

Long-term oxygen therapy: Are we missing the patient experience?

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Long-term oxygen therapy (LTOT) remains a cornerstone for managing chronic respiratory failure, yet assessing its true impact on a patient's daily life extends beyond simple physiological metrics. Clinicians often struggle to capture the subjective burden and benefits of oxygen use, relying on indirect measures or lengthy, cumbersome questionnaires. A new assessment tool, the Questionnaire for Oxygen Therapy Evaluation (QuOTE), aims to simplify this process, offering a direct, patient-reported outcome measure for LTOT.

KEY TAKEAWAYS

- **The Pivot:** The QuOTE questionnaire provides a concise, patient-centric method for evaluating the subjective impact of long-term oxygen therapy.
- **The Data:** QuOTE focuses on key domains including physical activity, social interaction, and emotional well-being, offering a comprehensive snapshot of patient experience.
- **The Action:** Clinicians can integrate QuOTE into routine follow-up to better understand patient challenges and tailor oxygen delivery strategies.

Patients living with chronic respiratory conditions, such as severe chronic obstructive pulmonary disease (COPD) or interstitial lung disease, frequently require supplemental oxygen to maintain adequate tissue oxygenation and improve quality of life. The decision to initiate and continue long-term oxygen therapy is typically based on arterial blood gas measurements, demonstrating chronic hypoxemia. But the real-world experience of living with oxygen, including the practicalities of portable devices, the social stigma, and the impact on daily activities, is often overlooked in clinical assessments.

Existing tools for evaluating quality of life in respiratory patients, while valuable, are often broad and not specifically tailored to the unique challenges posed by oxygen therapy. These generic instruments may miss the specific nuances of how oxygen impacts mobility, sleep, or social engagement. The need for a focused, easy-to-administer tool that directly addresses these aspects has been a persistent gap in respiratory care, particularly for European GPs and specialists who manage these patients in diverse settings.

Designing a Patient-Centric Assessment

The development of the QuOTE questionnaire aimed to create a simple, yet comprehensive, instrument that captures the patient's perspective on LTOT. This involved identifying key domains that are most affected by oxygen use, moving beyond purely physiological parameters. The focus was on areas such as physical activity, emotional state, social interactions, and the practical aspects of managing oxygen equipment.

The design process typically involves extensive patient interviews and expert consensus to ensure relevance and face validity. Questions are formulated to be clear, unambiguous, and easily understood by a diverse patient population, including those with varying levels of literacy. The goal is to minimise the burden on the patient while maximising the utility of the collected information for clinical decision-making. This iterative process refines the questionnaire to ensure it measures what it intends to measure, consistently and reliably.

What the QuOTE Questionnaire Measures

The QuOTE questionnaire is structured to assess several critical dimensions of a patient's experience with long-term oxygen therapy. It typically includes items related to physical limitations, such as the ability to perform daily tasks or engage in light exercise while using oxygen. Patients are asked about their perceived breathlessness during various activities, providing a subjective but important measure of functional capacity. This contrasts with objective measures like the six-minute walk test, offering a complementary perspective on how patients feel in their own environment. Another significant domain covered by QuOTE is the psychosocial impact of oxygen therapy. This includes questions about social isolation, embarrassment associated with using oxygen in public, and the emotional burden of living with a chronic condition that necessitates continuous support. These aspects are frequently underreported in standard clinical consultations but profoundly affect a patient's overall well-being. Understanding these challenges can help clinicians offer more holistic support, perhaps by referring patients to support groups or advising on discreet oxygen delivery systems.

The practicalities of oxygen equipment also form a key part of the assessment. QuOTE probes issues such as the weight and portability of oxygen tanks, the noise of concentrators, and the perceived reliability of the equipment. These seemingly minor details can significantly impact a patient's willingness to adhere to therapy and their ability to maintain an active lifestyle. For instance, a patient struggling with a heavy portable tank may restrict their outdoor activities, negating some of the intended benefits of LTOT. For a deeper dive into how equipment can impact patient mobility, consider advances in cardiopulmonary exercise testing, which often highlight the functional limitations patients face.

Interpreting the Results

The scoring of the QuOTE questionnaire provides a quantitative measure of a patient's experience, allowing for tracking over time and comparison between different therapeutic interventions. A higher score in certain domains might indicate greater distress or functional limitation, prompting a review of the oxygen prescription or delivery method. Conversely, an improvement in scores could reflect successful adaptation to therapy or the positive impact of rehabilitation programs. Clinicians can use QuOTE results to initiate more targeted conversations with patients, moving beyond a simple check of oxygen saturation levels. If a patient reports significant social anxiety due to oxygen use, for example, the clinician can explore options for more discreet cannulas or discuss strategies for coping with public perception. This patient-centered approach ensures that therapy is not just physiologically effective but also improves the patient's quality of life in a meaningful way. The OxiPro OX2 Pulse Oximeter, for example, provides a quick, objective measure of oxygen saturation, but it does not capture the subjective experience that QuOTE aims to address.

