

Appendix G

ABSTRACT SUBMITTED FOR ALS/MND ANNUAL MEETING IN VANCOUVER, CANADA, 2002

Improving End-of-Life Care in ALS: Report of the *Promoting Excellence* ALS Peer Workgroup

Hiroshi Mitsumoto, New York; Mark B. Bromberg, Salt Lake; Wendy Johnston, Calgary; Rup Tandan Burlington.

Objective: Identify gaps in end-of-life care for patients with ALS, recommend standards of care, generate research, and initiate health policy changes to ensure optimal care for dying patients with ALS.

Methods: *Promoting Excellence in End-of-Life Care* and The ALS Association jointly established the ALS Peer Workgroup who identified four areas of care for study: psychosocial, communication, symptom management, and costs. The Workgroup (1) identified the current state of care in each area, (2) determined what constitutes ideal care, and (3) provided recommendations to close the gap between current care and ideal care.

Results: Selected recommendations include: Psychosocial Care: incorporate multidisciplinary approach to facilitate spiritual care; use validated quality of life instruments; establish proactive caregiver programs; Communication: improve communication about end-of-life issues, and promote a patient bill of rights to facilitate patient awareness; Symptom Management: develop end-of-life care algorithms; Cost: implement policy changes to ensure improved coverage for medical care, hospice, and caregiver costs.

Conclusions: This analysis demonstrates that end-of-life care begins at diagnosis and clinical practices vary and depend on access to care, among others.

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Filling the Gaps in End-of-Life Care in ALS: Report of the *Promoting Excellence* ALS Peer Workgroup*

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Objective: The aims of this initiative were to define the end of life clinically for patients with ALS, recommend standards of care, generate research, and initiate policy changes to ensure patients with ALS and their families are provided with optimal care during the end of life.

Background: There is substantial variance in end-of-life care for patients with ALS. End-of-life care in ALS has not been consistently defined, and decision making in this setting is complicated by logistical and financial processes. Medical care providers face challenges in defining parameters for the end of life, and in establishing standards of care specific for the ALS patient.

Methods: *Promoting Excellence* and The ALS Association jointly established the ALS Peer Workgroup to improve palliative and end-of-life care specific to ALS. Based on consensus, four areas of care were identified: psychosocial (ie. bereavement, quality of life, spirituality, caregiver issues), communication (ie. ethics, decision making), symptom management (nutritional, respiratory, pain, speech/communication), and cost (ie. resources, funding, policy). The Workgroup (1) identified the current state of care in each area, as based on published evidence (if no evidence was available, the state of care was defined by expert consensus), (2) determined what constitutes ideal care, as based on consensus, and (3) provided recommendations on how to fill the gap between current care and ideal care.

Results: The Workgroup first defined six factors that trigger the end-of-life discussion with patients and caregivers: signs of severe psychological and/or social or spiritual distress or suffering; pain requiring opiate analgesia; dysphagia requiring consideration of artificial nutrition; dyspnea or symptoms of hypoventilation and/or FVC of 50% or less; or loss of function in two or more body regions. Selected consensus recommendations include:

Psychosocial Care: incorporate multidisciplinary approach to facilitate spiritual care; use validated quality of life instruments to assess patients/caregiver quality of life; establish proactive caregiver program (education, counseling, support); Communication: intensify communication about end-of-life issues with patients and caregivers, and promote a proposed patient bill of rights to facilitate patient awareness and ensure access to good end-of-life standards of care for communication; Symptom Management: develop end-of-life care algorithms for symptom management; Cost: implement policy changes to ensure improved coverage for medical care, hospice, and caregiver costs. A need for extensive research is recognized to expand the evidence base for improving end-of-life care in ALS.

Conclusions: This needs analysis demonstrates that end-of-life health care begins at the time of diagnosis, and clinical practices vary and depend on access to care, state and Medicare regulations, health plan coverage, medical expertise and training, and time constraints in accessing care. These results clearly suggest a need for improving and standardizing care for patients with ALS, during the terminal phase of their illness.

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