cognitive deficits (such as memory loss) developed detailed routines to remind themselves to take medication and to check the dosage taken. Participants taking on-demand medication described strategies to monitor symptoms and adjust the dosage accordingly. Alternative/complimentary medicine and non-pharmacological treatments were sometimes used to relieve physical symptoms (e.g., pain or stiffness). Other strategies were preventative, for example making changes to environments to limit falls or risk of seizures.

3.1.2. Healthy behaviour strategies

Many participants highlighted the importance of staying active, however, exercise at the level required for cardiovascular health was unrealistic for many participants. Any type of physical activity, ranging from gym exercises, to stretching stiff limbs while sitting in a wheelchair, to walking short distances, was described as exercise. To continue being active despite limited function participants adapted exercises to their ability and needs. When limited physical function prevented exercise, weight control through diet was emphasized as the only available option. Participants also described deliberate use of specific foods as "medicine", for example as a laxative or to gain energy.

Participants' awareness of and concern for cognitive decline often let to efforts to sustain or improve cognitive function. They described deliberate use of "mental exercises" that challenged concentration and memory such as mind-teasers, being active on a governance board or staying abreast of recent news. Poor sleep was associated with poor concentration and balance, and increased "brain fog" and/or fatigue, requiring creation of routines and strategies to improve sleep quality.

3.1.3. Internal strategies

A future of uncertainty and the unpredictability of everyday life demanded strategies to remain positive and control negative emotions. Internal strategies were especially important to participants who experienced radical life changes as a result of their neurological condition. Some participants managed their reality by seeking a balance between accepting their limitations while continuing to push themselves in other areas of life. They stressed strategies to focus on their abilities instead of inabilities and on aspects of their situation they could control. Participants also described using distraction, deep breathing techniques, self-talk, and/or withdrawal from stressful situations. Some described using religious or spiritual beliefs as an essential part of finding comfort.

3.1.4. Activities strategies

Participants offered rich, innovative and extensive strategies to manage everyday life activities. For example, participants living with severe fatigue described the complex planning process required to perform daily activities. They described pacing, planning, monitoring fatigue levels and altering the way activities were performed to reduce energy demands. Aids and devices were often integrated into the strategies. Similarly, participants experiencing cognitive problems, described strategies to organize their belongings, home and daily life in order to stay in control.

3.1.5. Social interaction strategies

Mobility and cognitive symptoms limited contact with family or friends for some participants. When mobility difficulties limited participants' ability to leave their homes or visit others, e-mail and social media were used to stay connected. Email and text messaging were also preferred by people with memory deficits who could look back over a conversation.

