Development of an explainable clinical decision support system for the prediction of patient quality of life in amyotrophic lateral sclerosis

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A Computer System to Alert Clinicians of Patients' Low Quality of Life

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What is it about?

This is a study towards the development of a computer system that could be part of the clinical workflow of the treatment of Amyotrophic Lateral Sclerosis (ALS) in the future. This is known as a clinical decision support system and it will alert clinicians when the caregiver of a person with ALS experiences low quality of life. This study was based on information collected from people with ALS and their caregivers in Ireland via interviews on a variety of topics (such as demographic, financial, psychological, use of services), and through the Irish ALS Registry, which contains clinical details on the patients.

The method we used was Machine Learning: a popular field of Computer Science that allows computers to be trained on large amounts of information, identify associations and complex relationships among them, and “learn” how to predict a specific outcome. In our case, the models were trained on the information we had from the people with ALS and their caregivers, and “learned” to predict whether a patient experiences high or low quality of life. It is important to clarify that the Machine Learning models “learn” from existing patients, and they can predict the outcome for future patients. Finally, we are working on the explainability of our

system, i.e. our system will not only predict "low" quality of life, but it will also explain the logic behind this decision to allow the clinician's and patient's evaluation, if needed.

Why is it important?

As ALS is currently incurable, treatment is mostly palliative and aims to alleviate symptoms and improve quality of life. Quality of life is defined as the general well-being of a person, and it includes the individual's perception of their physical, social, and psychological state. Knowledge of the determinants of a patient's QoL is of interest to clinicians as they can better guide their treatment and support. The clinical decision support system we are developing, can alert clinicians if a person with ALS is having low quality of life. This alert would facilitate the initiation of a discussion with them and the healthcare team to identify ways to assist them.

Perspectives

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The clinical decision support system is under development, but it still requires evaluation. This would include user studies to improve its usability for the clinicians that will be using it and for the improvement of the machine learning model, as well as evaluation on new patient information. Additionally, we are also working on a similar model to predict the quality of life of the caregivers, as they are key figures in the care of ALS and their well-being is also affected. We aim to incorporate these models in one system that will assess the well-being of both patient and caregiver, and that this will lead to more awareness of this aspect by the clinical team and more timely and tailored supports for them.
The involvement of clinical researchers in this project has been very important as they can better identify the needs of clinicians, while they are also experts in the disease, and could provide the necessary guidance for the development of the clinical decision support system according to these aspects.

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