

Exploring Patient Experiences with Long-Term Oxygen Therapy (LTOT) in Chronic Respiratory Diseases: Impacts on Daily Life, Challenges, and Perceived Benefits

Othman K. Abahoussin¹, Hashem F. Alsamannoudi²

Respiratory Therapist
Health affairs at the ministry of National Guard

Abstract:

Objective: This study explores patient experiences with Long-Term Oxygen Therapy (LTOT) in chronic respiratory diseases, focusing on its impact on daily life, challenges encountered, and perceived benefits.

Methods: A qualitative research design was employed, using semi-structured interviews and focus groups with 20 patients undergoing LTOT. Data were analyzed thematically to identify key themes and sub-themes related to patients' experiences.

Findings: The analysis revealed four main themes: Impact on Daily Life, Challenges of Using LTOT, Perceived Benefits, and Support and Education. Participants reported significant changes in daily activities, social interactions, and emotional well-being due to LTOT. Challenges included equipment-related issues and adherence difficulties, while benefits included improved symptoms and enhanced quality of life. The need for better training and emotional support was also highlighted.

Conclusion: LTOT has a profound impact on patients' lives, with both benefits and challenges. Improved equipment design, comprehensive patient education, and enhanced support services are crucial for optimizing the management of LTOT and improving patient outcomes.

Keywords: Long-Term Oxygen Therapy, Chronic Respiratory Diseases, Patient Experiences, Daily Life Impact, Therapy Challenges, Quality of Life

Introduction

Background

Long-Term Oxygen Therapy (LTOT) is a critical component in the management of chronic respiratory diseases, such as Chronic Obstructive Pulmonary Disease (COPD) and interstitial lung disease (ILD). It aims to improve oxygenation, enhance survival, and alleviate symptoms in patients with severe hypoxemia (Fabbri and Hurd, 2003). LTOT has been associated with various clinical benefits, including reduced mortality and improved exercise tolerance (Spruit et al., 2013; Neri, et al., 2006).

Rationale

Despite its proven efficacy, the experience of patients undergoing LTOT can be complex and multifaceted. Patients often face significant challenges related to the use of oxygen equipment, adherence to therapy, and adjustments to daily life. These challenges can affect their overall quality of life and psychological well-being (Ring and Danielson, 1997; Neri, et al., 2006). Understanding these patient experiences is crucial for optimizing LTOT practices and improving patient outcomes.

Objective

The objective of this study is to explore the experiences of patients using LTOT, focusing on its impact on daily life, the challenges encountered, and the perceived benefits. By gaining insights into these aspects, the study aims to identify areas for improvement in LTOT management and provide recommendations for enhancing patient support.

Significance

This research is significant as it addresses gaps in the current literature regarding patient experiences with LTOT. While clinical outcomes of LTOT are well-documented, less is known about how the therapy affects patients' daily lives and psychological states. The findings of this study could inform healthcare practices and policies, leading to better patient-centered care and improved quality of life for individuals undergoing LTOT (Eaton et al., 2004).

Literature Review

Overview of Long-Term Oxygen Therapy (LTOT)

Long-Term Oxygen Therapy (LTOT) is a treatment designed to improve oxygenation in patients with chronic respiratory diseases, particularly those with chronic hypoxemia. LTOT has been well-established as a life-extending therapy for patients with severe Chronic Obstructive Pulmonary Disease (COPD) and other conditions leading to significant oxygen desaturation (Fabbri and Hurd, 2003). Clinical guidelines emphasize the importance of LTOT in improving survival rates and exercise capacity (Spruit et al., 2013).

Impact on Daily Life

While the clinical benefits of LTOT are well-documented, its impact on patients' daily lives can be profound. Research indicates that LTOT can significantly alter patients' daily routines, affecting their ability to perform everyday activities and participate in social interactions (Ring and Danielson, 1997). Patients often report feeling stigmatized or socially isolated due to the visible presence of oxygen equipment, which can affect their self-esteem and social engagement (Neri, et al., 2006).

Challenges Associated with LTOT

Patients on LTOT face numerous challenges. Adherence to therapy is a significant issue, with factors such as discomfort, inconvenience, and complexity of equipment contributing to difficulties in maintaining consistent use (Eaton et al., 2004). Technical issues, such as malfunctioning equipment and inadequate training on its use, further complicate adherence. Additionally, psychological barriers, including anxiety and depression, are commonly reported among LTOT users, impacting their overall therapy experience (Doi, 2003).

