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Editorial

Assessing communication, beyond just words

The Mariam-Webster dictionary defines "communication" as the "process by which information is exchanged between individuals through a common system of symbols, signs, or behavior." [1] Most standardized measures of communication focus on expressive and receptive language abilities primarily through use of spoken words, giving less attention to non-verbal communication skills. The Observer-Reported Communication Ability (ORCA) scale set out to capture and quantitatively assess the rich non-verbal and pre-verbal abilities of individuals with neurodevelopmental disabilities. This is through a proxy-report measure completed by the true expert in their communication abilities, their caregiver. The ORCA was initially developed for the Angelman syndrome population, however, with significant phenotypic overlap between various genetic neurodevelopmental disorders, it is anticipated that this measure will be applicable broadly across the field, filling an important gap in psychometric assessment of communication abilities in this population [2].

Rett syndrome, like Angelman syndrome, is a genetic neurodevelopmental disorder that is typically characterized by global developmental delay, intellectual disability, and severe communication impairment. As highlighted by Reeve et al. Rett syndrome tends to affect females more than males and often has more severe motor impairment than Angelman syndrome [3]. There is evidence that communication abilities are among the top concerns for caregivers of individuals with Rett syndrome across nearly all age groups, demographics, and genotypes as well as the top reason for improvement on the clinical global impression scale [4]. Finally, when defining clinically meaningful improvement in communication, caregivers had variable expectations ranging from faster eye gaze, improved fine motor hand control with the ability to point, as well as desires for spoken or written language [5]. Importantly, Reeve et al. note that the ORCA measure has the capability to capture all of the major forms of communication concepts identified as important to the Rett syndrome caregivers including requests or refusals, sharing feelings, seeking attention, conversational and pragmatic skills, as well as capturing communication via gestures or assistive adaptive communication devices [3]. Through this study, the field now has a valid and reliable measure of the broad landscape of communication abilities in individuals with Angelman and Rett syndromes, filling a critical gap in clinical outcome measure assessments that may have a huge impact on clinical trial success in the coming years.

One final consideration, however, is whether the field will require each individual genetic neurodevelopmental disorder with communication impairment to seek a validation study of the ORCA scale in their population? In training, we are taught the difference between "lumpers and splitters." "Lumpers" are those who group conditions based upon unifying features while "splitters" divide conditions according to unique characteristics. With the genetic evolution of neurodevelopmental and epileptic disorders, it seems we are in the era of the "splitters", dividing neurodevelopmental disorders into groups according to a gene of interest, and sometimes further sub-grouping by type of genetic variant, functional consequences on the protein, or other clinical features present. However, it may be worth considering whether splitting by gene is ethically or financially viable when evaluating tools or treatments which could have broadly applicable uses, like the ORCA.

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