

Emotional Regulation in Amyotrophic Lateral Sclerosis

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Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disorder involving motor neurons of the cerebral cortex, brain stem and spinal cord. The loss of motor neurons quickly generates a progressive muscle paralysis usually leading to death from respiratory failure in 3-5 years. The cause of the disease is unknown and there is currently no effective treatment. Emotional regulation has not often been studied in ALS. Most published studies have assessed the psychopathological manifestations involved in this disease, essentially depression and less frequently anxiety [1]. They have shown that major depressive or anxious episodes are not frequent in ALS patients, although moderate depressive or anxious symptoms are often observed [2], but less frequently than in other neurological diseases like multiple sclerosis or Parkinson's disease [3]. Thus depressive symptoms are not correlated to the duration or the severity of the disease [4]. However anxiety symptoms appear to be present more often in the months following the diagnosis, and then they decrease. When considering the rapid evolution and the dire consequences of ALS, these observations are surprising. In order to better understand how the patients cope with their disease, it seems interesting to investigate their coping mechanisms on one hand, and the emotional regulation processes involved on the other. Coping has been described by Lazarus and Folkman [5] as "the constantly changing cognitive and behavioural efforts to manage the specific external or internal demands that are appraised as taxing or exceeding the resources of the person". Different coping strategies are described which can be grouped into two main domains: problem-focused coping, where the person tries to adapt by modifying the stressful situation and emotion-focused coping, where the person tries to modify his cognitive and emotional state. Literature shows that problem-focused coping is considered a more efficient way to reduce stress, anxiety and depressive symptoms.

In a previous study with a population of 169 ALS patients, we observed that 50% of them presented depressive symptoms and 60%, anxious symptoms, although scores were low for anxiety and very low for depression. Patients experienced more negative subjective emotions than positive ones, and preferentially used emotional regulation as a coping strategy [6]. Emotional regulation and palliative coping strategies were positively correlated with negative emotions, depressive and anxiety symptoms and apathy. Distraction and cognitive avoidance strategies were negatively correlated with anxiety, depression and apathy, and positively with positive emotions. Such strategies can be considered as adaptive ones. These results confirm that emotion-focused coping is related to more psychological distress, which has been observed in various somatic and neurological disorders. Baker's model of emotional processing divides it into five domains: emotional experience, emotional expression, labelling, linkage and awareness [7]. This model refines our comprehension of the patient's adaptation, and has been carried out in multiple sclerosis [8] for example and is being used with ALS patients.

The relative psychological well-being of ALS patients could be partially explained by the attitude of their caregivers. In fact the ALS caregivers play an important role while the patient is becoming rapidly physically dependent [9]. Studies have observed that the caregivers are often more anxious and depressed than the patients, even if their emotional state does not seem related to the duration or severity of the disease [10]. Thus, it seems necessary to assess not only

the caregivers' psychological states, but also the interaction between the patients and the caregivers. In fact if the caregiver is anxious or depressed, the patient will probably feel that he is more of a burden. The dyadic coping model of Bodenmann [11] details how couples manage relational stress. In fact, dyadic coping is supposed to be a major predictor of how couples are dealing with chronic illness [12]. According to Bodenmann, dyadic coping concerns the strains that affect one partner of the dyad, as well as the efforts of both partners to handle the stressful events. It includes the stress signals of one partner, the verbal or nonverbal coping responses of the other partner, and coping efforts of both. Different kinds of dyadic coping are described, grouped into two main categories. A positive type of dyadic coping which corresponds to a supportive approach, a delegated type of dyadic coping and a common type in which one partner takes over daily tasks, communicates empathy and conveys solidarity. Finally, there is a negative form of dyadic coping characterized by hostility, with one partner disparaging, distancing himself, mocking, using sarcasm, or minimizing his partner's stress. Dyadic coping can also be ambivalent, with one partner providing support, but unwillingly, or of a superficial nature. In ALS, Olsson et al. [13] have observed the positive effect on one partner of a psychological intervention on the other partner of the dyad. We are currently conducting research to assess these variables in ALS patients and their spouses, and this is the topic of the Unglik's PhD.

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