

# TitleChronic Fatigue Syndrome: State of the Evidence and<br/>Assessment of Intervention Modalities in QuébecAgencyAETMIS, Agence d'évaluation des technologies et des modes d'intervention en santé<br/>2021 avenue Union, suite 10.083, Montréal, Québec H3A 2S9, Canada;

Tel: +1 514 873 2563, Fax: +1 514 873 1369; aetmis@aetmis.gouv.qc.ca, www.aetmis.gouv.qc.ca**Reference**ETMIS 2010 6 [2]. Printed French edition 978-2-550-59049-1, English summary (PDF)<br/>978-2-550-59050-7. www.aetmis.gouv.qc.ca/site/en\_publications2009.phtml

### Aim

To review the evidence on chronic fatigue syndrome (CFS)/myalgic encephalomyelitis etiology and pathogenesis, best practices for clinical management, and organizational issues surrounding optimal management; and to inquire into Québec health professionals' need for education/training, patient care and service needs, and the cost of addressing them.

### **Results and conclusions**

CFS is a complex, heterogeneous illness affecting an undetermined number of persons in Québec. Defined by diagnostic criteria for research purposes, this condition is officially recognized as a disease by the World Health Organization. Research to date has been unable to establish a single cause for this illness, although it has been linked to various infections, including Epstein-Barr virus and xenotropic murine leukemia virus-related virus. Numerous immunologic, endocrine, and psychoneurologic abnormalities have been described in sufferers. In the absence of a specific test, this condition can only be diagnosed by exclusion. Therapies such as cognitive behavioral therapy and graded exercise therapy seem to be effective and safe in the short term, while others, mostly pharmaceutical, have proven useful in treating comorbidities (mostly depression). Several health and social service professionals have admitted their lack of knowledge about the syndrome and voiced skepticism about its existence. Québec patients bemoaned the generalized lack of knowledge about CFS among professionals and the absence of care services and psychosocial support. In light of these findings, AETMIS recommends that organizers of continuing education in professional associations and corporations include CFS in their programs, and that the Ministère de la Santé et des Services sociaux and network administrators designate one or two centers of expertise dedicated to diagnostic and therapeutic/rehabilitation services, professional training, and research on epidemiology, etiology, pathophysiology, and care.

# Methods

An evidence synthesis on CFS epidemiology, etiology, and pathogenesis; a systematic review of the efficacy and safety of CFS treatments; a review of clinical practice guidelines on the diagnosis and treatment or rehabilitation of patients with this illness; an economic analysis of treatment options; a literature search strategy including literature reviews and health technology assessment reports (Jan. 1994 to Feb. 2009); primary studies (Jan. 2005 to Feb. 2009) in English, French, Spanish, and Italian; an exhaustive grey literature search in May 2008 and a literature watch initiated in Feb. 2009; a contextual analysis performed by examining complementary documents for nonscientific literature and from Québec's medico-administrative databases and by consulting with care providers and key stakeholders; an online survey involving specialist physicians and GPs; and a primary study based on patient interviews to examine the needs of Québec patients.

## Further research/reviews required

Observational studies are needed to determine the prevalence of CFS in Québec to analyze the impact of CFS on health and social service delivery and the disease's societal consequences.

Written by Guylaine Rouleau, Ugo Ceppi, Vibe Hjelholt Pederson, and Pierre Dagenais, AETMIS, Canada