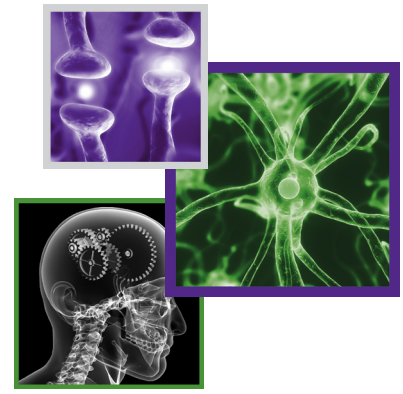
EDITORIAL

Optimizing patient autonomy in amyotrophic lateral sclerosis: inclusive decision-making in multidisciplinary care



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"The absence of a cure, a small number of evidence-based treatment options and a rapidly progressive disease course generate a 'worst case' decision-making context."

A dynamic and complex condition such as amyotrophic lateral sclerosis (ALS) presents many challenges to patient autonomy in healthcare decision-making. Patients face a range of complex decisions as their condition deteriorates. Yet the nature of the disease, and the impact of the prognosis on patients and their families, undermines patients' control of their healthcare choices. ALS is a multisystem disorder and has an average survival time of 2–3 years [1]. The absence of a cure, a small number of evidence-based treatment options and a rapidly progressive disease course generate a 'worst case' decision-making context. A delayed diagnosis can further complicate decision-making. Achieving a diagnosis can take 12 months or more. If patients have difficulty accepting the diagnosis, their uptake of ALS services may be similarly delayed.

ALS symptoms also create barriers to the patient's participation in their care. Many patients develop communication difficulties [2]. A smaller number experience subtle changes to cognitive function [3] and behavior [4]. Apathy, executive dysfunction and memory loss potentially reduce patients' participation in decision-making, and may impede the timing and quality of their decisions. Several interventions for ALS care, including nutrition, hydration and respiratory support, are contingent on well-timed implementation [5,6]. However, optimal timing of symptom management may be at odds with patients' readiness to consider these complex interventions.

Patients and families need time to come to terms with their changing situation before they can fully participate in decision-making. Reactions to the diagnosis can have an influence on patients' willingness to engage with healthcare services [7] and their preferred role in decision-making. Desire for autonomy is an individual choice, reflecting patients' attitudes to life, personal circumstances and healthcare experiences [7]. Patients and families are confronted by escalating degeneration and loss, over which they have no control. Autonomy over choices of symptom management and quality of life may become a way for patients to exert control over their continually changing situation [8]. Three aspects of ALS service delivery have been found to facilitate patient autonomy in decision-making: access to specialized ALS multidisciplinary care [7];

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use of patient-centered approaches to decision-making [9]; and the inclusion of family carers in decision processes [10]. Their influence on patient autonomy is discussed below.

Access to specialized multidisciplinary care

Specialized ALS multidisciplinary clinical care offers comprehensive, coordinated and expert care to patients and families [11]. Patient survival times are improved [12], and clinic settings provide a supportive environment for decision-making between patients, families and health professionals [7,10,13]. Patients and carers value the expert information and care they receive [7,10], while clinicians view the clinic as the ideal setting to guide patients through difficult and complex decisions [13]. Patient autonomy is facilitated by the patient-centered service offered by specialized ALS multidisciplinary models of care [11]. As many decisions require consultation with multiple health professionals, the structure of multidisciplinary clinics streamlines communication between patients, carers and health professionals within a single healthcare setting.

Nevertheless, access to coordinated, specialized ALS services can be difficult to achieve outside of metropolitan areas. Patients in regional or rural settings rely on generalist health service providers who may lack experience or understanding of ALS [8]. Patients and families become the educators of their health professionals on the complexities of their care. Moreover, priority systems of busy health services are rarely in step with the rapidly changing needs of people with ALS [13]. Patients' autonomy over the way they live their life becomes compromised by the availability and timing of their care options.

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Patient-centered care

Patient autonomy in healthcare decision-making is a tenet of patient-centered approaches to care [9]. Patient-centered care, encompassing shared decision-making, seeks to promote collaboration between patients and health professionals, and optimize consumer engagement in treatment decisions. Patients are empowered to make the best possible decisions for their individual circumstances. The preferences and values of the patient are taken into account, the available options are deliberated, and a treatment is selected. Patient-centered models of care facilitate autonomy throughout the decision process [14], and offer a structure for patients to maintain control over their treatment choices.

Shared decision-making models, developed for chronic disease and cancer care, are considered to be the gold standard. Yet these linear process models lack the complexity needed to support decision-making in multisystem and rapidly progressive conditions. ALS patients use a cyclical pattern of decision-making, as they react and adapt to ongoing change [15]. Many ALS patients avoid looking at the future and the decisions that lie ahead of them [7,16]. Others prefer to rely on family and health professionals to make decisions on their behalf [10]. Experiences of grief, recurrent loss and poor adjustment to change potentially hinder patients' acceptance of well-timed, evidence-based care [13]. Tension arises between health professionals' respect for patient choices, and clinical goals of delivering high-quality care [13]. Patients' autonomy is at odds with their best interests should patients choose to disengage with services and risk compromising their health status.

Carer inclusion

Conflict between patient autonomy and participation in care is also of concern to family carers [10]. Carers have substantial involvement in ALS patient care [17] and value patients' autonomy over their choices [10]. As well as offering emotional and logistical support, carers promote patient autonomy through synthesis of ALS health information and advocacy in healthcare appointments [10]. Patient-centered care recommends the inclusion of family carers in decision-making to form collaborative relationships for care [18]. Decision-making partnerships develop between patients, carers and health professionals when they work together to achieve the patients' best possible outcomes [10].

However, carer participation in decision-making and advocacy is moderated by the high burden and distress they experience [17]. Similar to health professionals, carers may find themselves torn between respect for patient autonomy and supporting patient participation in care. Divergence develops between patient and carer views of the patient's best interests, particularly when carers consider the patient's judgement to be affected [10]. Barriers to patient autonomy may also arise from the patient–carer relationship. The need to maintain normality and privacy prevents patients and families exploring

the options available to them [7]. Should carers act as gate keepers to protect patients from discomforting information and intrusion by health providers [10,13], patient engagement is likely to be constrained.

The dynamic nature of ALS shapes patient participation in decision-making. The issues surrounding patient autonomy in ALS are complex, requiring multiple strategies to optimize patient engagement. One approach is to strengthen ALS decision-making processes and partnerships. ALS multidisciplinary care presents an ideal context for decision-making models that reflect the changing needs of ALS patients; that is, cyclic patterns of adjustment as patients adapt to ongoing change [15]. Development of cyclic, rather than linear, patient-centered care models [19] could facilitate patients' movement through stages of complex decision processes, and enhance health professionals' understanding of the challenges that patients encounter. Clinics are then better positioned to work with the range of patient responses to ALS, and establish enduring partnerships with patients and carers. ALS-specific decision support tools have the potential to enhance communication between patients, carers and health professionals. However, decision aids specific to the ALS disease course are yet to be developed. Tools that reflect the patient experience and support care partnerships, as well as informing them of treatment options, can only promote patient autonomy within the specialized ALS multidisciplinary care setting.

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