



SELF-MANAGEMENT PROGRAMS OF FATIGUE SYNDROME IN CHILDREN AND ADOLESCENTS LIVING WITH CHRONIC CONDITIONS: A SYSTEMATIC REVIEW

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ABSTRACT

Chronic fatigue syndrome is a debilitating illness of unknown cause that affects physical, psychological, emotional, and social aspects of life, manifesting in poor physical stamina, reduced social interaction, and depression. Self-management programs involve the deliberate practice of specific tasks, activities, and behaviors aimed at managing the medical, psychosocial, and daily life impacts of chronic illness. These programs include strategies such as symptom monitoring, adherence to treatment plans, and maintaining healthy practices. Aim to evaluate the effectiveness of self-management programs in reducing fatigue so as to improve quality of life. In a study utilizing the PICO search strategy related to self-management activities for reducing fatigue, 396 articles were found in the Cochrane, PubMed, Medline, Taylor & Francis, ProQuest, ScienceDirect, and Sage databases between 2020-2024; four articles meeting the inclusion criteria were analyzed in depth using quality assessment tools such as PRISMA. The study protocol was registered in the Prospective Register of Systematic Reviews (PROSPERO) with the following registration number: CRD42024622785. Based on the literature search was conducted without restrictions on the start year, including publications up to 2024.", 415 articles were identified, 19 duplicate articles were selected, until 5 eligible articles were obtained based on the selection of design, participant, intervention, and outcome This review concludes that self-management, such as lifestyle advice, web-based programs, and physical activity, is effective in reducing fatigue, and to achieve better quality of life and fatigue reduction outcomes, tailored to patient needs and conditions needed to be strengthened.

Keywords: adolescents; children; chronic conditions; fatigue syndrome; self-management

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INTRODUCTION

Chronic Fatigue Syndrome (CFS) in children and adolescents with chronic illness is a complex and difficult-to-diagnose condition. Children and adolescents with CFS often present with symptoms of severe and prolonged fatigue that does not improve with rest and may worsen with physical or mental activity. This condition can have a significant impact on children's quality of life, including sleep disturbances, psychological distress, and reduced health-related quality of life (Sommer et al., 2023). The prevalence of CFS varies with some studies suggesting that between 0.5% and 3.28% of children and adolescents may be affected by the condition (Leveret et al., 2022). Children and adolescents with CFS also often experience comorbidities such as depression and anxiety, which are higher compared to age-matched controls (Clery et al., 2022). This suggests that CFS affects not only physical but also mental health. Research conducted by Sommer et al (2023) showed that severe fatigue is more common in children and adolescents with chronic pain with a prevalence of 11.4% compared to 1.3% in children and adolescents without chronic pain. This fatigue can persist for several months and often worsens, indicating the need for early identification and treatment to prevent negative long-term consequences.

A surveillance study conducted in the United Kingdom (UK) and the Republic of Ireland also found 33 confirmed cases of severe chronic fatigue syndrome in children and adolescents aged between 5 and 16 years. The prevalence rate was 3.18 cases per million children and adolescents (95% CI 2.19 to 4.47). However, epidemiological prevalence estimates vary depending on the diagnostic standards and methods used (Brown et al., 2024). Chronic fatigue syndrome can have a significant impact on development and functioning in children and adolescents including: development, education (such as decreased school attendance), and career plans (Royston et al., 2024). Fatigue causes physical, psychological, emotional, and social impacts, such as poor physical stamina, reduced social skills, and depression (Bench et al., 2021). Common problems include loss of identity and self-esteem as patients become more dependent on others and are no longer able to perform their previous roles (Brown et al., 2024).

