

Using the Flinders Care Model to Develop a Self-Management Program for Patients with Fatigue

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Rationale for Self-Management of Fatigue

Available literature highlights:

- that less than a quarter of patients with MS are using any self-management strategies to address fatigue.
- that pharmacologic agents are as of yet not a replacement for self-management strategies (in part due to an absence of FDA-approved medications for the management of fatigue).

A gold standard self-management program has yet to be identified in the literature on MS-related fatigue.

Many of the ones that have been piloted in research are not yet promising and are subject to design flaws that restrict them from being truly self-management based:

- they involved other- rather than self-imposed goals.
- they incorporated interventions that were not accessible to the patients once participation in the program was concluded.
- they were not easily integrated into the patient's daily lives (e.g., the strategies were too novel to the patients).
- they may incidentally promote learned helplessness by supporting the patient's perception that he/she lacks external resources necessary for managing fatigue and by not accessing the patient's own internally-derived motivation for applying the individual's internal and external resources to manage fatigue.

Fatigue Self-Management Project Proposal

We are endeavoring to introduce a patient directed self-management program following the Flinders Program for self-management of chronic conditions developed by the Flinders Human Behavior and Health Research Unit of Flinders University.

Fatigue Self-Management Program Model

This model is a patient centered approach in which patients collaborate with a health "coach" to decide on factors that contribute to their identified health problem and develop a care plan to follow that utilizes concrete action-based goals that patients set for themselves.

Patients rate themselves on a variety of 12 domains related to managing their health condition and are interviewed by their coach, who also rates them, according to these domains.

Consensus ratings, with pt having ultimate say, determine areas in which the patient is experiencing problems that form the basis of patient-derived intervention.

With respect to domains in which problems are identified, the patient articulates what he/she wants to achieve and generates small steps to get there.

Follow-up is provided at selected intervals to promote accountability, goal refinement and achievement.

Interview of 12 Domains, Adapted for MS Fatigue

Domain 1: Knowledge of Fatigue, Sample Item

- What do you know about your fatigue (e.g., what causes it, what makes it worse, what makes it better)?

Domain 2: Knowledge of Treatment, Sample Item

- What options are you aware of that are available for treating or managing fatigue?

Domain 3: Medications and Treatment Management, Sample Item

- What stops you from trying out other ways of treating or managing fatigue (e.g. knowing what to do and why, time, energy, physical disability, other barriers)?

Domain 4: Sharing in Decisions, Sample Item

- Are you able to talk to your provider about your fatigue?

Domain 5: Accessing Services, Sample Item

- Does the treatment for fatigue or MS fit in with your culture, values and beliefs about how to treat fatigue or MS?

Domain 6: Attending Appointments, Sample Item

- What prevents you from attending your appointments (e.g. transport problems, costs, physical disability, fatigue)?

Domain 7: Symptom Monitoring, Sample Item

- What are the early warning signs or symptoms of fatigue (e.g., shakiness, pain, shortness of breath, being more forgetful, thinking more slowly, moving more slowly)?

Domain 8: Response and Symptom Management, Sample Item

- What do you do to manage your early warning signs and symptoms of fatigue?

Domain 9: Managing Impact of Fatigue on Physical Activity, Sample Item

- What things can you no longer do or are more difficult to do because of fatigue?

Domain 10:: Managing Impact of Fatigue on Emotional and Spiritual Well-being, Sample Item

- Does your fatigue ever get you down?

Domain 11: Managing Impact of Fatigue on Social Aspects of Life, Sample Item

- How does fatigue affect the way you socialize?

Domain 12: Healthy Lifestyle, Sample Item

- Is there anything that you do that could worsen your health or fatigue (e.g., poor diet, dehydration, etc.)?

Next Steps

- 1) Developing care plans for patients with MS fatigue.

2) Assessing people at intake and 2 follow-up time periods on a variety of measures examining health behaviors, isolation, stigma, fatigue severity and impact, pain, and disability.

Currently we have 17 patients who have participated in the clinical interview for construction of a care plan and completed the intake assessment.

Currently 3 of our staff have completed training for license to use the Flinders tools.