Perceived Benefits of LTOT

Despite the challenges, many patients perceive significant benefits from LTOT. Improved oxygenation can lead to enhanced exercise capacity, reduced breathlessness, and overall better quality of life (Neri, et al., 2006). LTOT has been associated with better symptom control and a positive impact on patients' physical and psychological well-being (Ring and Danielson, 1997). Patients often report that the therapy enables them to engage more fully in daily activities and improve their overall health status.

Gaps in Literature

While existing studies highlight both the benefits and challenges of LTOT, there are gaps in understanding the full scope of patient experiences. Most research has focused on clinical outcomes rather than the nuanced

experiences of patients living with LTOT over the long term (Spruit et al., 2013; Eaton et al., 2004). Further qualitative research is needed to capture patients' perspectives in detail, providing insights into how LTOT affects their daily lives and identifying strategies to address the challenges they face.

Conclusion

Understanding patient experiences with LTOT is essential for optimizing therapy and improving patient outcomes. While LTOT offers substantial clinical benefits, the impact on daily life and the challenges faced by patients must be addressed to enhance the overall effectiveness of the therapy. This review highlights the need for further research to explore these aspects in depth and to develop interventions that support patients in managing their therapy effectively.

Methodology

Research Design

This study utilized a qualitative research design to explore patient experiences with Long-Term Oxygen Therapy (LTOT) in chronic respiratory diseases. A qualitative approach was chosen to gain in-depth insights into the personal and subjective experiences of patients, focusing on the impact of LTOT on daily life, the challenges faced, and the perceived benefits.

Participants

A purposive sampling method was employed to select participants who were currently using LTOT for chronic respiratory conditions such as Chronic Obstructive Pulmonary Disease (COPD) or interstitial lung disease (ILD). Twenty patients were recruited from a Tertiary Hospital. Inclusion criteria included being over 18 years of age, having been on LTOT for at least six months, and providing informed consent to participate. Exclusion criteria included patients with cognitive impairments that would hinder their ability to provide informed consent or participate in interviews.

Data Collection

Data were collected through semi-structured interviews and focus group discussions. Semi-structured interviews allowed for detailed, individual accounts of patient experiences, while focus groups facilitated the exploration of common themes and collective experiences.

- **Semi-Structured Interviews:** Individual interviews were conducted with 12 patients, each lasting approximately 45 to 60 minutes. The interviews were guided by a set of open-ended questions designed to elicit detailed responses about patients' experiences with LTOT, including its impact on their daily lives, challenges faced, and perceived benefits. All interviews were audio-recorded and transcribed verbatim.

- **Focus Groups:** Three focus group discussions were held, each consisting of 4 to 5 participants. These discussions aimed to explore common themes and shared experiences among patients using LTOT. Each focus group lasted about 90 minutes and was facilitated by a trained moderator. Sessions were audio-recorded and transcribed for analysis.

Data Analysis

The data were analyzed using thematic analysis, following the steps outlined by Braun and Clarke (2006). This process involved:

1. **Familiarization with Data:** Reading and re-reading transcripts to gain a comprehensive understanding of the data.

2. Generating Initial Codes: Identifying and coding significant features of the data relevant to the research questions.
3. Searching for Themes: Collating codes into potential themes by grouping related codes.
4. Reviewing Themes: Refining and reviewing themes to ensure they accurately represent the data and address the research questions.
5. Defining and Naming Themes: Clearly defining each theme and sub-theme to encapsulate the main findings.
6. Writing the Report: Integrating and presenting the themes with illustrative quotes from participants.

Ethical Considerations

Ethical approval for the study was obtained from the ethics committee. All participants provided written informed consent before taking part in the study. To ensure confidentiality, all identifying information was removed from the transcripts, and participants were assigned pseudonyms. Data were securely stored and accessible only to the research team.

Limitations

The study's limitations include a relatively small sample size and the potential for selection bias, as participants were recruited from specific clinics and therapy centers. Additionally, the subjective nature of qualitative data means that findings may not be generalizable to all LTOT users.

Findings

The thematic analysis revealed several key themes and sub-themes regarding patient experiences with Long-Term Oxygen Therapy (LTOT). The findings reflect the multifaceted nature of LTOT and its impact on patients' lives.