Patients also reported sleep disturbances in 14% and cognitive fatigue in 31%, which presents as difficulties in concentration, thinking, and remembering. A previous systematic review identified no existing rehabilitation interventions specifically for the child and adolescent population.(Bench et al., 2021; Mochon et al., 2023). Guo et al.'s (2024) study showed that disease-related treatments and their side effects can cause long-term negative impacts. Of the 255 respondents, 67.1% reported experiencing side effects of treatment, namely: 52.7% had mild anxiety scores and 43.2% showed mild depression, and 33% reported impacts on studies. In addition, lack of knowledge about disease-related processes and coping mechanisms can lead to inadequate support during the treatment and care process.(Cocorpus et al., 2023). Parents of children and adolescents with chronic conditions may demonstrate this by discussing the condition in depth, but they may overlook the child and adolescent's emotional responses, as well as the overall impact of the illness on their child's life (Costa-Cordella & Luyten, 2024).

Globally, the idea of helping patients with chronic physical conditions acquire self-management skills has been considered an important health approach to address the burden of non-communicable diseases and the medical costs associated with living with chronic conditions (Gauci et al., 2022). According Rimmer et al. (2024)to adjusting to the “new normal”, dealing with health issues, psychological health, and rebuilding routines and social roles, involvement in self-management is required. Others tend to need support so that they can manage themselves effectively. *The Taxonomy of Self-Management Support Review Practices* divides the different types of self-management support, including psychological strategy training or practice and condition monitoring with feedback, as well as protocols regarding the number and length of sessions. (Rimmer et al., 2024). *Self-management programs* are the deliberate implementation of specific tasks, activities, and behaviors that have been learned to manage the medical, psychosocial, and life impacts of chronic illness. *Self-management program strategies* include monitoring symptoms, following treatment plans, and ensuring health-maintenance practices. *Self-management programs* are essential as a starting point for self-care and their illness (Poku et al., 2023).

Self-management of chronic conditions is defined as active involvement in managing one's own illness and not simply receiving information from health educators who are considered experts in the field.(Palmeirim et al., 2024). When clients are involved in the decision-making process about their chronic conditions, they have more confidence in their medical care plans. This increases clients' knowledge and confidence and results in better outcomes. Therefore, effective *self-management* , assisted by health professionals and carried out by the individual themselves, is essential. This literature review was conducted to determine how effective self-management is in reducing fatigue levels in children or adolescents with chronic conditions.

METHOD

Systematic review based on PRISMA (*Preferred Reporting Items for Systematic Reviews and Meta-Analyses*) statement (Page et al., 2021) to assess the effectiveness of *self-management programs* on reducing *fatigue* in children and adolescents with chronic disease conditions. This study protocol has been registered in PROSPERO (*Prospective Register of Systematic Reviews*) with registration number CRD42024622785 before the data search was conducted.