Integrating QuOTE into Clinical Practice

The simplicity and brevity of the QuOTE questionnaire make it an attractive tool for routine clinical practice. It can be administered during regular follow-up appointments, either by the patient themselves or with assistance from nursing

staff. The time investment is minimal, but the insights gained can be substantial. Integrating such a tool can help identify patients who are struggling with adherence, those who require additional psychosocial support, or those whose current oxygen delivery system is inadequate for their lifestyle.

The utility of QuOTE extends beyond individual patient management. Aggregated data from QuOTE assessments could inform broader quality improvement initiatives within healthcare systems. Identifying common challenges faced by LTOT patients can lead to the development of better patient education materials, improved access to portable oxygen devices, or enhanced rehabilitation programs. This data-driven approach allows for continuous refinement of care pathways for chronic respiratory conditions. This is particularly relevant when considering optimising COPD outcomes through comprehensive management strategies.

The questionnaire also serves as a valuable communication aid between patients and their healthcare providers. It provides a structured framework for patients to express their concerns and for clinicians to listen and respond effectively. This can foster a stronger therapeutic alliance and empower patients to take a more active role in their own care. The focus on patient-reported outcomes aligns with modern healthcare trends that emphasize patient engagement and shared decision-making. For clinicians seeking a comprehensive resource on respiratory conditions, the Oxford Handbook of Respiratory Medicine offers an excellent reference.

Where it Falls Short

While QuOTE offers a valuable addition to the assessment toolkit, it is not without limitations. Like any patient-reported outcome measure, its accuracy relies on the patient's ability to accurately self-report and their willingness to be candid. Subjectivity is inherent in such tools, and individual interpretations of questions can vary. The questionnaire may not fully capture the experiences of patients with severe cognitive impairment or those with significant communication barriers, necessitating alternative assessment methods for these subgroups.

The initial validation of such a tool typically involves a specific patient population, and its generalisability to all patients on LTOT, across different etiologies of respiratory failure and diverse cultural backgrounds, requires further investigation. The impact of different oxygen delivery systems, such as liquid oxygen versus concentrators, or continuous flow versus pulse dose, on QuOTE scores also warrants specific exploration. These nuances are critical for ensuring the tool's applicability in a wide range of clinical scenarios.

The questionnaire provides a snapshot of a patient's experience at a given point in time. Fluctuations in symptoms, changes in social circumstances, or modifications to oxygen therapy might not be immediately reflected if assessments are not conducted regularly. The frequency of administration and the optimal timing for re-evaluation are practical considerations that need to be established for QuOTE to be maximally effective in long-term patient management. This ongoing monitoring is essential, much like the continuous evaluation needed for understanding the dual role of IL-33 in COPD.

The Next Steps for QuOTE

The introduction of a tool like QuOTE represents a step forward in patient-centered care for long-term oxygen therapy. The next phase involves widespread implementation and further validation in diverse clinical settings. This will help refine the questionnaire, establish normative data, and confirm its sensitivity to change over time. The goal is to ensure that QuOTE becomes a standard component of LTOT assessment, providing clinicians with a more complete picture of

their patients' lives. This will allow for more personalised and effective management strategies, moving beyond purely physiological measures to encompass the full spectrum of patient well-being.

CLINICAL IMPLICATIONS

The QuOTE questionnaire offers a much-needed lens into the lived experience of patients on long-term oxygen therapy. For too long, clinicians have relied on objective measures, overlooking the profound subjective impact of continuous oxygen use. This tool provides a structured way to capture those critical, often unspoken, challenges.

Integrating QuOTE into routine practice could significantly enhance the quality of care. It moves the conversation beyond oxygen saturation levels to address the practical and psychosocial hurdles patients face daily. This direct feedback can inform more tailored interventions, whether it is adjusting oxygen delivery methods or providing targeted psychosocial support.

The industry, particularly manufacturers of oxygen delivery systems, should pay close attention to the insights gleaned from QuOTE. Patient-reported difficulties with portability, noise, or stigma highlight areas ripe for innovation. Designing devices that are not only effective but also less burdensome and more discreet could dramatically improve adherence and quality of life.

QuOTE empowers patients by giving them a voice in their own care. It shifts the focus from merely sustaining life to enhancing its quality, ensuring that therapy aligns with individual needs and preferences. This is a pragmatic step towards truly patient-centered respiratory medicine.

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