

What we know about fatigue self-management programs for people living with chronic conditions: A scoping review

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ARTICLE INFO

Keywords:

Fatigue
Chronic conditions
Self-management
Intervention
Scoping review
Patient, education

ABSTRACT

Objective: The significant impact of fatigue on the lives of patients with chronic conditions has demanded a response. One response has been the development and testing of self-management programs. Little is known about what these programs have in common or how they differ. This scoping review compared the key components of fatigue self-management programs.

Methods: Scoping review methodology was employed. Databases of CINAHL, Academic Search Premier, PsycINFO, Cochrane and Medline were searched to identify relevant sources.

Results: Included fatigue programs were compared using a three-component framework: 1) self-management strategies; 2) active patient participation; and 3) self-management support. Although all programs included some aspects of these components, the extent varied with only a few domains of these components found across all programs.

Conclusion: The three self-management components employed in this study showed potential benefits in identifying similarities and differences across fatigue programs with comparable and distinct underlying theories. This three-component framework could facilitate identification of domains associated with positive outcomes.

Practice implications: It is essential that authors of programs provide detailed descriptions to enable inter-program comparison. The three-component framework chosen for this review was capable of describing and comparing fatigue self-management programs, paving the way for more effective interventions.

1. Introduction

Fatigue is considered one of the most common and disabling symptoms experienced by people with chronic conditions including multiple sclerosis (MS) [1], Parkinson's disease (PD) [2], rheumatoid arthritis (RA) [3], and cancer [4] and result in a comparable magnitude of impact and severity across conditions [5]. Multiple frameworks and conceptualizations have been proposed to define this type of chronic, ongoing fatigue [6], yet universal consensus across conditions and disciplines remains elusive [7–9]. However, regardless of conditions, fatigue is complex and can persist for months or even years. Unlike transient tiredness, this type of fatigue does not disappear with rest and can significantly interfere with daily activities [7,10].

This type of fatigue impairs performance in household activities,

leisure, employment, and social participation and is frequently found to be associated with decreased quality of life [11–17]. It is a complex experience that can manifest as cognitive and/or physical symptoms [18]. While sleep and depression are known to be related to fatigue, the direction and nuances of this relationship are still unknown [7]. Despite its huge impact, fatigue is relatively overlooked in the research [19].

Currently, there is no cure and no definitive cause has been identified for fatigue within or across conditions, emphasising the importance of non-pharmacological interventions. Among non-pharmacological treatments, interventions focusing on self-management have shown improved health outcomes in people with chronic conditions [20,21]. Self-management programs often aim to build self-efficacy and acquire helpful behaviors and strategies that enable patients to manage their health and care [22]. These behaviours and strategies are commonly

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<https://doi.org/10.1016/j.pec.2023.107866>

Received 13 November 2022; Received in revised form 8 June 2023; Accepted 20 June 2023

Available online 22 June 2023

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referred to as medical management (e.g., monitoring and adhering to medication or diet), role management (e.g., building and maintaining daily roles) and emotional management (e.g., coping with depression due to disease [23]. The goal of self-management programs is to empower patients to collaboratively and actively determine goals for their health and care that are derived from their personal choices and life requirements [24–26]. The role of the “active, engaged patient” was first introduced in the Chronic Care Model developed by Wagner et al. [24]. Supporting individuals to learn and use their knowledge and skills to manage their condition and its impact on daily life is integral to improve disease symptoms and functional outcomes [23].

There is an extensive variety of theories underpinning and conceptualizing self-management programs in general [20,27,28]. This points to the need to find ways to compare programs and identify the active components of successful programs [22]. While many fatigue interventions are described as self-management programs, the extent to which self-management components are included, the skills presented, and the support provided vary across programs. Yet, few comparisons have been undertaken to analyze the level of similarity and diversity of these programs [29].

The impact of fatigue on the lives of people with chronic conditions and the importance of integrating self-management programs into their care is significant. The objective of this scoping review was to provide a comprehensive understanding of fatigue self-management programs and their key components. The study investigated and characterized the breadth of information relevant to fatigue self-management programs for individuals living with chronic fatigue. Additionally, the review examined the theoretical frameworks, setting and delivery formats, and logistics of these programs, as well as the definitions of self-management and fatigue within the context of these programs. This work sets the stage for future investigations to determine which program components/characteristics are associated with positive health outcomes.

2. Methods

2.1. Design

This study employed the five-step scoping review methodology suggested by Arksey and O'Malley [30]. The extent of reporting details was also guided by PRISMA Extension for Scoping Reviews (PRISMA-ScR) [31]. The protocol was registered with the Open Science Framework (<https://osf.io/z9u3s>).

2.2. Step 1: identify the research question

The main purpose of this study was to review and compare fatigue self-management programs for people living with fatigue secondary to a chronic condition. The questions this study aimed to answer were 1) What is known about the theoretical frameworks, setting and delivery formats, and logistics of fatigue self-management programs? 2) How is self-management defined? 3) How is fatigue defined? (4) What are the self-management components in the programs and how are they implemented?

2.3. Step 2: identify relevant studies

The search strategy was developed in collaboration with a university librarian with experience in scoping and systematic review methodology. CINAHL (EBSCO Publishing, Glendale, CA), Academic Search Premier, PsycINFO, Cochrane and Medline databases were searched in February 2021 to identify relevant sources. The search focused on the concepts of self-management and fatigue, with the team identifying and selecting articles reporting on patients with chronic conditions through rigorous screening procedures. Due to the absence of a feasible approach or predetermined classification system encompassing all specific chronic conditions related to fatigue, our review refrained from imposing

restrictions based on particular chronic conditions. However, the authors utilized the description of a chronic condition as defined by Bernell and Howard [32]. This definition encompasses a long duration of the disease, which requires lifelong medical intervention and has a substantial impact on daily functioning. Detailed search strategies are presented in appendix A.