Literature Search

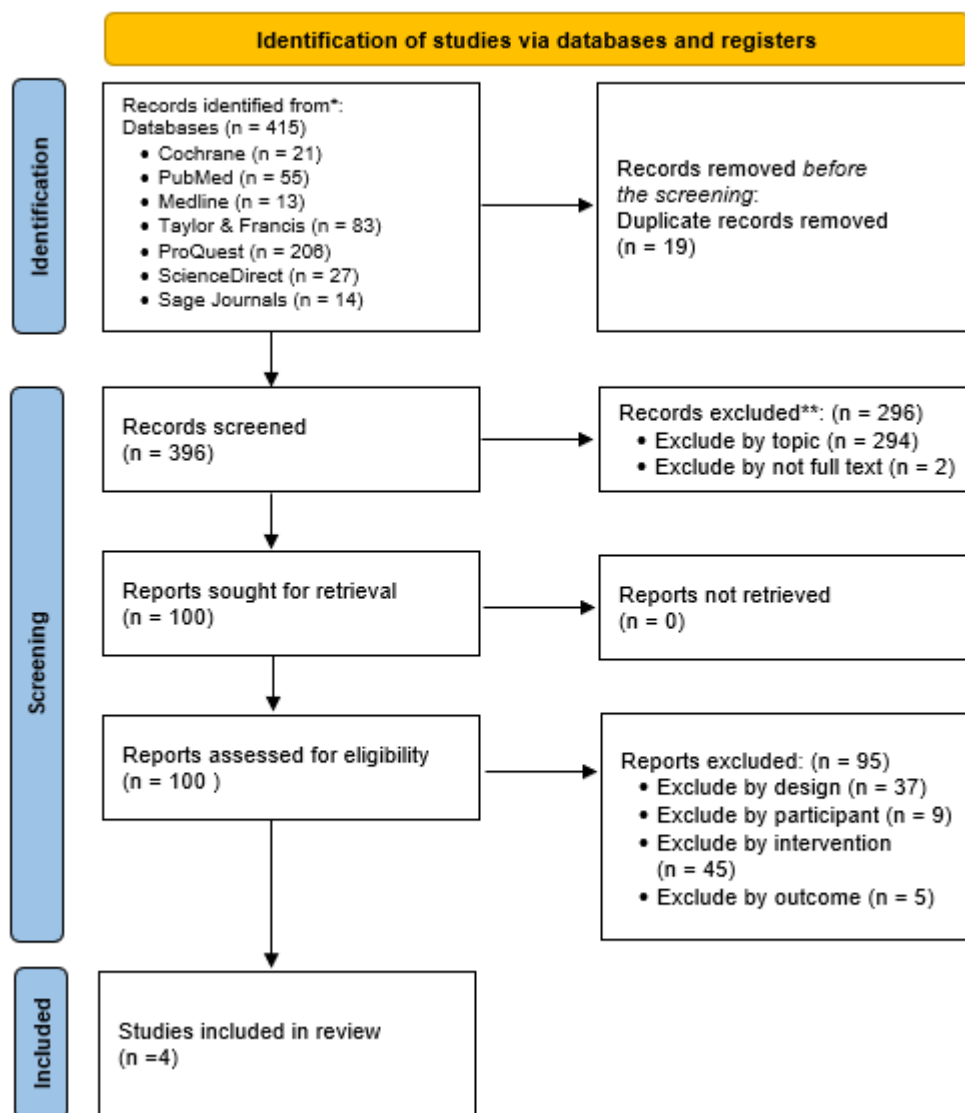
The systematic review search in this study used the PICO strategy. The PICO question used was " *do self-management programs can reduce fatigue for adolescents living with chronic conditions?*" Literature searches were conducted in several databases, such as: Cochrane, PubMed, Medline, Taylor and Francis, ProQuest, ScienceDirect, and Sage Journals. The keywords used were "*Children with chronic conditions*" OR "*Adolescents with chronic conditions*" OR "*Teenager with chronic conditions*" AND "*Self-Management*" OR "*Self-Management Program*" OR "*Management Self-Efficacy*" OR "*Self-Management Intervention*" OR "*Self-Management Skills*" AND "*Reduce fatigue levels*" OR "*Reduces fatigue syndrome*" OR "*To relieve signs and symptoms of fatigue*" OR "*Overcome fatigue*" OR "*Chronic fatigue syndromes*". Studies that assessed the level of fatigue that received *self-management interventions*, and were *Randomized Control Trial (RCT)* studies and clinical trials were included. Only studies published without a year up to 2020-2024 were considered.

Inclusion and Exclusion Criteria

The inclusion criteria include children and adolescents with chronic illnesses, *self-management interventions* , with outcomes *that* reduce fatigue levels, while the exclusion criteria include: children and adolescents with chronic conditions who experience worsening conditions, children and adolescents with psychological disorders.

Study Selection and Search

The initial search results found 415 studies. After data management with the EndNote *reference manager*, 19 articles were found to be duplicated, then the duplicates were removed, resulting in 396 articles. Article selection was based on *design, participant, intervention, outcome* , topic, and *full text* resulted in 4 articles (Figure 1).



