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Using Patient Information for the Prediction of Caregiver Burden in Amyotrophic Lateral Sclerosis

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ABSTRACT

The aim of this study is to create a Clinical Decision Support System (CDSS) to assist in the early identification and support of caregivers at risk of experiencing burden while caring for a person with Amyotrophic Lateral Sclerosis. We work towards a system that uses a minimum amount of data that could be routinely collected. We investigated if the impairment of patients alone provides sufficient information for the prediction of caregiver burden. Results reveal a better performance of our system in identifying those at risk of high burden, but more information is needed for an accurate CDSS.

KEYWORDS

Amyotrophic Lateral Sclerosis; Machine Learning; Random Forest; Caregiver Burden

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1 EXTENDED ABSTRACT

Amyotrophic Lateral Sclerosis (ALS) is a fatal and currently incurable neurodegenerative disease that leads to the progressive death of motor neurons. The inevitable and progressive nature of the disease can prove very challenging for the patients and their caregivers. Our work has focused on using technology in the form of Clinical Decision Support Systems (CDSS), to assist with the timely prediction of a caregiver's feelings of burden. We have previously created a model using 76 parameters (the patient's and caregiver's demographic, financial, and health status)[1]. Despite that model's good performance, in this work we aim to reduce this number of features that the system uses in order to increase its usability and its compliance with the General Data Protection Regulations' data minimisation principle. A review of papers on the factors associated with caregiver burden found evidence of correlation between caregiver burden and the patient's physical functioning and behavioural impairment[2]. At this stage we wanted to discover how accurately we can predict caregiver burden using these features alone.

The data we used to build the model were collected at three time-points, via interviews and electronic records from 90 patient-caregiver pairs. The predictive variables included the patient's sex, age, site and age of onset, first symptom, El Escorial diagnosis, the ALS Functional Rating Scale-Revised (ALSFRS-R) scores , the patient's stage at the time of interview, and the patient's cognitive and behavioural impairment. The burden was split in two to create the high and low burden classes. The method used for the creation of the model was Random Forest, which was trained in 10-fold cross-validation (CV). For the training set we used of 75% of the full dataset, and the remaining 25% was kept as an independent test set.

The average sensitivity and specificity from the CV were 0.67 and 0.66 respectively, which gave an average Matthews correlation coefficient (MCC) of 0.33. Based on the independent test set, the sensitivity and specificity were 0.84 and 0.61, while the MCC was 0.47. The results suggest that we can more accurately predict caregivers at risk of experiencing high burden while caring for a patient with ALS. But it is clear that the patient's physical and cognitive impairment are not the only predictors of caregiver burden and a CDSS would require more information.

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