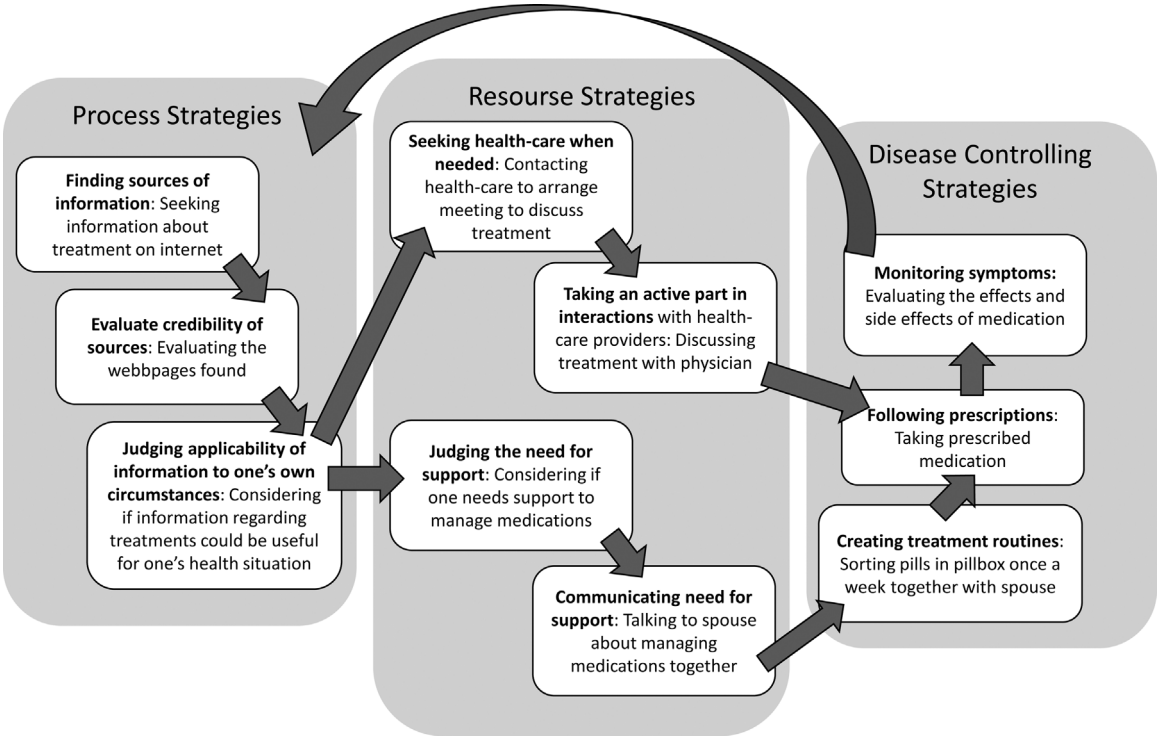

Fig. 1. Sample schematic, illustrating how chains of strategies are used.

Table 3
Self-management strategies sorted according to the support-oriented domains and subdomains of the TEDSS.

Domain	Subdomain	Self-management strategies	Example quotes
Process Strategies . . . include problem-solving, learning and integrating self-management strategies into everyday life.	**Awareness and Problem solving**	-Keeping up motivation -Figuring things out -Being open to alternative solutions -Considering alternatives and thinking through decisions -Self-monitoring health issues -Goal-setting	*"Carefully picking through everything. Thinking carefully on decisions. Think through very carefully."* (man, age ~50, MS) (Considering alternatives and thinking through decisions)
	Information seeking	-Finding sources of information -Evaluating credibility of sources -Understanding and integrating information -Combining and weighing different sources of information -Judging applicability of information to the one's own circumstances	*"There is a wealth of knowledge out there but interpreting it, finding it, making sense of it is a giant task in itself. The information wasn't there before, but it's like a maze now, and trying to find solutions on your own is frustrating and overwhelming. Even trying to find organizations that can probably help, trying to contact . . . negotiate all that is a pretty daunting task."* (man, age ~55, brain inj, epilepsy) (Understanding and integrating information & Combining and weighing different sources of information)
Resource Strategies . . . are used to seek and manage both formal and/or informal supports and resources.	**Seeking and Managing Everyday Support**	-Accepting the need for support -Judging the need for support -Communicating the need for support -Developing a network of support persons -Planning and coordinating support -Showing appreciation	*"I've started using [on-line] calendar to input when everybody is here so that I can manage it and provide a copy to my family so that they know when I have homecare."* (woman, age 35, 3 neurological conditions) (Planning and coordinating support)
	Seeking and Managing Health/Social Care Needs and Paid Support	-Seeking healthcare when needed -Arranging health check-ups -Attending appointments -Preparing for appointments, tests and procedures -Taking an active part in interactions with health-care providers -Adapting activities to care-givers availability -Considering availability of healthcare and/or support when making life decisions -Adapting or limiting support to available finances	*"[I] prepare lists of questions for doctors prior to appointments."* (woman, age ~65, 3 neurological conditions) (Preparing for appointments, tests and procedures)
	Self-advocacy	-Considering which "battles" to fight -Dealing with misunderstandings -Taking on responsibility for organizing, prompting, or advocating for healthcare	*"I got into an argument on the bus with a person who did not understand I was handicapped. Dealt with it directly by speaking with the bus driver and explained that I was handicapped and in need of a seat, the bus driver then provided me with a place to sit."* (man, age ~60, Huntington) (Dealing with misunderstandings)

Participants described struggling to avoid stigma, limit embarrassment and social exclusion. They described using strategies to limit visible symptoms/disabilities considered socially awkward (speaking difficulties, drooling, or spasms). They reported choosing to speak less, preparing before speaking, avoiding eating during social events, or being cautious of how they sat or held their limbs. Participants also made deliberate choices about relationships, often prioritizing closer relationships and limiting relationships they experienced as draining.