Quality of the Studies

Each relevant article was evaluated for eligibility based on the inclusion and exclusion criteria. The articles in this systematic review were experimental studies, the authors used the Cochrane Risk of Bias V2 to determine whether they had a high, low, or moderate risk of bias (Centre for Evidence-Based Medicine Odense (CEBMO) & Cochrane Denmark , 2019). Table 1 shows the results of the bias assessment.

Table 1 Risk of Bias Assessment Results 2

Writer	Risk of Domain Bias*					RoB Conclusion
	1	2	3	4	5	
(Erickson et al., 2021)	+	!	!	!	+	!
(Gaunt et al., 2024)	+	!	!	!	+	!
(Stinson et al., 2020)	+	!	+	!	+	!
(Vroegindewij , et al., 2023)	+	!	+	!	+	!

= low risk
 = some concern
 = high risk

* Risk of Bias domain :
 1 = Randomization process
 2 = Deviations from intended interventions

- 3 = Missing outcome data
- 4 = Measurement of the outcome
- 5 = Selection of the reported results

Evaluation of the methodological quality of the four studies using the *Risk of Bias 2* (ROB 2) tool showed that most studies had a low to medium risk of bias, mainly related to the *blinding process* and *missing data*. Erickson (2021) studied physical activity interventions in cancer patients, using a well-documented randomization method, so the risk of bias in randomization and allocation was low. However, because it is difficult to apply *blinding* in physical activity-based interventions, there is a possibility of medium bias in outcome measurements, a study conducted by Gaunt (2024) comparing gradual exercise therapy with activity management in children with chronic fatigue syndrome, also showed a medium risk of bias. Despite good randomization, compliance declined after 12 months, increasing the potential for bias in reporting outcomes. Stinson (2020) who tested the online program "*Teens Taking Charge*" for adolescents with idiopathic arthritis, showed a lower risk of bias due to the use of a good RCT approach, although there was potential bias in participant engagement and the influence of subjectivity in pain assessment, while Vroegindewij's (2023) study comparing tailored self-management strategies with general strategies for fatigue also showed a moderate risk of bias, mainly due to limitations in participant *blinding* and the possible effect of subjectivity in reporting fatigue symptoms. Overall, although these articles have strong methodology, issues with *blinding* and long-term participant compliance still need to be addressed to improve the validity of future research results.

Characteristics of Research Articles

Based on 4 articles, the search results showed that the number of samples varied from 47 (Erickson et al., 2021) to 294 (Stinson et al., 2020) respondents who were divided into two groups, namely: the intervention group and the control group. *Self-management interventions* to reduce *fatigue* include: lifestyle changes that are modified by providing education related to sleep hygiene, physical activity, and mental health which are then monitored by health workers over a period of 4 weeks (Vroegindewe ij, et al., 2023). Providing physical activity and methods for managing daily activities are also intervention strategies in *self-management* (Gaunt et al., 2024; Erickson et al., 2021). The research period ranged from 12 weeks (Erickson et al., 2021) to 12 months (Gaunt et al., 2024).

RESULT

Table 2.
Article Review Results

Author, year Country	Objective	Sample	Method Study	Intervention	Results and Recommendations
Erickson et al., 2021 USA	Exploring the effectiveness of physical activity interventions in managing fatigue in AYA undergoing chemotherapy.	Total: 47 participants (G1: 25 PA programs; G2: 22 using brochures)	RCT with 12-week design	Home-based physical activity program	PA programs increase physical activity, self-efficacy, and decrease fatigue. Recommended for integration into standard care.
Gaunt et al., 2024 UK	Comparing the effectiveness of measured exercise therapy (GET) with management (AM) in children with ME/CFS.	Total: 241 children (G1: 123 received GET therapy; G2: 118 received AM).	Pragmatic RCT with parallel group design	GET therapy and activity management (AM)	The results of both groups were similar, AM was safer and more acceptable. Recommended as the primary approach.
Stinson et al., 2020 Canada	Evaluating a web-based self-management program for adolescents with JIA.	Total: 294 participants (G1: 147 received <i>Teens Taking Charge</i> ; G2: 147 received web-based education)	RCT with two groups (intervention and control)	<i>Teens Taking Charge</i> web program and telephone support	Intervention reduces pain, web fatigue and improves QoL. Recommended for adolescent health services.

