

Original article

Defining Patient and Caregivers' Experience of Home Oxygen Therapy[☆]



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ABSTRACT

Introduction: Home oxygen therapy has a great impact on the lives of patients and their families. The aim of this study is to define the opinions, perceptions and attitudes of patients and their caregivers regarding home oxygen.

Method: Qualitative, phenomenological study of a sample of 57 subjects, consisting of 18 family members and/or caregivers and 39 patients receiving home oxygen in urban centers. Five focus groups were formed between March and July 2014 in hospitals in Barcelona, Madrid and Alicante. Prior informed consent was obtained from patients and families. The study material consisted of audio recordings of all focus group interviews, transcription of selected materials and field notes. Data analysis was performed using constant comparison method, establishing 2 levels of analysis.

Results: Data from the focus groups were analyzed on 2 levels. A first level of analysis gave 21 categories. In a second level of analysis, these were integrated into 6 meta-categories: care provided by health professionals, psychological impact, care provided by commercial companies, impact on daily life, problems and satisfaction.

Conclusions: Home oxygen has a major psychological impact on the daily lives of both patients and their families, and can cause social isolation. Although the results show that healthcare professionals are highly appreciated, better coordination is needed between different levels of care and companies supplying oxygen in order to provide patients and families with consistent information and useful strategies.

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Aproximación a la experiencia del paciente y sus cuidadores en la oxigenoterapia domiciliaria

RESUMEN

Introducción: Las terapias respiratorias a domicilio suponen un gran impacto en la vida del paciente y de sus familiares. El objetivo de este estudio reside en conocer las opiniones, percepciones y actitudes de los pacientes y sus cuidadores sobre la oxigenoterapia domiciliaria.

Palabras clave:

Opinión del paciente
Oxigenoterapia
Atención domiciliaria

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Método: Estudio cualitativo-fenomenológico de una muestra de 57 personas: 18 familiares y 39 pacientes que reciben oxigenoterapia domiciliaria en núcleos urbanos relevantes. Se realizaron 5 grupos focales entre marzo y julio de 2014 en centros hospitalarios de Barcelona, Madrid y Alicante. El material de análisis constó de las grabaciones en audio de las entrevistas en los grupos focales, la transcripción de las mismas y las notas de campo registradas. El análisis de los datos se realizó a partir del método de las comparaciones constantes.

Resultados: Los datos se analizaron en 2 niveles. En un primer nivel de análisis se obtuvieron 21 categorías que, posteriormente, en un segundo nivel de análisis, se integraron en 6 metacategorías: atención facilitada por los profesionales sanitarios, impacto psicológico, atención facilitada por las casas comerciales, impacto en la vida cotidiana, inconvenientes y satisfacción.

Conclusiones: La oxigenoterapia domiciliaria tiene un gran impacto psicológico y en la vida diaria tanto de los pacientes como de sus familiares. Por otro lado, sería conveniente mejorar la coordinación entre los diferentes niveles asistenciales y las empresas suministradoras de oxigenoterapia para facilitar información coherente y estrategias útiles para los pacientes y familiares.

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Introduction

The ultimate goal of healthcare is to propose interventions that increase value for patients. A simple formula to identify this value, proposed by Porter,¹ is the ratio between outcomes and cost, with the focus on aspects of concern to the patient. Although patient satisfaction is traditionally assessed in relation to the care received, this approach is biased because perceptions of quality by persons without medical training may focus on less important aspects, such as satisfaction according to current health status (which yields little information regarding improvement) or according to subjective preferences.²

The Beryl Institute³ defines the patient experience as “the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care”. The areas in which patient experience has greatest impact⁴ are considered to be health system integration, care coordination, end-of-life care, medication reconciliation and emergency care management. Medication reconciliation and emergency care management, in particular, have a great impact on outcomes and costs. The interest in patient perspectives is in line with the notion of patient-reported outcome measures.⁵

In the healthcare sector, the right to choose is exercised through personal autonomy and informed consent.^{6,7} In general terms, encouraging patients to become involved in decisions about their health is crucial.^{3,4} Evaluating the patient experience—as a way to introduce improvements in medical care—requires a systematic approach to all patient interactions with the healthcare system.

Home respiratory care⁸ encompasses a set of varied treatments with certain common characteristics, in particular, the participation of various individuals, the great impact on patient and caregiver lifestyles, and (almost invariably) lifelong use. Although use of home respiratory care⁹ has been recognized for many years to be frequently inappropriate, no data are available that point to the role of the patient in choosing alternatives. The best results would be achieved by combining objective criteria with patient circumstances and preferences. Wise et al.¹⁰ summarize this notion, and highlight the need for care packages adapted to the requirements of each patient and the availability of local resources.

The aim of this study was to collect information on the opinions, perceptions and attitudes of patients and their caregivers regarding home respiratory care, specifically, home oxygen therapy (HOT).

Material and Methods

Study Sample

Ten patients receiving HOT were each selected from 2 hospitals in Barcelona, 2 hospitals in Madrid and 1 hospital in

Table 1
Sample Characteristics.

N = 57 participants , distributed as follows: 39 patients: 6 women and 33 men 18 caregivers: 15 women and 3 men Mean age (patients): 71.05 years Maximum age: 87 years Minimum age: 55 years Mean time using home oxygen therapy: 5.7 years Maximum time: 16 years Minimum time: 4 months Underlying condition: chronic obstructive pulmonary disease Oxygen source: static concentrator, supplemented with a portable concentrator, 16 hours mean subjective use per day
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Alicante, for a total sample of 50 patients. The patients were selected, not as a statistically representative sample, but directly by pulmonologists—members of the Spanish Society of Pulmonology and Thoracic Surgery (SEPAR)—on the basis of the relevance of each case. Unlike quantitative methods (based on probability sampling to ensure randomness), qualitative methods based on purposive sampling seek to describe and understand individual cases¹¹ as a potential source of detailed information and insights regarding the subject of study. The main goal is not measurement but understanding a phenomenon in all its complexity.¹² The criteria used to select patients from the database of each hospital were as follows: a diagnosis of chronic obstructive pulmonary disease (COPD), use of static-source and portable HOT equipment, ability to attend appointments either independently or with the assistance of a caregiver (a family member or other helper), signed informed consent and actual attendance at interview. A total of 50 patients were contacted by telephone, resulting in 57 individuals—39 patients and 18 caregivers—finally attending interviews (Table 1).

Data Collection

A phenomenological approach was adopted for this qualitative study aimed at collecting information on the experiences, opinions, beliefs and values of patients and caregivers. Data collection was through focus group interviewing, a technique that encourages disclosure of experiences, opinions, beliefs, emotions and values.¹¹ Fieldwork was conducted between March and July 2014 in 5 hospitals in Barcelona, Madrid and Alicante (Table 2). Contributors are listed in Appendix 1.

Procedure

After obtaining the informed consent of participants, focus group sessions were conducted, digitally recorded and transcribed

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