2.4. Step 3: study selection and operationalizing the definitions

To consider a program self-management, the inclusion of a very broad starting definition as proposed by Van de Velde et al. [20] was used: “Self-management is the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of his chronic condition (s) in partnership with his social network and the healthcare provider (s).” (p.10).

According to this definition, which is also consistent with the Chronic Care Model, patients living with chronic conditions are considered experts in their own lives [33,34]. Therefore, programs that included any indication of decision making and taking actions by patients and with an active partnership between patients and interventionist were considered self-management programs. As stated by Bodenheimer et al., [35], self-management is the shift from traditional care to collaborative care in which patients are experts in their lives and healthcare providers are experts in the disease.

Studies were included if they were published in English, peer-reviewed journals between 2001 and 2021, and focused on fatigue as the main purpose of the intervention. Participants had to be adults aged 18 years or older with fatigue secondary to one or more chronic conditions. Programs that focused strictly on medical adherence or acquisition of information, or were composed solely of symptom monitoring, dietary changes, or exercise were excluded. Programs that were not delivered by healthcare providers (e.g., delivered only by lay leaders) or programs with an absence of an active partnership between patients and interventionists were also excluded. Finally, interventions directed at clinicians or caregivers were also excluded. Studies prior to 2001 were considered to have limited currency and were excluded since self-management science has developed primarily in the last two decades [36].

All results from searches were uploaded to the Covidence Software [37] where duplicates were removed. Before beginning the abstract/-title review, inter-rater reliability of the selection criteria was tested. First, reviewers (NA, YTC, TLP, YA) screened the same five articles using the preliminary selection criteria. After considering discrepancies and building a common understanding between reviewers, definitions were refined and the screening and data extraction manuals were amended. Next, reviewers individually screened the same 50 articles, chosen randomly, then discussed differences until consensus was reached. The process of reviewing articles in blocks of 50 was repeated three times until the kappa level of agreement reached ≥ 0.8 , which represents a high level of agreement [34].

All citations deemed relevant were procured for subsequent full-text review. Those articles that could not be obtained through institutional holdings available to the authors were requested by document delivery or from the source author or journal when available. The reviewers repeated the reliability process, first with five articles to gain preliminary consensus. They then reviewed 10 randomly selected articles. After three trials of 10 articles, the team's level of agreement reached ≥ 0.8 kappa score. In the full-text review, articles were included if there was evidence that the intervention program used in the study focused on fatigue and met the operational definition of a self-management program.

2.5. Step 4: charting the data

A systematic and purposeful approach was applied to chart the

findings. A data extraction form was created by the first author to capture the characteristics of studies based on the research questions. The form was tested by reviewers who each extracted data from the same two articles. After a round of discussion, revisions were made, and the final agreed-upon form was reproduced in the web-based software platform: Covidence (Table 1).

Data from each article were extracted by two reviewers. Once all data were extracted, two reviewers (NA and YTC) were assigned to clean, collapse, or consolidate the extracted text into a single entry.

Table 1
Extraction form with definitions and examples.

Type of Data	Data Extracted, Definitions and Operationalization of Terms
Description of studies	The following data were extracted: title, author (s), publication year, country, research objectives, study design, main diagnosis, and fatigue outcome measures (primary vs secondary).
Participants' characteristics	The following data were extracted: age, gender, disease severity, disease severity (e.g., stage 4 Parkinson's disease)
Description of programs	The following data were extracted: program name given by author; underpinning theories; program goal as defined by authors, logistics, delivery mode and setting; skill and qualifications of program providers. Logistics were operationalized as the time, duration, and number of sessions. Mode of delivery was categorized as in-person, online, telephone, or videoconference. Setting was defined as the patient location when the program was delivered and categorized as if not home, hospital, clinic, research lab. Underpinning theory was defined as any theoretical framework/theory/ supporting evidence that authors used as the bases of their fatigue intervention. This could refer to a previously developed theory such as the Social Cognitive Theory or other resources such as a literature review.
Description of fatigue	Any information authors used to describe fatigue, its types and/or measures in their programs was extracted. **" Typology" refers to the focus of the program regarding type of fatigue if described such as cognitive, physical, general fatigue or not separated. *** Measures" refers to any fatigue measure used in the study to screen or measure fatigue
Description of self-management and self-management components	Any information authors used to define/ describe "self-management" anywhere in the text was extracted. Any information authors used to describe the content and delivery of the program was extracted. This included details of any skills, practice, education, activities designed for patients to learn/practice in the program, and/ or any kind of support that providers gave to patients with fatigue (Lecture, role playing, any type of encouragement, etc.). In coding stages, following components were specifically used to categorize the extracted data: 1. Self-management strategies as defined in the Taxonomy of Everyday Self-management Strategies (TEDSS) 2. Self-management support as defined in the Practical Reviews in PRISMS taxonomy 3. Active patient participation which refers to any evidence for patient active decision making in the program (e.g., whether patients can choose the content, or activities in the session, or if there are any homework pieces)

When there was a query, the original extractors were consulted. Finalized extracted data was then exported to an excel spreadsheet to be coded.

To categorize the self-management components, two taxonomies and thematic analysis were used. The active patient participation component was categorized using thematic coding. The Taxonomy of Everyday Self-management Strategies (TEDSS) was used to analyze self-management program content. It describes five goal-oriented and two support-oriented domains. The goal-oriented domains are the "Activities", "Internal", "Social Interaction", "Disease Control", and "Healthy Behaviour" domains. The support-oriented includes the "Process" and "Resource" domains [38]. The TEDSS Framework was designed as a patient-centred framework identifying self-management strategies used to manage a chronic condition [38].

