Quality of Life Study in Chronic Diseases: More Needed Than Ever

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Numerous thyroid diseases can impact patients' lives, one of which is Graves' ophthalmopathy (GO). Graves' ophthalmopathy is a progressive thyroid-related disease which causes eye symptoms due to autoimmune reaction targeting thyrotropin/thyroid stimulating hormone (TSH) receptors in the orbital space.[1] This condition can be easily recognized by the patient's, including exophthalmos, pain, swelling, double vision, and impaired vision.[2] Globally, the estimated incidence of GO is 3.3–8 per 100,000 in women and 0.9–1.6 per 100,000 in men with peak incidence between 30-60 years old. The prevalence of GO is 9 per 100,000, with the prevalence of GO among patients with Graves' disease reaching 30%.[3]

Graves' ophthalmopathy (GO) is primarily associated with Graves' hyperthyroidism but can also occur in 7%–8% of cases with euthyroid or hypothyroid chronic autoimmune thyroiditis (ie Hashimoto thyroiditis).[3-4] The disease is driven by autoimmune reactions against the thyrotropin receptor (TSHR), as mentioned before, and evidenced by TSHR overexpression in orbital tissues and its role in promoting adipocyte differentiation, leading to orbital fat expansion. Circulating TSHR antibodies (TSHR-Ab or TRAb) are closely correlated with GO activity, severity, and outcome, making them a valid and reliable biomarker. Recent studies highlight the higher sensitivity and specificity of novel TSHR-Ab bioassays compared to traditional immunoassays for evaluating GO activity and severity. Strong evidence establishes TSHR and TSHR-Ab as central to the pathogenesis of GO.[4]

As mentioned in the study from Anggraini C and Nusanti S from Department of Opthalmology Cipto Mangunkusumo Hospital, symptoms experienced by GO patients significantly affect their quality of life. Therefore, assessing quality of life becomes crucial in GO. This condition not only causes clinical disturbances but also impacts the patient's appearance, well-being, and self-confidence. Quality of life assessments using various tools have started to be implemented in this era, one of which is through questionnaires. In Indonesia, there is currently no specific questionnaire designed to assess the quality of life of patients with thyroid diseases. Thus, before using questionnaires in Bahasa Indonesia, a validation process must be conducted using a wellknown and popular questionnaire such as Grave's ophthalmopathy-quality of life (GO-QoL) questionnaire. This questionnaire has been made by the European Group on Grave's Orbitopathy (EuGOGO) and has been used by many countries in Europe. GO-QoL questionnaire is a validated tools used to assess the quality of life in patients with Graves' ophthalmopathy (GO).[5]

GO-QoL questionnaire includes two domains such as visual functioning that assess the impact of GO on daily activities that require vision, such as reading, driving, or watching TV. The questions focus on difficulties caused by double vision, light sensitivity, or reduced visual acuity. The other one is the appearance domain which evaluates the patient's emotional well-being and self-confidence related to changes in their appearance, such as exophthalmos or swelling. The scoring system of this questionnaire uses the Likert scale (from "no difficulty" to "extreme difficulty"). Scores for each domain are converted to a scale from 0-100 with 0 means worst QoL (severe impact) and 100 means best QoL (no impact). Higher scores indicate better quality of life in the respective domain.[5]

The adaptation process of GO-QoL questionnaire into Indonesian context in this study ensures cultural relevance, linguistic accuracy, and applicability to the local population. Validation studies focus on ensuring the questionnaire's reliability, validity, and sensitivity in capturing QoL variations. A validated tool allows clinicians to monitor the disease's impact comprehensively and aids in tailoring individualized management plans. More precisely, this questionnaire can offer several advantages such as enhanced patient-centered care, monitoring treatment outcome, and supporting research initiatives.

GO-QoL questionnaire can enhance patient-centered care by incorporating QoL assessments. Clinicians can address both physical and emotional burdens of GO, aligning treatment goals with patient priorities. This tool can also monitor treatment outcomes by enabling evaluation of therapeutic interventions' effectiveness, such as corticosteroids, radiotherapy, or surgery (decompression). Lastly, data from the GO-QoL questionnaire can contribute to regional and global research, fostering collaborations to improve GO management strategies.[5] The correlation between QoL scores and clinical parameters also provides insights into disease progression and prognosis. For instance, understanding how QoL changes from time to time with clinical improvement can help refine treatment protocols.[6]

The relationship between clinical activity (measured by the Clinical Activity Score, CAS) and severity (assessed through exophthalmometry, diplopia, and lid retraction) with QoL has been well-documented. Patients in the active inflammatory phase often report lower QoL scores due to pain, functional impairment, and psychological distress. These reports also include data from outside Europe, such as Brazil, Korea, and Thailand, which conducted studies on the validation of the GO-QoL questionnaire to assess the quality of life in patients with GO. These studies indicate that the questionnaire has high validity and reliability. Additionally, the studies support the finding that the more active a patient's condition (based on the CAS assessment), the lower the GO-QoL score, particularly in both domains. Other studies also suggest a decrease in GO-QoL scores as the severity of the disease increases.[6-8]

An important consideration when using this questionnaire, especially for research purpose, is that researchers must recognize that it consists of two domains: the visual domain and the appearance domain. There is a specific reason why this questionnaire is divided into two domains. Assessing the quality of life in GO patients may not be sufficient if only based on the clinical condition, as patients experiencing active inflammation or severe disease may still report high questionnaire scores due to various factors, such as inactive disease states.[7,9] Assessment of two domains in the GO-QoL allows clinicians and researchers to assess the quality of life from multiple aspects, not solely based on clinical conditions. This highlights the importance of using the GO-QoL questionnaire to comprehensively evaluate the quality of life in GO patients.

Anggraini and Nusanti's study is one from only few studies in Indonesia aim to adapt quality of life questionnaire into Bahasa Indonesia and find out patient's quality of life afterwards, specifically in thyroid field. The steps for translation, validation, and adaptation of the questionnaire and thus exploring patients quality of life can be a model for similar studies. Today, our patients not only need assessment for clinical symptoms, signs, laboratory, or radiology results, but also need assessment for their wellbeing and unmet needs which are summarized in the quality of life questionnaires. At the end, optimal quality of care will be the ultimate goal for all chronic disease patients.

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