Guidelines on Self-Management of Gaucher Disease

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The IGA and IWGGD are finalising guidelines on self-management of Gaucher disease, that will be published soon.

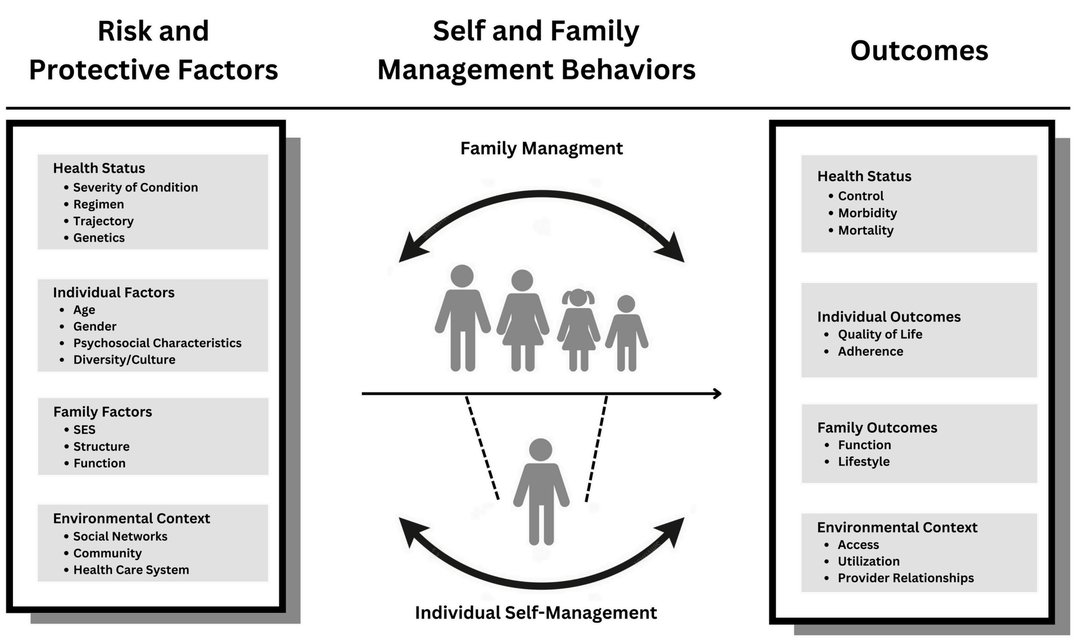
Gaucher Disease is a chronic disease impacting daily life, including emotions and relationships. Its management is not only clinical; self-management is also perhaps an even more important part.

We extensively explored the literature on self-management and related concepts and from it developed draft guidelines including 15 recommendations to health care professionals.

Summarised recommendations

Self-management is defined as the tasks that individuals must undertake to live well with one or more chronic conditions, and must be recognised as crucial for the quality of life and quality of care. Self-management support and empowerment add to that significantly, tailored to each patient's needs.

The patient is an expert on his/her own, therefore not partnering yields suboptimal outcomes. Observations gathered by the patient and patient-reported outcomes are as relevant as the physician's data and should be addressed in the management plan. Other health care providers like emergency responders will benefit from the attending physician providing the patient with knowledge and information they need.



Self- and family-management framework

Rebuilt from: Schulman-Green, Dena, Sarah S. Jaser, Chorong Park, and Robin Whittemore. "A Metasynthesis of Factors Affecting Self-Management of Chronic Illness." Journal of Advanced Nursing 72, no. 7 (2016): 1469–89.

The daily life implications of the disease are to be discussed initially and regularly, as well as the patient's illness perceptions. Self-management benefits from e.g. home therapy, a care coordinator or case manager, and a psychologist or psychotherapist where needed.

Finally, we recommend including the family, both in paediatric and adult care, in the disease management and to ask if other people in the patient's life are relevant for the broader management of Gaucher disease.

About the IGA

The IGA is a patient-led international organisation that has become the 'go to' global voice for over 90% of the Gaucher community and has built its reputation through listening to and delivering outcomes that have impacted on patients and their carers' lives. The IGA is an independent charity with a clear code of practice for working with industry. In 2024, the IGA is celebrating its 30th anniversary with a series of events throughout the year.

Visit the IGA website

About the IWGGD

The aim of the IWGGD is to promote clinical and basic research into Gaucher disease for the ultimate purpose of improving the lives of patients with this disease; it brings together clinicians, scientists and patients in an open forum for discussion on all aspects of the condition. The opportunity for presenting unpublished scientific data as well as free discussion is a central premise of the Group. The Working Group has always been an independent organization with a charitable purpose and a clear code of practice to work with industry.

Visit the IWGGD website