The Practical Reviews in Self-Management Support (PRISMS) Taxonomy was used to categorize self-management support. The PRISMS proposes 14 domains that can be used by healthcare providers to support self-management for people with long-term conditions [39]. Pearce et al., (2016) synthesized over 100 systematic reviews for self-management support which resulted in the PRISMS taxonomy [39]. The domains of the PRISMS taxonomy were developed specifically based on self-management support studies rather than behavioral change theories [39]. Therefore, it is more inclusive and has a broader lens when compared with other existing frameworks such as the taxonomy of Behavioral Change Techniques (BCT) developed by Michie et al., [40] which focus only on client interactions and excludes services required.

At least two reviewers independently coded/categorized the extracted data and each pair of reviewers then met to discuss and resolve conflicts. If consensus was not reached, the conflicts were discussed within the larger research team. Once consensus occurred, the data was coded again by the same reviewers, using the final agreed-upon codes, and the final codes with detailed examples were discussed with the whole research team.

2.6. Step 5: collating, summarizing, and reporting the results

To decipher the concept and components of fatigue self-management program a qualitative content analyzing approach was utilized [41]. The programs in the included studies were then mapped to the domains of three main self-management components. A combination of a descriptive numerical summary and a thematic analysis were used to summarize and report data based on research questions. Inclusion average percentages was calculated using the average numbers of included domains for each self-management components across programs.

As presented in the PRISMA flow diagram (Fig. 1), 75 full-text studies met the study criteria. There was great diversity in setting and delivery formats of the programs. Closer reviews revealed that the included articles were comprised of two distinct groups of programs: group vs one-to-one delivery. Some studies used a mixed of formats. To reduce the variability among programs and allow better comparison, only programs that fully or partially included one-to-one delivery are reported here. Future papers will report results of the other group. During data extraction at the full text level, two additional articles were excluded as detailed reading of the articles revealed that they were not consistent with the inclusion criteria.

3. Results

In total, 15 interventions, described in 14 studies, were included in this review. The study designs varied and included nine full-scale randomized controlled trial designs (RCTs), one quasi-experimental design, and two pilot and/or feasibility studies. Two protocol papers for RCTs were also included. Overall, the findings from completed effectiveness studies demonstrated some level of positive impacts on multiple outcomes, including fatigue impact [42–49], participation [42,48,50], quality of life [42,43,49], mental health -including depression, anxiety

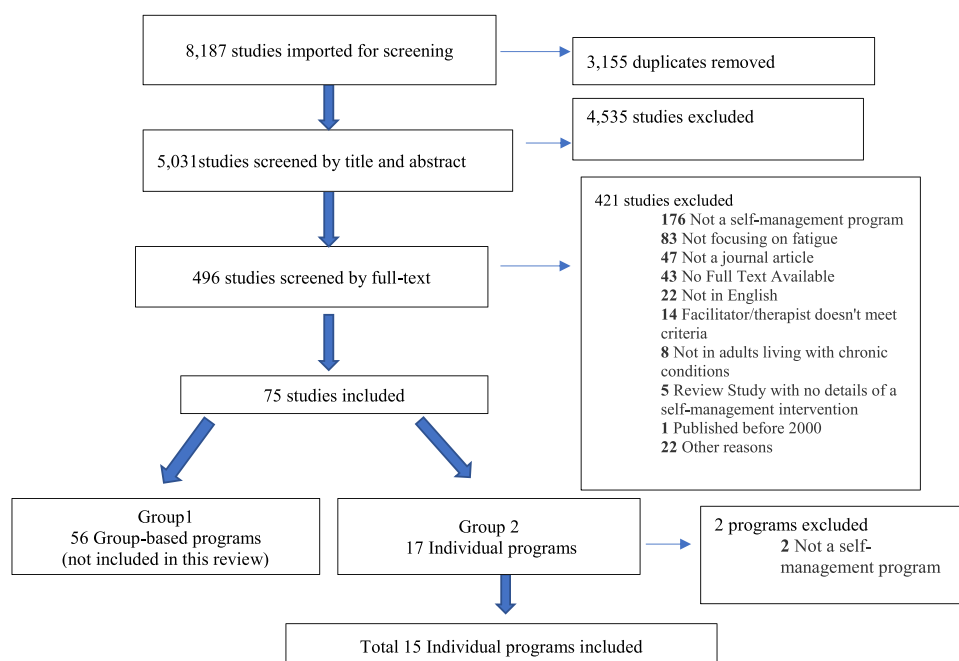


Fig. 1. PRISMA diagram of study selection for scoping review of fatigue self-management intervention.

and emotional distress [42,45,49], and self-efficacy [43].

3.1. What is known about the theoretical frameworks, setting and delivery formats, and logistics of fatigue self-management programs?

Included programs reported a range of underpinning theoretical frameworks, goals, delivery settings, and fatigue measures (Table 2). Fully in-person delivery was the most common approach ($n = 10$), followed by a mixed format of telehealth and in-person ($n = 3$) and telehealth-only ($n = 2$). Telehealth formats included videoconferencing and teleconference calls. The mixed delivery formats were a combination of phone calls, online modules, and in-person sessions.

Programs were divided into three main types according to their theoretical foundation: 1) developed based on cognitive behavioural therapy (CBT) ($n = 4$); 2) were a version of the Managing Fatigue program developed by Packer et al. (1995) ($n = 5$); and 3) "Other" programs that were based on one or a combination of theories ($n = 6$). These included the energy envelop theory, energy management education, psychobiological entropy model, and the chronic care model. There was one program, "Fatigue and Activity Management Education (FAME)", which was developed based on the results of a qualitative study [38]. Another program described a cognitive therapy treatment that focused on developing cognitive strategies to better tolerate and reduce stress and self-criticism [40].

