Psychosocial factors and MND

Although often overlooked by clinicians, psychosocial factors seem to play an important role in ALS outcome (Chio and others 2009). Psychosocial care is the responsibility of everyone working with those affected by ALS (Gallagher and Monroe 2006).

Gallagher and Monroe 2006

Psychosocial care is concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into and adaptation to the illness and its consequences, communication, social functioning and relationships (National Council for Hospice and Specialist Palliative Care Services 1997).

Chio and others 2009

A longitudinal study has found that patients with psychological distress (measured with a battery of psychological assessment scales evaluating perceived stress, depression, hopelessness, anger expression, and purpose in life) had a 2.24-fold (95% CI 1.08–4.64) increased risk of dying than patients with psychological well-being. A longitudinal assessment of mood and self-esteem on survival showed that lower mood predicted a faster progression and a shorter survival. However, it is also possible that this effect is related to the fact that low mood is the consequence of having a more rapidly progressive disease.

In an analysis of the effect of quality of life (QoL) on outcome, the physical health summary measure of the SF-36 was found to be independently related to outcome, whereas only a trend was found for the mental health summary measure. In the same paper, marital status was also shown to be relevant in the outcome of ALS; patients who lived alone had a significantly worse prognosis than patients who were married.

Summary of observations

Although relatively few studies have been performed on psychosocial factors, these factors seem to have a profound effect on ALS outcome, both influencing the patients' choices on the use of life-supporting interventions, such as PEG and NIPPV, and acting on their health behaviour, on the behaviours of family and professional carers and on psychological mechanisms relevant to disease progression.

Mitsumoto and others 2005

Current clinical practice focuses predominantly on the patient's medical needs. However, emerging evidence suggests that psychosocial factors significantly influence decisions regarding advance directives and other issues including health care choices, palliative care, and attitudes about living and dying with ALS.

Psychosocial care entails many different areas, some of which are listed in Table II. Results from the analysis of the gaps in this area of care indicate that there is a lack of focus, and in some cases, a lack of awareness regarding the importance of addressing psychosocial concerns in patients with ALS.

Many physicians feel uncomfortable in approaching patients to offer psychosocial support, and others do not know what type of psychosocial care is needed. We believe that being aware of the patient's values and assisting patients in applying these values may be helpful in identifying their preferences for care at end of life.

TABLE II. Components of psychosocial care in patient, caregivers, spouses, and families

- Caregiver wellness
- Knowledge of disease-related issues
- Spirituality
- Coping
- Sexuality and intimacy
- Addressing the needs of children
- End of life expectations
- End of life choices
- Life closure
- Dying process in ALS
- How to be present with a dying person
- Withdrawal of ventilation
- Bereavement
- Role of health care team in psychosocial care

**Recommendations to the field for development**
Implement an interdisciplinary approach to care in ALS that includes psychosocial evaluation.

**Research and program development recommendations**
Increase awareness of physicians of the importance of psychosocial care for patients with ALS and their caregivers (through brochures, literature, and educational booklets, among others).

Develop specific training materials to facilitate this goal (such as case-based vignettes, teaching curricula, patient care plans, guidelines, among others).