Author, year Country	Objective	Sample	Method Study	Intervention	Results and Recommendations
Vroegindeweij et al., 2023 Netherlands	Exploring the effectiveness of tailored versus generic self-management strategies for persistent fatigue in adolescents and young adults.	Total: 60 participants (G1:30 received tailored advice; G2: 30 received general lifestyle advice)	Open randomized crossover trial	Tailored lifestyle advice (PROfeel) and in general.	Tailored lifestyle advice is more effective in reducing fatigue and improving QoL. Integration into clinical practice is recommended.

Intervention of the Studies

Physical Activity as a Fatigue Management Strategy

A study conducted by Erickson (2021) examined the effectiveness of a 12-week physical activity program in managing fatigue in adolescents and young adults undergoing chemotherapy. Although there was a positive trend in increasing physical activity, self-efficacy, and self-regulation, the results showed that there was no significant difference in fatigue levels between the intervention and control groups. Patients in the intervention group mostly continued to do light-intensity physical activity, and their fatigue was slightly worse than the general population. These results indicate that although physical activity has potential as a fatigue management strategy, its effectiveness in patients undergoing chemotherapy still needs to be studied further.

Progressive Exercise Therapy vs. Activity Management for Chronic Fatigue Syndrome

In a study conducted by Gaunt (2024), Graded Exercise Therapy (GET) was compared with Activity Management (AM) in children with chronic fatigue syndrome (ME/CFS). The results showed that GET was not more effective than AM in improving physical function or reducing fatigue over a period of 6 to 12 months, and there was even an indication that some participants in the GET group experienced a slight increase in anxiety compared to the AM group. Thus, this study suggests that a more flexible approach to managing chronic fatigue, such as activity management, is more appropriate than graded exercise which has the potential to increase stress in patients.

Online Program to Improve Self-Management of Chronic Patients

A study conducted by Stinson (2020) evaluated the effectiveness of the online program "Teens Taking Charge", which aims to help adolescents with juvenile idiopathic arthritis (JIA) manage their condition. The program consisted of self-education, coping skills training, and telephone support. The results showed that participants in the intervention group experienced significant reductions in pain intensity and pain interference, as well as improvements in quality of life that were sustained up to 12 months after the intervention. This suggests that online education programs combined with personal support can be an effective program in helping chronic patients improve their self-management and well-being.

Self-Management Strategies for Dealing with Chronic Fatigue

A study by Vroegindeweij (2023) compared the effectiveness of individualized self-management strategies versus general self-management strategies in adolescents and young adults with fatigue syndrome or rheumatic conditions. The results showed that both strategies were equally effective in reducing fatigue and improving quality of life, but there was no significant difference between the customized and general strategies, suggesting that patients may benefit from self-management strategies without the need for complex adjustments, making it a practical and widely applicable approach.

DISCUSSION

Research on tailored self-management strategies for chronic fatigue has shown positive results in reducing fatigue levels, increasing self-efficacy, and improving physical and emotional quality of life in adolescents with fatigue syndrome or rheumatic diseases. This crossover trial

showed clinically significant improvements in the majority of participants who completed the program, although both tailored strategies and generic diets provided similar benefits. This underscores the importance of a biopsychosocial-based approach to delivering meaningful short-term impact (Vroegindewij, et al., 2023). In line with these findings, several studies have shown that a low-fat diet can reduce fatigue in patients with multiple sclerosis (MS), with results suggesting that this nutritional approach can reduce fatigue severity and improve physical and mental quality of life in patients (Snetselaar, L. et al., 2022).