Overall, five main program goals were identified in the data (Table 2). The most common were "To improve participation in daily life activities" ($n = 8$) and "To build and improve self-management behaviour/skills" ($n = 5$). Participants in the programs were from nine disease groups: MS ($n = 4$), cancer ($n = 2$), chronic fatigue syndrome ($n = 3$), end-stage renal disease ($n = 2$), systemic lupus erythematosus (SLE) ($n = 1$) and acquired brain injury ($n = 1$). One study included participants with multiple chronic conditions (MS, Guillain-Barré syndrome, SLE, Myasthenia gravis, and Muscular dystrophy).

Fatigue was measured for two main reasons: as a screening tool for participant inclusion and/or as an outcome measure. The only measure used to screen participants in more than one study was the Fatigue Severity Scale (FSS) ($n = 3$). Fatigue as an outcome measure was most commonly assessed with the Fatigue Severity Scale (FSS) ($n = 5$), Modified Fatigue Impact Scale (MFIS) ($n = 4$) and/or Checklist

Individual Strength (CIS20r) ($n = 3$).

3.2. How are fatigue and self-management defined?

3.2.1. Fatigue

Fatigue: Nine programs included definitions of fatigue that ranged from "a sense of exhaustion or lack of physical and/or mental energy" [54,57,51] to "a decreased capacity to fulfill daily life activities" [43,49,58]. Three key themes emerged after coding and categorizing the data: "a multifaceted/complex symptom"; "excessive tiredness not proportional to activity"; and "a chronic symptom interfering with activities". The identification and categorization of fatigue dimensions (ex. physical, mental, etc.) was not possible as it was not discussed in any of included studies.

3.2.2. Self-management

Despite using inclusion criteria that comprised components of self-management programs (e.g., evidence for goal setting, problem-solving, active decision-making, and active partnership between interventionists and patients), only four of the included studies explicitly defined self-management. The lack of data meant coding/identifying themes was not possible.

3.3. What are the self-management components in the programs and how are they implemented?

All programs reported evidence of all three self-management components: 1) self-management strategies, 2) active patient participation, and 3) self-management support. However, the combination of these components varied. Since there were multiple programs based on either CBT principles or the Packer Managing Fatigue Program, data were also grouped and compared by subgroups.

3.3.1. Self-management strategies

All programs included content in at least one TEDSS domains with a range of 1–6 out of seven possible domains across programs (Median=4). Among program types, the inclusion range varied least in CBT-based program types ($n = 4–5$) (Appendix B). CBT-based programs also had the highest mean number of TEDSS domains (64.28%) compared to two other program types (Table 5).

Table 2

Overview of characteristics of included programs.

Author (s)/Year	Name of intervention	Theoretical Foundation	Goal (s) of the program	Participant Condition (s)	Fatigue Measures (Screening and/or outcome measure)	Setting/Delivery Format
Picariello/2018 [51]	Cognitive-behavioural therapy (CBT) for renal fatigue (BReF)	CBT	Positive believes, attitudes and behaviour to cope with disease	End stage renal disease (ESRD)	Screening: Chalder Fatigue Questionnaire (CFQ) Outcome measure: Chalder Fatigue Questionnaire (CFQ)	Mix- In person and telephone calls-Consists of 3–5 sessions over 4–6 weeks. Delivered by the primary researcher, or a registered health psychologist
Jason/2007 [52]	Cognitive Behavior Therapy (CBT)	CBT"Cognitive Therapy (Approach) Chronic Care Model"	To improve participation in daily life activities Positive believes, attitudes and behaviour to cope with disease	Chronic fatigue syndrome (CFS) also known as Myalgic Encephalomyelitis or MyalgicEncephalopathy (ME)	Screening: None Outcome measure: Fatigue Severity Scale (FSS).	In person-Consists of 13 sessions (45 min) every 2 weeks Delivered by registered nurses
Friedberg/2013 [46]	Fatigue Self-Management (FSM)	CBTClinical model of CFS	To build and improve self-management behaviour/skills	Medically unexplained chronic fatigue (UCF) and chronic fatigue syndrome (CFS)	Screening: None Outcome measure: Fatigue Severity Scale (FSS).	In-person-Consists of two Session over three weeks Delivered by registered nurses
Ehde/2015 [53]	Telephone-delivered self-management intervention (T-SM)	CBT	To build and improve self-management behaviour/skills	MS	Screening: Modified Fatigue Impact Scale (MFIS) Outcome measure: Modified Fatigue Impact Scale (MFIS)	Telehealth-Telephone calls Consists of 8 weekly sessions (45- to 60-minute) plus15-minute follow-up calls at 4 and 8 weeks post-treatment Delivered by social workers and psychologists
Blikman/2017 [54]	Individual energy conservation management (IECM)	Managing Fatigue program	To build and improve Self-Management Behaviour/ Skills To Improve Self-Efficacy To Improve energy Conservation Skills To reduce the severity of fatigue	MS	Screening: Checklist Individual Strength (CIS20r) subscale fatigue Outcome measure: Checklist Individual Strength (CIS20r) subscale fatigue and Fatigue Severity Scale (FSS)	In-person- consists of 12 sessions (45 min) over 4 months. Delivered by OTs.
VanHeest/2017 [43]	one-to-one format of the 6-wk Managing Fatigue course developed by Fox (2010)	Managing Fatigue program	To improve participation in daily life activities	MS, Fibromyalgia, Cancer PoststrokeGuillain-Barr'e syndrome Systemic Lupus Erythematosus (SLE) Myastheniagravis, Muscular dystrophy.	Screening: Fatigue Severity Scale (FSS), Outcome measure: Functional Assessment of Chronic Illness Therapy–Fatigue Scale (FACIT FS)	In-person-consisted of 5 modules over four to six sessions of 1–2 hr. Delivered by OTs and/or OT students
Kos/2016 [50]	Individual self-management occupational therapy intervention program (SMOoTh)	Managing Fatigue programEnergy Envelope Theory Behavioural Change Theories	To improve participation in daily life activities To Improve Self-Efficacy	MS	Screening: Visual Analog Scale developed by Kos et al. [55]. Outcome measure: The Modified Fatigue Impact Scale (MFIS) The Checklist Individual Strength (CIS-20R)	In-person-consisted of three sessions of 60–90 min for three consecutive weeks. Delivered by OTs.
Plow/2020 [56]	Managing Fatigue Program	Managing Fatigue programSocial Cognitive Theory	To build and improve self-management behaviour/skills To improve self-efficacy To Improve energy	MS	Screening: Fatigue Severity Scale (FSS), Outcome measure: Fatigue Impact Scale (FIS)	In-person-the number and length of sessions is tailored to participants' needs and preferences. over the 6 weeks Delivered by OTs.