Decisions regarding when and with whom to disclose their condition were thoughtful and deliberate yet they differed between participants. Some participants wanted others to understand their condition and symptoms. Others worried that disclosure could be perceived as whining, or lead to misunderstandings or discrimination. Depending upon stance, participants chose to be open with their diagnosis or to hide and down-play signs of their condition. Some participants chose a compromise position, disclosing only to certain people or in certain situations. Some participants also described using humor to de-dramatize a situation, put other people at ease and/or limit others' attentions to their condition.

3.2. Self-management is a chain of decisions and behaviours

Strategies to manage everyday life with a neurological condition were not described in isolation. Instead, strategies were interconnected and interdependent, forming chains of complex decisions and behaviours. Strategies from the same or different domains, were used simultaneously or sequentially to meet a single goal. Fig. 1 provides a schematic example of how strategies can interact.

Strategies from the two TEDSS domains, Process Strategies and Resource Strategies (Table 3), were most often described as

underpinning the development of or enactment of other self-management strategies with 28 different process and resource strategies used to learn new and/or further expand other everyday self-management strategies.

3.2.1. Process strategies

Participants deliberately searched for and analyzed available information, weighed risks, benefits and consequences of potential decisions and calculated resources required for implementation. One woman described the importance of being informed; "*Getting informed about what was happening was very helpful. This helps me understand my health so that I can have reciprocal conversations with medical professionals rather than just having them talk at me.*" (age ~50, epilepsy) People were intentional in scrutinizing credibility of information sources, integrating information from different sources and/or trying to understand how information could be applied to their unique situation. However, seeking out and managing information was also described as exhausting, and sometimes overwhelming.

3.2.2. Resource strategies

Participants described how they judged their need for help, communicated these needs, and created support networks. They planned and organized support, for example by 'saving up' heavier household chores for a visiting friend or making schedules involving both paid and voluntary home-care. The need for support could bring with it the risk of "*being felt sorry for*" (woman, age ~35, dystonia). Finding ways and opportunities to add reciprocal elements to a supportive relationship was described as one way to mitigate this risk.

Seeking and managing formal support was described in relation to a wide range of different health-care providers and home care services. The main goal behind this planning and managing was to remain involved, retain control and obtain needed treatment(s). Participants described using self-advocacy strategies when they felt misunderstood or mistreated. These strategies included proactively requesting services they felt they needed or were missing (e.g., they organized appointments, demanded referrals, requested test results, changed health-care providers or sought out specialists).

4. Discussion and conclusion

4.1. Discussion

Living with a neurological condition often requires substantial and deliberate management of all parts of everyday life. In total, participants described 118 different strategies (90 everyday life strategies and 28 support strategies). Strategies were evaluated and chosen by each individual depending on their condition(s), life circumstances and previous experience. No single participant used all strategies and it is possible that other people have found and use their own unique strategies and solutions. For health providers, however, the key to providing quality self-management support is in the understanding of the depth and breadth of strategies needed and used.

While many self-management support programs for people with neurological conditions focus on prevention of complications and/or symptom control (managing seizures [20], preventing falls [21,22], preventing a second stroke [23,24]) participants in this study reported many and varied strategies beyond medical management. Participants also emphasized strategies to maintain everyday life and well-being. These findings are consistent with the well accepted descriptions of role and emotional management described originally by Corbin and Strauss and confirm that while there is a place for narrowly focused self-management interventions (e.g., preventing falls), there is also a large need for comprehensive self-management interventions that support people with neurological conditions to incorporate strategies to improve social interaction (e.g., staying in contact despite limitations and taking part in social outings despite cognitive impairments), and to manage wellbeing and emotions.

Understanding and respecting the complexities of everyday life for people with neurological conditions should inform discussions with patients regarding how they choose to manage their neurological conditions. Knowing that attending appointments requires participants to draw on multiple and intertwined strategies, such as preparing for the appointment, planning rest periods before and after the appointment, seeking help with transportation, and investigating accessibility can inform not only interventions, but also how appointments are made and scheduled. Other qualitative studies have also described use of varied self-management strategies among people with neurological conditions [2,3,10]: research in both epilepsy and MS has described the need to manage symptoms and limitations, information, as well as relationships [3,25].