Theme 1: Impact on Daily Life

1. Sub-theme 1.1: Changes in Daily Activities

- Participant A: "I used to enjoy gardening, but now I find it difficult to keep up with it. The oxygen tank is heavy and makes moving around the garden quite cumbersome."
- Participant B: "My daily routine has changed significantly. I have to plan my errands around the need to take my oxygen concentrator with me, which limits what I can do."

2. Sub-theme 1.2: Social and Emotional Impact

- Participant C: "It's hard to go out socially. I feel self-conscious about carrying the oxygen tank and worry about what others think."
- Participant D: "I've become more isolated. I avoid social gatherings because I don't want to be the center of attention because of the oxygen equipment."

Theme 2: Challenges of Using LTOT

1. Sub-theme 2.1: Equipment-Related Issues

- Participant E: "The equipment can be really noisy and disruptive, especially at night. It affects my sleep and overall comfort."
- Participant F: "There have been times when the machine malfunctioned or the oxygen levels weren't correct. It's frustrating when you rely on it for your breathing."

2. Sub-theme 2.2: Adherence and Compliance

- Participant G: "Sometimes I forget to use the oxygen as prescribed, especially when I'm busy. It's easy to fall into bad habits when you're feeling okay."

- Participant H: "The oxygen mask can be uncomfortable, and it's easy to take it off for short periods. I know it's not ideal, but it happens."

Theme 3: Perceived Benefits of LTOT

1. Sub-theme 3.1: Improvement in Symptoms

- Participant I: "Using LTOT has made a significant difference in my breathing. I can walk short distances without feeling as breathless as before."

- Participant J: "The therapy has helped me feel less tired during the day. I have more energy and can do more around the house."

2. Sub-theme 3.2: Enhanced Quality of Life

- Participant K: "Even though there are challenges, LTOT has given me a better quality of life overall. I feel like I'm getting the oxygen I need to stay active."

- Participant L: "The therapy has helped me stay out of the hospital more often. I feel more secure knowing I have the oxygen support I need at home."

Theme 4: Support and Education

1. Sub-theme 4.1: Need for Better Training

- Participant M: "I think more comprehensive training on how to use and maintain the equipment would be really helpful. Sometimes I feel unsure if I'm using it correctly."

- Participant N: "Clearer instructions and more regular follow-ups from healthcare providers would help in understanding how to manage the equipment better."

2. Sub-theme 4.2: Emotional and Psychological Support

- Participant O: "It would be beneficial to have more support groups or counseling options. Dealing with LTOT can be emotionally challenging, and having someone to talk to would help."

- Participant P: "Sometimes I feel anxious about my condition and the therapy. Access to psychological support or counseling would be a great addition to the treatment."

Discussion

Impact on Daily Life

The findings of this study align with existing literature on the impact of Long-Term Oxygen Therapy (LTOT) on daily life. Participants reported significant changes to their daily activities and social interactions due to the presence of oxygen equipment. These changes are consistent with previous research highlighting the restrictive nature of LTOT on patients' ability to engage in daily activities and social events (Neri, et al., 2006). The physical burden of carrying or transporting oxygen equipment can limit mobility and reduce the spontaneity of activities, reinforcing the need for more user-friendly designs and portable solutions (Ring and Danielson, 1997).

Challenges Associated with LTOT

The challenges identified in this study, such as equipment-related issues and difficulties with adherence, echo findings from other studies. Equipment malfunctions and the discomfort of using oxygen masks are well-documented issues that can affect patient compliance. The problem of adherence, exacerbated by the inconvenience and discomfort of the therapy, has been widely reported. The findings underscore the need for improvements in equipment reliability and patient education to enhance adherence and overall therapy effectiveness (Eaton et al., 2004).

Perceived Benefits of LTOT

Despite the challenges, participants reported significant benefits from LTOT, including improved symptoms and enhanced quality of life. These benefits are supported by research indicating that LTOT can lead to improvements in oxygenation, physical stamina, and overall well-being (Neri, et al., 2006). The reported increase in energy levels and reduction in breathlessness are consistent with the established clinical benefits of LTOT, which contribute to a better quality of life for many patients (Spruit et al., 2013).

Support and Education

A key finding from this study is the need for improved training and emotional support for LTOT users. Participants expressed a desire for more comprehensive training on equipment use and better psychological support. These needs align with previous studies that highlight the importance of thorough patient education and the benefits of additional support services (Doi, 2003). Enhanced training could address issues related to equipment use and maintenance, while psychological support could help patients manage the emotional challenges associated with LTOT.

