Original Article

Medical and Supportive Care Among People with ALS in the Months Before Death or Tracheostomy

Steven M. Albert, PhD, MSPH, Adriene Whitaker, RN, MPH, Judith G. Rabkin, PhD, MPH, Maura del Bene, NP-P, MS, Toby Tider, MSW, Ita O'Sullivan, NP-P, MS, and Hiroshi Mitsumoto, MD

Department of Behavioral and Community Health Sciences (S.M.A., A.W.), University of Pittsburgh, Pittsburgh, Pennsylvania; Department of Neurology (S.M.A., J.G.R., M.d.B., T.T., I.O., H.M.), Eleanor & Lou Gehrig MDA/ALS Center, and Department of Psychiatry (J.G.R.), Columbia University Medical Center, New York, New York, USA

Abstract

People with amyotrophic lateral sclerosis (ALS) who choose tracheostomy demonstrate a strong and mostly consistent attachment to life from the point of diagnosis. It is unclear if these patients also use medical and health services to a greater degree than patients who decide against tracheostomy. In this research, patients with a high likelihood of dying over six months (forced vital capacity < 50% predicted) were followed monthly until death or tracheostomy with long-term mechanical ventilation (LTMV). Patient service use was measured by caregiver reports of 1) ALS-specific prosthetic devices, 2) allied health or medical services, 3) legal preparation for medical care or the end of life, and 4) medical care episodes. Caregivers also reported all patient prescription medications. At follow-up, 57 patients died and 14 elected to have tracheostomy and LTMV. Patients who opted for LTMV were younger and had higher household incomes. They were significantly more likely to use nasal ventilation, paid home care, and family or personal counseling over follow-up, and they were also more likely to remain on medications. The proactive orientation to health and desire to live despite severe disability reported for people choosing LTMV thus extends as well to more intensive use of medical and supportive care in the months before tracheostomy. A challenging task for clinicians is to acknowledge this strong desire to live while providing appropriate expectations for life after tracheostomy. J Pain Symptom Manage 2009;38:546–553. © *2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Amyotrophic lateral sclerosis, palliative care, mechanical ventilation, service use, tracheostomy, mental health, decision making

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Address correspondence to: Steven M. Albert, PhD, MSPH, Department of Behavioral & Community Health Sciences, Graduate School of Public Health, University of Pittsburgh, A211 Crabtree, 130 DeSoto Street, Pittsburgh, PA 15261, USA. E-mail: smalbert@pitt.edu

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Introduction

The choice of tracheostomy and long-term care in people with amyotrophic lateral sclerosis (ALS) remains relatively rare but shows wide variation across treatment sites (1.4%−15% in the United States)[1] and countries (45% in Japan).[2] It also may be increasing. In a cohort followed across the last six months of life at one multidisciplinary ALS clinic, 18% opted for tracheostomy and long-term mechanical ventilation (LTMV).[3] Prior research has examined psychosocial and demographic correlates of this choice. Patients choosing tracheostomy are younger, more likely to have children in the home, less likely to report depressive symptoms, and more likely to demonstrate strong attachment to life at the point of diagnosis.[4–6]

In this research, we asked if patients choosing tracheostomy also demonstrate greater medical and health service use relative to patients who decide against tracheostomy. Evidence of increased service use in the period before tracheostomy would indicate a consistent, continuing preference for treatment and prolongation of life in this subset of patients. Their orientation to disease management may accordingly differ from that of patients unwilling to consider tracheostomy. Patients who opt for tracheostomy may be more likely to seek alternative or experimental therapies, for example. They may also be more likely to report frustration with standard patient education and clinical management. In our experience, these patients seek more engagement by clinicians and report great frustration when they are told "go home, get your things in order, there is nothing you can do," as one patient recently complained. This broad orientation may also lead to more strain within families, who must cope with disease progression and the prospect of post-tracheostomy care. For all these reasons, we sought to investigate whether patients opting for tracheostomy differ systematically in disease management over the course of disease progression.

Method

Sample

Over 90% of patients were enrolled from the Eleanor & Lou Gehrig MDA/ALS Research Center at Columbia University. Other patients were referred from hospices, ALS support groups, or two other ALS multidisciplinary clinics. The clinic coordinator identified potential participants whose forced vital capacity was less than 50%, a value related to the risk of hospice admission and death or need for mechanical ventilation within six months.[7] Eligible patients did not meet criteria for dementia, spoke English, had an unpaid caregiver who was available for interview, were not using mechanical ventilation at baseline, were able to communicate at least "yes" and "no," and lived within a three-hour drive from the medical center. Study enrollment began in January 2000 and ended in June 2004. The Institutional Review Boards of Columbia-Presbyterian Medical Center and the New York State Psychiatric Institute approved the research protocol.

Procedures

After the clinic coordinator identified potential participants, she described the study to patients and caregivers and obtained consent for the research team to make contact. The principal investigator then called for further explanation, answered questions about the study, and obtained verbal consent; informed consent from patients and caregivers was obtained during a home visit, when interviews were conducted. Interviews were scheduled at one-month intervals until patients met a study endpoint of tracheostomy or death. Patients and caregivers completed a separate interview on the same schedule. Caregivers also completed an interview after the death of patients.

Measures

Patient service use was measured by caregiver reports of 1) ALS-specific prosthetic devices (augmentative communication, feeding gastrostomy [percutaneous endoscopic gastrostomy (PEG) placement], nasal ventilation, suction device); 2) allied health or medical services (paid home care, personal or family counseling, alternative/complementary medicine, clinical trial participation, hospice); 3) legal preparation for medical care or the end of life (health care proxy, living will, power of attorney, autopsy consent); and 4) medical care episodes (emergency department, hospital, or skilled nursing facility admissions). This