In addition to nutrition-based interventions, another study compared graded exercise therapy (GET) with activity management (AM) for children with ME/CFS. The results showed that GET was not more effective or cost-effective than AM in improving physical function and reducing fatigue. Although there was a small improvement in anxiety in the GET group, the overall effect was not significant. This highlights the need to explore additional approaches to optimally improve patient outcomes (Gaunt et al., 2024). Furthermore, research on physical activity as a method of managing fatigue in adolescents with cancer showed that although there were no significant differences in levels of fatigue, self-efficacy, or self-regulation between the intervention and control groups, the trend of improvement suggests potential benefits of incorporating physical activity into clinical care. Physical activity that is tailored to individual needs and integrated into treatment may be an important step in improving patients' quality of life during cancer therapy (Erickson et al., 2021).

Overall, lifestyle-based approaches, such as physical activity and dietary adjustments, have shown a positive association with reducing chronic fatigue symptoms. However, gaps in study design have led to inconsistent results, so more standardized and comprehensive studies are needed to strengthen the evidence of the effectiveness of these interventions (Vroegindewij, et al., 2023; Erickson et al., 2021). On the other hand, cognitive behavioral therapy (CBT) remains the main effective method in treating chronic fatigue, especially through cognitive restructuring, behavioral activation, and stress management. However, the effectiveness of CBT is highly dependent on the type of disease suffered by the patient, so it is necessary to combine other interventions for more optimal results (Gaunt et al., 2024).

In addition to physical activity and psychosocial approaches, two other studies have addressed self-management-based interventions for adolescents with chronic conditions. A study by Gauci et al. (2022) highlighted the importance of self-management in the transition to adult healthcare for adolescents with asthma and diabetes. The study used a modified version of the Flinders Program™, which combines cognitive behavioural therapy with an individualised approach. The intervention included structured assessment, care planning and booster sessions, aimed at improving self-management skills, quality of life and adherence to therapy. Expected outcomes included improved disease control, reduced unscheduled hospital visits and increased confidence in managing their condition.

Meanwhile, Stinson et al. (2020) evaluated the effectiveness of a web-based program for adolescents aged 12–18 years with juvenile idiopathic arthritis (JIA). The intervention included online educational modules, telephone support by a health coach, and content specifically for parents. The results showed that the program was effective in reducing pain intensity, reducing the impact of pain on daily activities, and improving health-related quality of life (HRQL) up to 12 months post-intervention. Both studies confirm that a structured intervention-based self-management approach, whether in-person or online, can support adolescents in coping with the challenges associated with their chronic condition. However, differences in method (face-to-face vs. web-based) provide insight into adolescents' individual preferences and needs, which may impact program success.

Furthermore, a web-based *self-management intervention* developed for patients with inflammatory bowel disease (IBD) demonstrated positive outcomes in reducing fatigue, pain, and urgency. The intervention used a cognitive-behavioral approach, supported by theory and input from patients and caregivers. The trial results showed that the intervention was easy to access and use, and could improve patients' quality of life (Sweeney, L. et al., 2022). However, although many *self-management interventions* have shown positive results, their effectiveness still varies depending on the type of intervention and patient condition. For example, programs involving physical exercise tend to show more consistent results in reducing fatigue, compared to other interventions such as energy conservation or cognitive-behavioral therapy (Campanini et al., 2022; Kim et al., 2021). Another study conducted by Duncan et al. (2022) highlighted that small sample sizes and heterogeneity in intervention methods and reported outcomes make it difficult to draw strong and generalizable conclusions. This suggests that positive results may not always be replicable in a wider population, so designing comprehensive and individualized *self-management programs is needed to increase their effectiveness and sustainability*.

CONCLUSION

Self-management interventions have been shown to be effective in reducing fatigue and improving quality of life in children and adolescents with various health conditions. Multidimensional biopsychosocial-based approaches, such as lifestyle advice, web-based programs, and physical activity, have shown great potential in improving daily activity, self-efficacy, self-regulation, and reducing fatigue. However, interventions need to be personalized to individual needs for optimal results. Implementation of these programs is expected to support self-management of health and improve patients' quality of life.

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