Patients experienced physiological and psychological difficulties on long term home oxygen treatment

Ring L, Danielson E. *Patients' experiences of long-term oxygen therapy*. *J Adv Nurs* 1997 Aug;26:337-44.

Objective

To describe patient experiences of being dependent on continuous oxygen treatment and their views on managing their chronic pulmonary disease.

Design

Phenomenology.

Setting

Northern Sweden, up to 100 km from the hospital.

Patients

10 patients (age range 63-83 y, mean age 72 y, 50% men) who had used home oxygen for 1 to 10 years were recruited from the Swedish Oxygen Register. Inclusion criteria were ability to communicate verbally and use of oxygen treatment ≥ 16 hours per day.

Methods

Semistructured interviews were conducted in the patient's home, lasted between 30-60 minutes, and covered the following topics: being dependent on long term oxygen treatment, experience of daily life, important human beings, and thoughts about the future. Patients were encouraged to talk freely. Interviews were tape recorded and transcribed verbatim. Transcripts were analysed by independent researchers using content analysis; intersubjective agreement between researchers was achieved.

Main results

4 categories emerged about how patients experienced long term oxygen treatment. The first category, *restricted to time and room*, related to patients' feelings of being limited in the places they could go, in the length of time they could be away from the home, by the weather, and by the schedule of their vital routines.

Patients described coping methods to deal with their immobility problems.

The second category, *an advantage for the body*, related to patients' awareness that oxygen treatment was necessary for the body and how this awareness helped patients to accept the treatment.

The third category, *living in one's own life rhythm*, referred to patients' individual body needs, and the lifestyle adjustments required to accommodate these needs and the treatment routine. Patients described the physical limitations of the disease and the importance of keeping daily, weekly, and monthly routines.

The fourth category, *put up in order to live*, related to patients' realistic perceptions of their limitations and feelings that they could tolerate and manage their treatment. Understanding the necessity for treatment and having the desire to live were reasons given for adapting to the treatment. Patients described the strength they gained from close relationships with family or friends. Most patients expressed anxiety for the future because a part of living with long term oxygen treatment was being aware that the situation would worsen at some time in the future.

Conclusions

4 categories described patients' views of long term home oxygen. Patients described experiencing mobility problems which resulted in feelings of social isolation, an awareness and acceptance of the body's need for treatment, the lifestyle adjustments to accommodate the disease and treatment routine, an ability to tolerate the management of their long term oxygen treatment, and the importance of having a relationship with a significant other.

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For article reprint: L. Ring, Department of Health and Social Care, Mid-Sweden University, S-83125 Östersund, Sweden. Fax +46 6316 5626.

Commentary

There is increasing interest and commitment among nurses to understand the perspectives of their patients better. The study by Ring and Danielson examines the experiences of patients with chronic illnesses who receive oxygen treatment at home. Advances in medical technology and the shift towards community based care have resulted in an increasing number of patients with chronic illnesses living and being cared for in the home. Therefore, this is a timely study.

The findings of the study are consistent with publications describing the disrupted lives experienced by patients with chronic illness.^{1,2} Patients talked about physical and psychological difficulties arising from their illness. Physical mobility was hindered by the need to remain close to home in case breathing difficulties devel-

oped. Activities had to be carefully scheduled and adherence to routine was important. Feelings of social isolation were related to these restrictions on patients' mobility. Although patients identified the importance of significant others, more extended social networks were not available. The role of family and friends was not pursued in depth in this study and is, perhaps, an area for future study.

The study shows how important it is for community nurses to develop an empathic understanding of patients living with a chronic illness. It points in particular to the need for a flexible and sensitive service that respects the patient's need to maintain routines and conserve physical and emotional energy for the "work" of living.

Community nurses can help patients and their caregivers to connect with a

broad range of formal and informal supports. This could create new opportunities for social interaction and promote psychological wellbeing. Coordination of services and resources within the community and secondary care sectors, and collaborative working relationships between formal and informal caregivers would maximise the benefits for patients.

Ann Ewens, RGN, MA
Community Health Studies Lecturer
Department of Community Studies
The University of Reading
Berkshire, UK

- 1 Davey B, Gray A, Seale C, (eds). *Health and disease: a reader*. Second edition. Buckingham: Open University Press, 1995.
- 2 Nettleton S. *The sociology of health and illness*. Cambridge: Polity Press, 1995.