(continued on next page)

Table 2 (continued)

Author (s)/Year	Name of intervention	Theoretical Foundation	Goal (s) of the program	Participant Condition (s)	Fatigue Measures (Screening and/or outcome measure)	Setting/Delivery Format
Raina/ 2016 [44]	Maximizing Energy (MAX) intervention	Managing Fatigue program Behavior Activation Theory	conservation skills To improve participation in daily life activities	TBI / ABI	Screening: Fatigue Severity Scale (FSS), Outcome measure: Modified Fatigue Impact Scale (MFIS), Patient-Reported Outcomes Measurement Information System Fatigue Scale (PROMIS), Screening: None Outcome measure: Four visual analogue scales (VASs): subjective quantification of fatigue, subjective distress because of fatigue, and subjective assessment of effects of fatigue on chores/work and on pastimes/hobbies	Telehealth-Internet using Web-cameratechnology -consisted of two sessions of 30-minutes per week over an 8-weekperiod. Delivered by OTs.
Ream/ 2006 [45]	Beating Fatigue intervention	Winningham's Psychobiological Entropy model	To improve participation in daily life activities To improve energy conservation skills	Systemic Lupus Erythematosus (SLE)	Screening: None Outcome measure: The Fatigue Severity Scale (FSS)	In-person- The intervention program was provided over the first three treatment cycles. Diary entries were reviewed by support nurses who visited patients at home once during each treatment cycle. - Delivered by registered nurses
ORiordan/ 2017 [42]	Fatigue and Activity Management Education (FAME)	Based on a qualitative study for people with SLR	To improve participation in daily life activities	Systemic Lupus Erythematosus (SLE)	Screening: None Outcome measure: The Fatigue Severity Scale (FSS)	In-person-Mix of groups and one-to-one delivery- Consists of 6 weekly sessions (2.5 h). OTs with multidisciplinary input (PT and Dietitian) will deliver the program.
Kos/2015 [48]	Activity Pacing Self-management (APSM)	Energy Envelope Theory	No report	CFS	Screening: None Outcome measure: the Checklist Individual Strength (CIS) Screening: None Outcome measure: Four 11-point numeric rating scales developed from the literature	In-person-Three sessions over three weeks (60–90 min) OTs and/or PTs delivered the program
Yates/ 2005 [47]	The psychoeducational intervention for Managing Fatigue in Women Receiving Adjuvant Chemotherapy for Early-Stage Breast Cancer	Green's PRECEDE (Predisposing, Reinforcing, and Enabling Causes in Educational Diagnosis and Evaluation) model of health behavior.	To build and improve self-management behaviour/skills	Early-Stage Breast Cancer: (Stage I or II)	Screening: None Outcome measure: Four 11-point numeric rating scales developed from the literature	Mix- In person and telephone calls-Consists of 2 sessions conducted by phone (10 min) and 3 in-person sessions-Two additional booster sessions were employed. Delivered by registered nurses
Farragher/ 2019 [57]	the 'Personal Energy Planning (PEP)' programme	Energy Management Education (EME) Clinical model of Cognitive Orientation to Occupational Performance (CO-OP)	To improve participation in daily life activities	End stage renal disease (ESRD)	Screening: Fatigue Severity Scale (FSS) Outcome measure: Fatigue Severity Scale (FSS), Fatigue Management Questionnaire and Modified Fatigue Impact Scale (MFIS)	Mix: two educational computer modules (20–30 min each) and in-person or via telephone sessions (based on patient preference). delivered over 7–9 weekly sessions dependent on individual patient needs and rates of progress. Sessions are ~20–30 min in duration each and administered either in person or via telephone (based on patient preference). The programme is administered by a trained study clinician (occupational therapist or nurse)
Jason/ 2007 [52]	Cognitive Therapy Treatment (COG)	Cognitive Therapy Approach Chronic Care Model	To improve participation in daily life activities	Chronic fatigue syndrome (CFS), also known as Myalgic Encephalomyelitis/	Screening: None Outcome measure: Fatigue Severity Scale (FSS).	In person-Consists of 13 sessions (45 min) every 2 weeks

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Table 2 (continued)

Author (s)/Year	Name of intervention	Theoretical Foundation	Goal (s) of the program	Participant Condition (s)	Fatigue Measures (Screening and/or outcome measure)	Setting/Delivery Format
			Positive beliefs, attitudes and behaviour to cope with disease	MyalgicEncephalopathy (ME)		Delivered by registered nurses

In terms of frequency of cited domains, "Activities" domain (n = 13/15) was the most frequently reported, while "Resource" domain (n = 1/15) was the least reported across all programs. Analysing program types showed that the "Resource" domain was least reported in both CBT-based (n = 0) and *Packer Managing Fatigue*-based programs (n = 1). Domains of "Activities", "Internal", and "Healthy behaviour" were included in all CBT-based programs. All *Packer Managing Fatigue*-based programs included content in domains of "Process" and "Activities" whereas the "Healthy behaviours" domain was rarely incorporated into these programs (n = 1) (Table 4).