Implications for Practice

The findings suggest several practical implications for improving the management of LTOT. First, there is a need for innovations in oxygen delivery systems to make them more user-friendly and less obtrusive. Portable and lightweight equipment could reduce the physical burden and improve patient mobility. Second, healthcare providers should implement more robust patient education programs, ensuring that patients are well-informed about equipment use and maintenance. Finally, incorporating psychological support and patient counseling into LTOT programs could address the emotional and social challenges associated with the therapy.

Future Research Directions

Future research should focus on exploring the development of advanced, user-friendly oxygen delivery systems and evaluating their impact on patient adherence and quality of life. Additionally, qualitative studies examining the emotional and psychological support needs of LTOT users could provide valuable insights for designing comprehensive support services. Longitudinal studies investigating the long-term effects of LTOT on patient well-being and daily life would also contribute to a deeper understanding of the therapy's impact.

Conclusion

This study provides valuable insights into the experiences of patients using LTOT, highlighting both the benefits and the challenges of this therapy. By addressing the identified issues and focusing on improving equipment, education, and support, healthcare providers can enhance the effectiveness of LTOT and improve the overall quality of life for patients with chronic respiratory diseases.

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Appendix A: Semi-Structured Interview Guide

Introduction:

Thank you for participating in this interview. The purpose of this study is to explore your experiences with Long-Term Oxygen Therapy (LTOT) and understand its impact on your daily life, challenges you face, and perceived benefits. Your responses will be kept confidential and used solely for research purposes.

Interview Questions:

1. Background Information:

- Can you describe your current health condition and how long you have been using LTOT?

2. Impact on Daily Life:

- How has using LTOT affected your daily activities and routines?
- Can you provide examples of how LTOT has changed your ability to perform tasks or engage in hobbies?

3. Social and Emotional Impact:

- How does LTOT affect your social interactions and relationships?
- Have you experienced any emotional challenges related to using LTOT? If so, please describe.

4. Challenges and Difficulties:

- What challenges have you encountered with the LTOT equipment (e.g., portability, maintenance)?
- Have you faced any difficulties in adhering to the LTOT regimen? If so, what are they?

5. Perceived Benefits:

- What benefits have you experienced from using LTOT? How has it affected your overall well-being?
- In what ways has LTOT contributed to improvements in your daily life?

6. Support and Education:

- What type of training or information did you receive about using LTOT?
- Are there any additional resources or support that you think would help you manage LTOT more effectively?

7. Future Improvements:

- What future improvements do you think would be beneficial for LTOT users?

- Do you have any suggestions for improving the LTOT experience or equipment?
- How could healthcare providers better support patients using LTOT?

8. Additional Comments:

- Is there anything else you would like to share about your experience with LTOT?

Appendix B: Focus Group Discussion Guide

Introduction:

Thank you for participating in this focus group. We aim to discuss your collective experiences with Long-Term Oxygen Therapy (LTOT), focusing on its impact, challenges, and benefits. Your input will provide valuable insights for improving LTOT management. All discussions will remain confidential.

Discussion Topics:

1. General Experiences with LTOT:

- What has been your overall experience with using LTOT? How long have you been using it?
- Can you describe any significant changes in your daily life since starting LTOT?

2. Impact on Daily Life and Activities:

- How has LTOT influenced your ability to carry out daily tasks and activities?
- What specific activities have become more challenging or easier due to LTOT?

3. Social and Emotional Aspects:

- How has LTOT affected your social life and interactions with others?
- What emotional challenges, if any, have you faced while using LTOT?

4. Challenges and Equipment Issues:

- What difficulties have you encountered with the LTOT equipment?
- How do you deal with issues such as equipment maintenance and portability?

5. Benefits of LTOT:

- What benefits have you noticed from using LTOT?
- How has LTOT contributed to any improvements in your health or quality of life?

6. Support and Training:

- How well were you trained on the use of LTOT equipment?
- What additional support or resources do you think would be helpful?

7. Suggestions for Improvement:

- What improvements could be made to the LTOT equipment or therapy?
- How could healthcare providers better assist you in managing LTOT?

8. Wrap-Up: - Do you have any final thoughts or additional comments about your experience with LTOT?