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Converse Well-Being of Locked-In Patients and Caregivers

Simone Renault, BS, BA and Amar Dhand, MD, DPhil

Department of Neurology, Brigham and Women's Hospital, Boston, MA

We read with interest the study by Linse et al,¹ which examined the quality of life of both patients with locked-in state amyotrophic lateral sclerosis and their next of kin. They showed that patients' quality of life was inversely correlated with the quality of life reported by family members. The findings reveal the rippling and converse effects of disease beyond the index patient, forcing an expansion of the usual patient-centric view. Negative effects of illness on caregiver quality of life and mental health are well described.² However, the study also showed that family members may have adjusted to the situation less quickly; family members assumed that patients had lower quality of life than the patients actually did. These misperceptions have consequences for end-of-life expectations and conversations. Overall, this article is part of a growing literature that stresses the need to expand the understanding of neurological illness to include information on a patient's social circle.

Study of the social effects of neurological health and illness may be enhanced by a personal network approach to map and trend social information in a useful way. The personal network method situates the patient within a *social connectome*, identifying various individuals and characterizing the nature and strength of their relationship to the patient and to one another (Figure). The network is populated with both kin and nonkin joined by weak and strong ties. It can reveal distinct structural motifs, such as clusters of like-minded individuals, and compositional traits, like the diversity of health habits enveloping the patient, all of which may change over time.³

Most network analyses have been used to probe patient-level incidence and outcomes of breast cancer⁴ and type 2 diabetes.⁵ However, Dr. Linse et al's study shows the value of studying caregiver perspectives and outcomes separately from patients' outcomes.

Therefore, a network approach could map the network of the patient, map the network of the caregiver(s), and identify structural patterns (eg, shrinking over time) that may differ for the two parties. The approach could be valuable to assess mechanisms of the quality of life and well-being outcomes and their divergence within the social unit. Such network information could lead to network interventions to improve end-of-life care for patients and their loved ones.

Author Contributions

Both authors contributed equally to drafting this letter.

Potential Conflicts of Interest

Nothing to report.

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FIGURE.

Personal network of an 82-year-old single female who presented with stroke. The ego, or the patient, is connected to members of her personal network, by either a strong tie (solid line) or weak tie (dotted line). The personal network of this patient includes subgroups of friends and family members. The patient's niece, though strongly tied to the patient, is a stranger to the other members of the patient's network.