3.3.2. Active patient participation

Six main themes emerged for active patient participation (Table 3). The frequency of included themes for active patient participation ranged from 1 to 6 (median=4) across programs (Appendix B). "Homework" was the most common cited domain (11/15), followed by "Goal setting" (10/15). "Problem-solving" (7/15) was the least commonly reported domain.

Comparison among program types found that "Homework" was most commonly reported in 4 of the *Packer Managing Fatigue*-based programs and all CBT-based programs. However, these two program types differently addressed the domain of "Tracking, monitoring, self-evaluation". While this domain was present in all CBT programs, it was only reported in one *Managing Fatigue*-based program. "Goal setting", and "Practice activities, experiments, and discovery" were also frequently reported in the *Packer Managing Fatigue*-based programs (4/5 intervention). In CBT-based programs, domains of "Active discussion" and "Problem-solving" were rarely cited. Overall, the mean inclusion of active patient participation was mostly seen in the *Managing Fatigue*-based program type (63.3%) (Table 5).

3.3.3. Self-management support

All programs included a range between 3 and 8 of the total 14 PRISMS domains (median=6). This inclusion range was 5–8 for *Packer Managing Fatigue*-based programs and 4–6 across CBT-based programs (Appendix B).

Table 3

Emergent themes and definitions for active patient participation in fatigue management programs.

Themes	Definition/Examples
Goal setting	Process of collaborative prioritizing, identifying needs and preferences, and setting goals and planning a required course of actions.
Problem-solving	The cognitive process of identifying problems and analyzing the factors, facilitators, and barriers to solve or overcome them.
Practice activities, experiment, discovery	Generating strategies, trial and error of strategies, rehearsals, and practice of an active behavior-this usually happens in sessions and is one step before agreement for final practice activities.
Tracking, monitoring, self-evaluating	Using tracking sheets, logs, and diaries to actively document and/or record behaviors and/or feelings.
Homework	Agreed upon home-based activities/tasks/assignments to practice at home and/or between sessions.
Active discussion	Active communication between patients and therapists.

Two PRISMS domains, "Provision of/agreement on specific clinical action plans and/or rescue medication" and "Regular clinical review", were included in all programs. "Information about the condition and/or its management" (n = 13) was the next most prominent, followed by "Training/rehearsal for practical self-management activities" (n = 11). Conversely, "Training/rehearsal to communicate with healthcare providers", "Provision of equipment", and "Lifestyle advice and support" were not included in any of programs (Table 4).

Although "Training/rehearsal for everyday activities" was implemented in four programs based on the *Packer Managing Fatigue* program, CBT-based programs were not employed by this domain at all. Furthermore, although "Training/rehearsal for psychological strategies" was found in all CBT-based programs, this domain was present only in one *Packer Managing Fatigue*-based program. Among program types, the mean number of included self-management support domains was the highest in the *Packer Managing Fatigue*-based programs (42.8%) compared to other program types (Table 5).

4. Discussion and conclusion

4.1. Discussion

In total, 15 one-to-one fatigue self-management programs were examined in this scoping review. There is a lack of an agreed-upon model to describe and compare multicomponent self-management programs. This review is the first to delineate three important self-management components, namely, self-management strategies, self-management support and active patient participation. Two established frameworks, the TEDSS and the PRISMS were used to describe and quantify the first two components. Thematic analysis was used to define and then quantify the third. The analysis led to three main findings: 1) the three self-management components selected for this review appear to have the capacity to compare programs within and across program types; 2) this framework was also helpful in identifying the most and least frequently applied domains of self-management among programs; and 3) present programs lack description for self-management and its components.

4.1.1. The suggested three-component framework has the potential to compare self-management programs

All fatigue programs in this review included three components either fully or partially. However, the range and focus of included components and their domains varied. The application of the three-component framework in this study allowed us to compare program types with different underpinning bases in terms of their consistency and extent of incorporating self-management components and their domains.

The findings showed that each program type had a different constellation of components. TEDSS domains were consistently included or not-included in *Packer Managing Fatigue*-based programs. This is expected in programs based on a standardized protocol. The one exception was "Internal" domain strategies, which were reported in only 40% of *Packer Managing Fatigue*-based programs. In CBT-based programs, which have a consistent theory base but not the same standardized protocol, "Healthy behaviours" strategies were consistently reported in all CBT-based programs and strategies in the "Disease Controlling" domain

Table 4

Frequency of cited domains of self-management components by total and by program types.

Self-management component	Domains	Managing Fatigue-based programs (/5)	CBT-based (/4)	Others (/6)	Total (/15)
TEDSS	Activities	5	4	4	13
	Internal strategies	2	4	3	9
	Social interaction strategies	4	1	2	7
	Healthy behaviours	1	4	3	8
	Disease controlling strategies	3	2	5	10
	Process strategies	5	3	4	12
	Resource strategies	1	0	0	1
Active patient participation	Goalsetting	4	2	4	10
	Problem-solving	3	1	4	7
	Practice activities, experiment, discovery	4	2	3	9
	Homework	4	4	3	11
	Tracking, monitoring, self-evaluation	1	4	4	9
	Active discussion	3	1	5	9
	Information about condition and/or its management	5	3	5	13
PRISMS	Information about available resources	0	0	1	1
	Provision of/agreement on specific clinical action plans and/or rescue medication	5	4	6	15
	Regular clinical review	5	4	6	15
	Monitoring of condition with feedback	4	1	3	8
	Practical support with adherence (medication or behavioral)	1	2	1	4
	Provision of equipment	0	0	0	0
	Provision of easy access to advice or support when needed	0	0	1	1
	Training/rehearsal to communicate with healthcare professionals [and others]	0	0	0	0
	Training/rehearsal for everyday activities	4	0	2	6
	Training/rehearsal for practical self-management activities	4	4	3	11
	Training/rehearsal for psychological strategies	1	4	1	6
	Social support	1	0	1	2
	Lifestyle advice and support	0	0	0	0

were reported in half the programs.

