

Inclusive communication: a starting point for educational care with people with complex communication needs and minority diseases

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INTRODUCTION

Inclusive communication recognises that all people need to be heard, that their different ways of communicating should be respected and that the use of alternative and augmentative communication strategies that contribute to functional communicative exchange should be encouraged. People with severe intellectual disabilities (SID) have complex communication needs (CCN). They show a delayed pattern of acquisition of communicative competence compared to normative groups.

The aims of this work were:

- The identification of the communicative modalities used by the group of people with Complex Communication Needs-Severe Intellectual Disabilities and minority diseases (MiDi).
- The recognition of Augmentative and Alternative Communication System used by people with MiDi.

MATERIAL and METHODS

A survey divided into several sections was used. The first section included the demographic data of the respondents (age, gender, clinical diagnosis, relationship of the respondent to the person diagnosed with the rare disease). The second section of the questionnaire collected information about primary and secondary communication modality. In the following sections, following the Likert-type scale procedure from 1 to 5 (1 = never, 2 = sometimes, 3 = half the time, 4 = almost always and 5 = always), we asked about the modes of communication and the communicative functions presented by people with CCN-SID-MiDi.

Participants:

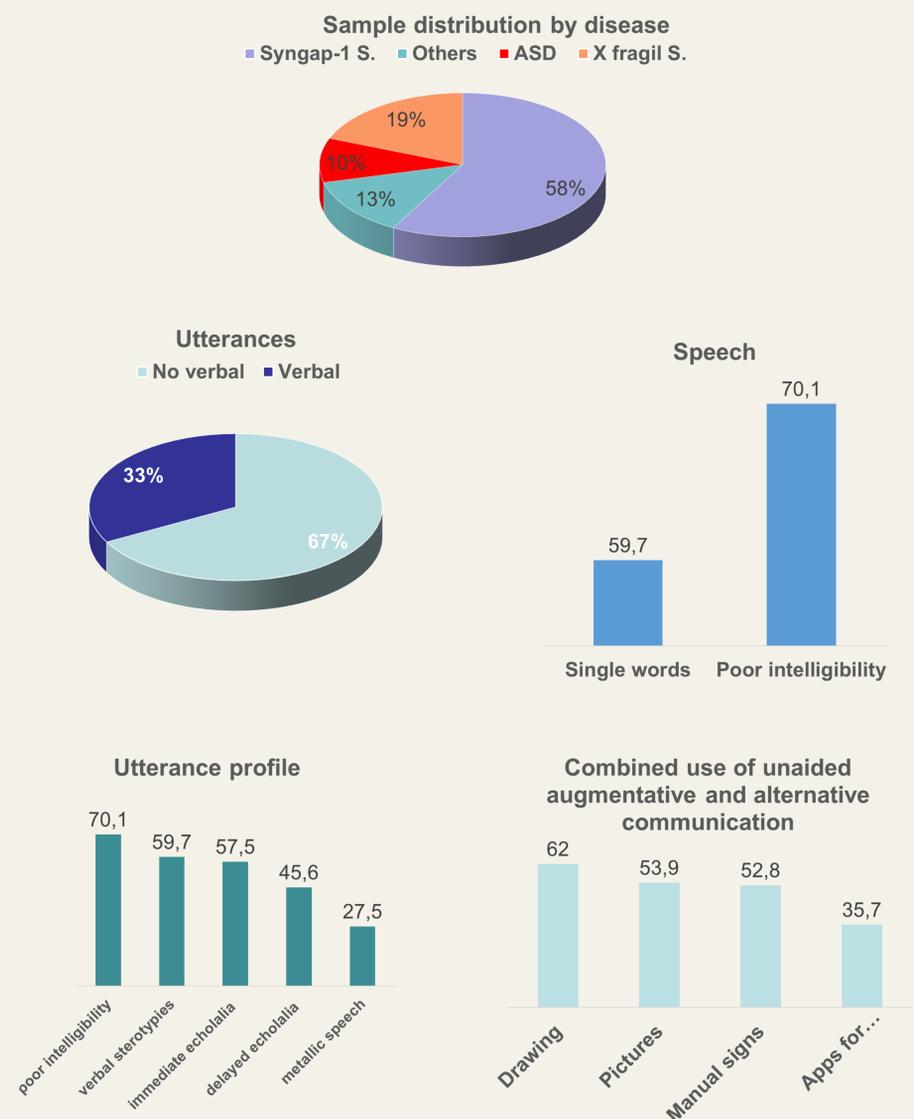
Parents or professionals provided information on 87 subjects with various diagnoses of minority diseases, complex communication needs and SID. 51 were from male (58.6%) and 36 were female (41.4%), ranging in age from 2 to 48 years ($M = 13.02$, $SD = 10.78$). Data were collected in several countries (Some Latin American countries, Spain and USA). Of the respondents, 79.3% were mothers, 13.8% were fathers, and 6.9% were professionals working with people with CCN-SID-MiDi. The data came from people with minority syndromes such as Angelman, Cornelia de Lange, Prader-Willis, Rett, Syngap1, among others.

RESULTS

Our results show that 67% of people with CCN-SID-MiDi use non-verbal means of communication (crying, vocalisations, idiosyncratic gestures), they are able to produce a few single words (59,7%) of very low intelligibility. Their productions present verbal stereotypies (59,7%), immediate echolalia (57,5%), delayed echolalia (45,6%), although they do not present a metallic tone (27,5%).

In terms of AAC systems, they tend to use a combination of low-tech aided AAC systems such as drawn communication boards (62%), picture communication boards (53.9%), and unaided AAC systems supported by manual signs with lexical linguistic value (52.8%). High-tech devices are used but to a lesser extent (35.7%).

FIGURES



CONCLUSIONS

- The communication modality of persons with MiDi is fundamentally non verbal. When they use a verbal modality, single words and severe intelligibility difficulties are the main speech features. Actually, single words display echolalic and stereotyped language forms suggesting communicative intention although scarce language ability.
- Everyday communication with persons with MiDi display combined unaided communication systems use based on drawings, pictures and manual sings suggesting basic symbolic forms of communication.
- To improve inclusive communication should be take into account the communication intention and the basic symbolic forms of communication that display persons with MiDi.

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