

End of life

Communicating with the patient

It is important to establish the patient's wishes in regard to end of life care and preferred place of death while they are still able to communicate easily.

Communicating may become extremely difficult at end of life but eye pointing or single response answers to closed end questions can be maintained (MND Australia 2011).

MND Australia 2011

The terminal stage is recognised as progressive weakness and often a sudden deterioration over a few days or hours. The most common cause of death is respiratory failure, usually following upper respiratory tract infection.

Miller and others 2009b

Do hospice care, spiritual interventions, or advance directives improve quality of life in the terminal phase of ALS?

- Systematic studies of hospice, spirituality, and advance directives in ALS are lacking.
- *Conclusion*
 - No controlled studies examined hospice, spiritual care, or advance directives in ALS.
- *Recommendation*
 - There are insufficient data to support or refute hospice, spiritual care, or advance directives in ALS (Level U).

Mitsumoto and others 2005

Evidence-based practice parameters in ALS have provided clear management direction in caring for patients during disease progression. However, recommendations are also needed specifically for end-of-life care in patients with ALS.

The results of our literature search confirmed that there were very few studies that specifically address the topics and issues related to quality of care and quality of life in ALS, through the end of life.

Quality of life

Assessing quality of life and psychosocial status and taking steps to improve them has been elusive at end of life. Physicians need a better understanding of what factors influence quality of life in patients with ALS and their caregivers. Despite advancing illness and disability, some ALS patients experience an acceptable or even high quality of life.

Recommendations to the field for development

- Use quality of life instruments validated in ALS, which also detect psychosocial issues that should be addressed (e.g., McGill scale [24] or SEIQOL-DW).

Research recommendation

- Develop a better ALS-specific instrument to assess quality of life and psychosocial status of patients with advanced ALS.

Ethics

Patient autonomy in end-of-life decisions, as in all medical decision-making, is the accepted Western paradigm. The ethical basis and legal status of most end-of-life decisions pertinent to ALS have been established. Accepting, foregoing, or withdrawing life-sustaining interventions are actions common in ALS in the United States. However, the decision-making process at this time involves consideration of values and beliefs that may not have been previously explored by patients, families, or physicians. Moreover, the public and medical debate concerning euthanasia and physician-assisted suicide has prominently featured patients with ALS. Thus, ethical issues in caring for patients with ALS are sensitive; many physicians are not comfortable addressing end-of-life issues because of the perceived ethical complexity. One of the most difficult issues surrounding end of life is physician-assisted suicide. Some physicians have difficulty differentiating accepted clinical practices in palliative care from physician-assisted suicide and euthanasia. In avoiding the topic of physician-assisted death raised by patients, physicians may be avoiding appropriate discussion of good end-of-life care and consequently not providing appropriate palliative care. In a recent survey, pain was both frequent and severe during end of life in ALS, and approximately one-third of caregivers were dissatisfied with some aspect of symptom management. There is a gap between available guidelines and clinical practice since guidelines are not uniformly implemented across all areas of palliative care in ALS.

Recommendations to the field for development

- Implement evidence-based recommendations for terminal care in patients with ALS.
- Clarify ethical and legal issues with an ethics consultant, ethics committee, or legal counsel, as necessary.
- Discuss end-of-life issues with patients when they ask questions regarding physician-assisted death. (For many patients, questions about physician-assisted death are raised based on fear of end-of-life experiences. This is an appropriate time to provide explicit assurances of continuity of care and commitment to relieve suffering).

Research recommendation

- Investigate the prevalence of the desire to end life by suicide or euthanasia, and determine what factors or interventions should be enacted to obviate this desire.

Communication and decision making

Although physicians fully support patient autonomy in end-of-life decisions, recognizing that patients or their surrogates have the right to refuse or legally withdraw life-sustaining interventions (including ventilation, hydration, and nutrition), many are unaware of their rights. Physicians should skilfully facilitate communication about decisions regarding life-sustaining interventions. Limited information is available that identifies what are effective clinical approaches to discussing sensitive issues such as sedation, pain relief, and withdrawal of life support (including ventilation, nutrition, and hydration). Additionally, the impact of these clinical discussions and subsequent decisions on end-of-life care in ALS has not been studied.

Good communication skills are especially important when discussing end-of-life care with patients and families; yet physician education and training in these skills are largely neglected. The challenge also lies in how to improve communication skills when working with ALS patients and their families.

Recommendations to the field for development

- Improve communication skills in order to effectively discuss end-of-life issues with ALS patients and family members.
- Establish a partnership with families, take a leadership role in end-of-life discussions, and communicate the decisions made by the patient and family to other physicians and other health care professionals who provide care for the



patients.

Research recommendations

- Identify decision points during end-of-life care, and investigate the impact of using standardized treatment discussions around these decision points.
- Study optimal timing and ways to address end-of-life issues.

Policy recommendation

- Support educational programs for all levels (medical school curricula, residency training programs, and AAN educational programs, among others) that focus on improving physician communication regarding end of life.