As noted, all CBT-based programs reported content from the “Healthy behaviour” domain but only one of the *Packer Managing Fatigue*-based programs did so. While “Social interaction” domain strategies were commonly reported in *Packer Managing Fatigue*-based programs, it was only present in one CBT-based program. This likely reflects the standardized protocol of the *Managing Fatigue* program which includes communication with others about fatigue [59]. Interestingly, *Packer Managing Fatigue*-based programs were delivered by occupational therapists while CBT-based programs were delivered by psychologists. Professional differences in approaches and theories may partially explain differences in content.

In terms of the inclusion of the active patient participation between program types, it is noted that even though the “Tracking, monitoring, self-evaluation” domain was found in only 20% of *Packer Managing Fatigue*-based programs, it was implemented in all CBT-based programs. Conversely, “Active discussion” and “Problem-solving” were less present in CBT group (25%) compared to *Packer Managing Fatigue*-based programs (60%).

Finally, self-management support for “Training/rehearsal for everyday activities” was implemented in 80% of *Packer Managing Fatigue*-based programs while it was not found in any of CBT-based programs. On the contrary, this comparison demonstrated that although “Training/rehearsal for psychological strategies” was cited in all CBT-based programs (100%), it was only present in 20% of *Packer Managing Fatigue*-based programs. This could be expected because the original *Managing Fatigue* program is primarily aimed to increase patient participation in everyday activities [59,60], while the CBT approach is focused on understanding the relationship between thoughts, feelings and behaviours and intends to enable behaviour change by understanding internal thoughts and beliefs [61].

Overall, despite the lack of explicit identification of self-management components and their domains supplied by authors, and the small number of programs per group type, we found that the three self-management components selected for this review appear to have capacity to compare and contrast program types. However, we recommend

additional research to confirm these findings.

4.1.2. Delineating inclusion of self-management strategies, supports, and active patient participation is possible

The average number of included domains of active patient participation was the highest across all programs compared to self-management support and strategies. In terms of self-management support, although, there were domains of that were applied in all programs, the mean number of self-management support domains found in programs was the least among all three components. For example, among the PRISMS domains, the regular clinical process activities such as “Provision of/agreement” and “Regular clinical review” were found in all programs, while there were ten domains that were implemented only in less than half of the programs.

Among self-management strategies listed in TEDSS, the three domains of “Activities”, “Process” and “Disease controlling” were the three most commonly reported content across fatigue programs. This is mostly consistent with results of a recent systematic review which found that “Process”, “Healthy behaviours”, and “Disease controlling” were the most frequent domains reported in all self-management programs for patients with long-term conditions [62]. However, strategies in the “Activities” domain were found to be the most frequent (13/15) in this study. The significant impact that fatigue has on everyday activities [11–13], is a likely explanation why “Activities” predominates in fatigue programs.

Among the PRISMS domains, “Provision of/agreement on specific clinical action plans and/or rescue medication” and “Regular clinical review” were reported in all programs, consistent with the findings of a recent scoping review of e-health self-management support interventions in musculoskeletal disorders [63]. However, contrary to the findings of this scoping review, which indicated that “Lifestyle guidance and support” was the most prevalent component of the PRISMS taxonomy (n = 59; 94%) [50], which suggested that “Lifestyle advice and support” was the most common component of the PRISMS taxonomy (n = 59; 94%), the current study’s findings revealed that this domain was absent in all programs. This could be due to either authors’ lack of

Table 5
Average inclusion of self-management components across programs reported by program types.

Programs	Managing Fatigue-based programs						CBT-based					Others						
	Blikman 2017 [54]	Kos 2016 [50]	Plow2020 [56]	Van Heest [43]	Raina 2016 [44]	Total Average of Domains Included (n, %)	Picariello 2018 [51]	Friedberg 2013[46]	Ehde 2015 [53]	Jason 2007 [52]	Total Average (%)	O'Riordan 2017[42]	Ream 2016 [45]	Kos 2015 [48]	Farragher 2019[57]	Yates 2005 [47]	Jason 2007 [52]	Total Average (%)
Inclusions of TEDSS domains (/7)	5	3	6	4	3	4.2	5	4	5	4	4.5	4	4	3	1	4	4	3.33
Inclusions of TEDSS domains (%)*	71.4	42.8	85.7	57.1	42.8	57.85	71.4	57.1	71.4	57.1	64.28	42.8	57.1	42.8	14.2	57.1	57.1	47.61
Inclusions of active patient participation domains (/6)	5	6	3	1	4	3.8	2	2	5	5	3.5	2	3	3	5	5	4	3.66
Inclusions of active patient participation domains (%)	83.3	100	50	16.6	66.6	63.3	33.3	33.3	83.3	83.3	58.3	33.3	50	50	83.3	83.3	66.6	61.1
Inclusions of prisms domains (/14)	6	8	6	5	5	6	4	6	6	6	5.5	3	5	5	4	7	7	5.16
Inclusions of prisms domains (%)	42.8	57.1	42.8	35.7	35.7	42.8	28.5	42.8	42.8	42.8	39.2	21.4	35.7	35.7	28.5	50	50	36.9

* The average inclusion percentage of each component in programs was calculated using the average of the number of included domains for each component divided by the total number of available domains in each component multiplied by 100.

reporting content in programs or the complexity of involved health conditions in the current study. The majority of diseases in our review were neuromuscular conditions, whereas Kelly et al. [63], solely examined musculoskeletal conditions in their scoping review.