An important finding of this study was the extensive self-management strategies participants used to live with and manage cognitive impairments. Attempts to enhance cognitive function through deliberate training, and to compensate for limitations using organization and tracking systems (often using digital devices) and preparation for social interactions were described. The commonality and importance to participants suggests that, at least some people with neurological conditions would benefit from support to select and develop strategies to manage cognitive impairment, a process made even more difficult by virtue of the cognitive impairment.

The data in this study has both strength and limitations. Data were drawn from a sample of participants who were self-selected, primarily by responding to recruitment efforts by the Neurological Health Charities of Canada. Participants were likely to be engaged in patient associations and LINC participants had a higher education than the general population [26]. Data collection was limited to answers to a few questions. Richer data would have been created if the interviews had included probes regarding details and intentions. The original data were collected in 2012; this detailed analysis builds on earlier work. The interviews include descriptions and use of digital devices for planning and monitoring, social media for contacting others and internet resources for information seeking. Use of eHealth and virtual care were not described. However, at the time of writing these are still not routinely used in these Canadian provinces. Few, if any major policy changes have altered the landscape for people living with neurological conditions in these provinces. A strength of this work is the length of the data collection period which spanned almost a full year with repeated interviews. The high number of participants (n = 117) also provided diverse material describing wide variation of self-management strategies. It should be noted that the same data material was used both in this study and the study that validated and refined TEDSS [7]. However, this paper did not intend to validate the TEDSS, but to explore and give a rich description of the underlying material with the intention to inform providers.

4.2. Conclusion

Calls for person-centered and individualized health care are growing louder across all areas of health care. To personalize self-management support requires a deeper understanding of how patients with neurological conditions self-manage, and the strategies they choose and use on a daily basis. This paper gives a detailed, comprehensive picture of the self-management strategies people with neurological conditions use in everyday

life. Self-management is complex, meaning that people use a number of different strategies that are often interacting and complementary. Participants especially emphasized their management of daily activities and social relationships as important to maintaining meaning in their lives. Describing strategies from a person perspective will allow providers to design more effective group and individual interventions that distinguish areas of need and tailor interventions accordingly.

4.3. Implication for practice

Several research articles describe how people with neurological conditions want more and individualized self-management support [27–30]. Patients value health-care providers who invite collaboration and involvement, instead of providing general advice [31]. Since peoples' life situations, concerns and illness experiences differ, managing a neurological condition differs by individual, by task, at different times during the day and at different points during the illness trajectory. Results of this study provide health providers and patients with broad groupings of strategies (domains and subdomains) along with concrete examples and options that can be discussed during self-management support sessions. Instead of giving advice, discussing options and supporting patients to evaluate different strategies has potential to generate strategies suitable for individual patients at each particular point in time. Inquiring about patients' context increases the potential to adapt the discussion to individual needs. People with neurological conditions interact with many different health care, community-care and social service providers, often managing a complex web of formal and informal support. Hence, it is important that all care providers have an understanding of the everyday management and challenges of living with and managing a neurological condition.

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CRediT authorship contribution statement

Åsa Audulv: Conceptualization, Methodology, Formal analysis, Writing - original draft, Writing - review & editing, Visualization, Funding acquisition. **Susan Hutchinson:** Formal analysis, Data curation, Writing - review & editing, Funding acquisition. **Grace Warner:** Validation, Writing - review & editing, Funding acquisition. **George Kephart:** Validation, Writing - review & editing, Funding acquisition. **Joan Versnel:** Methodology, Resources, Writing - review & editing, Project administration, Funding acquisition. **Tanya L Packer:** Conceptualization, Methodology, Resources, Writing - original draft, Writing - review & editing, Project administration, Funding acquisition.

Declaration of Competing Interest

This article is part of a research project regarding self-management among people with complex and/or multiple long term conditions. The TEDSS Framework is used as a way to understand self-management in several articles. The authors have no financial conflicts of interest.

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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.2020.07.025.

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