According to our findings, two PRISMS domains, "Social support" and "Information about resources", as well as content in the TEDSS's "Resource" domain were missing or hardly seen in programs. This contradicts the results of a recent systematic review, which found these domains to be frequently identified in effective interventions for chronic conditions [64].

Finally, as expected and in accordance with the results of prior systematic reviews, active patient participation was a key component of fatigue programs. We found that all but one program implemented two or more of the six domains of active patient participation. The most prevalent were "Homework" and "Goal setting." However, we were unable to compare our results to previous evidence since this review proposed these domains for the first time. Further research needs to be done to test the different domains of active patient participation in self-management programs.

Although it is unclear how many components/domains are needed or associated with positive patient outcomes, it has been suggested that inclusion of a greater number of components may benefit people to self-manage their long-term conditions [65]. Comparing all programs, this study found that the inclusion of proposed components and their domains was most frequently reported for the active patient participation component (60.46%) followed by TEDSS strategies (56.46%). PRISMS domains were the least reported (39.64%) which was slightly less than the findings of a recently published systematic review (43%) [66].

In this scoping review, the primary objective was to identify the self-management components within fatigue self-management programs. As a result, the inclusion criteria encompassed various study designs that described fatigue self-management interventions. The findings of this research create a way to compare and contrast self-management fatigue interventions and examine mechanisms for change, which is a prerequisite to the comparison of different programs and their outcome. Future research using meta-analysis designs is warranted to further investigate the relationship between the highlighted self-management components and their impact on changes in outcomes.

4.1.3. Existing programs lack a description of self-management programs and their components

Determining the active ingredient(s) in self-management programs is a well-known gap in self-management research. A contributing factor is the lack of consistent reporting of program components and the extent to which they have been implemented [64]. Related to this, as found in another review by Packer et al., (2018), there is diversity in the ways self-management is conceptualized, and the underlying theories used to form self-management programs. These differences lead to heterogeneity in describing and comparing self-management programs. This also contributes to the inability of systematic reviews and metanalysis to compare and identify specific strategies and active ingredients of self-management programs that may result in better health outcomes [22]. As a result, it is becoming increasingly important to synthesize and compare evidence on complex interventions such as self-management programs [67]. To reduce the risk of incorrect conclusions and enable more accurate comparison among programs, comprehensive descriptions of programs and their active components is essential [28].

The intent of this review was to gain an in-depth understanding of a specific type of self-management program. Therefore, this specific focus led to the consequent small sample size as a limitation, suggesting that future research should evaluate the value of the three components more across different self-management interventions. This three-component framework may be a preliminary step toward developing a more systematic reporting framework for self-management programs or a more consistent definition and implementation of self-management programs.

4.2. Conclusion

Overall, there was found to be a lack of information reported by authors about the included components of existing fatigue self-management programs which makes it difficult to compare them. Moreover, there is no commonly agreed upon framework to describe, report, or compare self-management programs. To overcome the challenges, this review selected three common self-management components to compare fatigue programs. It was found that the three-component framework is able to compare fatigue self-management programs developed based on similar or different underpinning theories and has the potential to be used as a tool for comparing programs in a more consistent and reproducible way. Consistent reporting and measurement of these three components holds potential to help understand the illusive mechanisms for change in self-management interventions.

4.3. Practical Implications

The most commonly included component and its domains found in fatigue self-management programs is active patient participation. All programs included 60.46% of the domains of this component. Among all programs, the most frequently reported domains of the three self-management components chosen for this study were strategies in the "Activities" domain in the self-management strategies component and three domains of the self-management support component: "Provision of/agreement", "Regular clinical review", and "Information about condition and/or its management". Although evidence is yet growing to link all these to positive outcomes, frequency of use does provide insight into best practice fatigue self-management programs.

When selecting or designing self-management programs for implementation, therapists should look for and assess three areas: the self-management strategies, active patient participation and self-management support. This information, together with clinical judgement is needed to select the best programs for their client groups.

The TEDSS and the PRISMS are useful tools for therapists to assess, not just structured programs, but their own practice. For active patient participation, more evidence is required to assess the domains suggested in this review.

CRedit authorship contribution statement

Neda Alizadeh: Conceptualization; Methodology; Data curation; Analysis; Investigation; Project administration; Validation; Visualization; Roles/Writing - original draft; Writing - review & editing. **Tanya Packer:** Conceptualization; Methodology; Supervision; Resources; Validation; Writing - review & editing. **Yu-Ting Chen:** Conceptualization; Writing - review & editing. **Yaser Alnasery:** Conceptualization; Writing - review & editing.

Declaration of Competing Interest

TLP is the developer and author of the original program namely "Managing Fatigue: a Six-week Course for Energy Conservation". Other authors declare no real or potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Acknowledgements

We would like to express our gratitude to Shelley McKibbin, our exceptional Information Services Librarian, for her substantial assistance and consultation. We would also want to extend our appreciation to Sabrena Jaswal for proofreading and editing this work.

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sector. NA was awarded several scholarships to support their PhD studies. These scholarships include the Abdulmajid Bader scholarship, the Nova Scotia

Graduate Scholarship Program (NSGS), a Funding Package for PhD studies from the School of Occupational Therapy at Dalhousie University, the Scotia Scholars Award from the George Turnbull Student Research Award, and the LSVT Global Student Grants (LSVT-S).

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2023.107866.

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