

Analysis of the Communicative Intention in People with Intellectual Development Disorder, Complex Communication Needs and Minority Diseases: First Step Towards Inclusion

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Introduction

The educationists are mainly concerned with the educational needs of students with any type of disabilities and try to develop an inclusive educational model based on the idea that children with special educational needs should spend most of their time attending regular classes in ordinary classrooms, together with other students of their age. However, the reality is quite different. There is a group of people with severe intellectual disabilities and complex communication needs for whom this formal model of education is almost inaccessible. Addressing the desire for acquiring knowledge of students with profound Intellectual Development Disorders (IDD) is a challenge for the policy-makers in the discipline of mass education.

Intellectual Disability (ID) is conceived as a set of significant limitations both in intellectual functioning (IQ score below 70) and in adaptive behaviour (abilities to adapt to practical, social, and conceptual demands). People with profound intellectual development disorders have complex communicative expressions because they have limitations in using the usual channels of communication such as speech or manual gestures with linguistic value at the lexical level. However, this group shows a communicative intention, i.e., they show a desire to

communicate verbally or non-verbally, trying to interact with others and taking the initiative to seek the resources available to them to interact (Postigo & Palacios, 2021). Furthermore, its origin must be before the age of 18.

The fifth edition of the Diagnostic Statistical Manual of Mental Disorders uses the term Intellectual Developmental Disorder (IDD), according to the degree of severity (mild, moderate, severe, and profound) of the incapacity (APA, 2014). Following the 11th edition of the International Classification of Diseases (ICD-11) published by the World Health Organization in 2019, the most affected IDD would be profound IDD. This is a condition that originates during mental development, characterised by very low intellectual functioning and adaptive behaviour. This group often has motor and sensory problems and needs help from their environment to achieve adequate care. This population acquires basic academic skills, though their communication competence is very limited (cf. WHO, 2018).

In relation to the above, people with profound IDD show little or no linguistic expressive ability and use facial expressions, body language, contact gestures, distal gestures, manual signs, vocalisations, verbalisation, disruptive behaviours, use of concrete object and use of the pictographic symbol (Cascella and McNamara, 2005) to convey their needs and feelings. In other words, most people with profound IDD have difficulties in carrying out functional communicative exchanges through conventional means of communication (speech, signs, pictograms, etc.) in everyday life situations. In this circumstance, the person is said to present what is known as Complex Communication Needs (CCN) (Balandin, 2002, Calleja & Rodríguez, 2018). CCN refers to severe impairments in speech, language, and communication at both the comprehension and expressive levels (Calleja et al., 2021).

The presence of CCN in individuals does not imply the absence of communicative intentions in them. Communicative intention is understood as the desire to communicate verbally

or non-verbally, seeking to interact with others and having the initiative to seek the resources available to interact (Postigo & Palacios, 2021). Intentional communicative acts follow an evolutionary sequence in the specific normo-typical population, first to express protests, then to make requests for actions or objects, to comment on an action or object and to respond at the end. This sequence is observed more slowly in individuals with IDD and CCN (Grieco et al., 2018).

Therefore, communicative competence in individuals with IDD and CCN is very difficult to assess accurately. Therefore, the Royal College of Speech and Language Therapy (RCSLT) mentioned in 2016 that the identification of the pre-linguistic communicative behaviours such patients present is vital to describe their communicative profile, as a starting point for intervention in communication and language (RCSLT, 2006). This profile identifies the strengths and weaknesses of the user and the communicative challenges faced by this population in their daily life activities. The communication profile is therefore a comprehensive list of the communicative forms and functions of the person with IDD (Casella & McNamara, 2005).

The communicative forms refer to the communicative modality used and the functions of the reasons why people with IDD and CCN initiate communicative attempts.

Among the communicative modes, a distinction is made between primary and secondary ones. The preferred and effective communicative mode which is mainly used to carry out communicative exchanges is called the primary communicative modality. The child resorts to a secondary communicative mode when it fails to communicate. Modes of communication in this population include the modes displayed by children during their first two years of life with normo-typical development as well as the use of Augmentative and Alternative Communication (AAC) systems (Quinn & Rowland, 2017). Augmentative and Alternative Communication (AAC) systems involve all the ways a person

undertakes to communicate when speech cannot be used. People of all ages are subjects for the use of AAC when they have speech, language, or communication problems. The American Speech-Language-Hearing Association (ASHA) in 2021 stated that the term augmentative refers to a mode of communication that helps to enhance oral-verbal expression, while the alternative mode is used for modes of expression that completely replace oral-verbal expression (ASHA, 2021).

Among the communicative functions presented by people with IDD and CCN, four are of vital importance. They make communicative attempts to refuse something, to obtain something, to initiate social interactions or to engage in information exchanges (Quinn & Rowland, 2017).

Conceptualization of Inclusive communication

Inclusive communication emphasizes that people with CCN should be heard, their different ways of communicating should be respected and the use of Alternative and Augmentative Communication strategies contributing to functional communicative exchange must be encouraged. Inclusion should therefore, aim to create a supportive and respectful environment that encourages and enhances the participation of all participants in each context. By knowing and incorporating inclusive communication skills into everyday exchanges, the possibilities for positive and effective interactions with all people are increased. In short, it is about giving a voice and promoting the provision of the necessary support so that people with CCN are heard and considered.

A case of special vulnerability is people with some distinct diseases that affect less than 5 cases per 10,000 people. These are called Minority Diseases (MIDI).

In Andalusia¹, a region in Spain the schooling of students with special educational needs takes place, preferably, in regular

1. Andalusia is a region in Spain bordering the Atlantic Ocean and the Mediterranean Sea.

educational centres. Special education centres are intended for students with severe or profound intellectual disabilities, with severe developmental disorders or affected by multiple disabilities. Therefore, we find three types of schooling in ordinary centres for pupils with special educational needs:

- In an ordinary group (Modality A).
- In an ordinary group with specialized support during different periods (modality B).
- In a specific special education classroom (Modality C).

People with CCN-IDD-MIDI are characterized by being very affected, very vulnerable, and unable to be included in mainstream schools due to their severe limitations. Few studies analyse the communicative intention and the communicative profile of people with CCN-IDD-MIDI.

In this paper, we have aimed to analyse the communicative intention of CCN people with IDD as a first step towards giving them a voice. Specifically, the aim has been

- a) To study the educational modality used by the group of people with CCN-IDD-MIDI.
- b) To analyse the communicative modality used by the group of people with CCN-IDD-MIDI.
- c) To examine the main communicative functions of people with CCN-IDD-MIDI.

This paper analysed the responses of 83 parents and caregivers of patients with Complex Communication Needs and Intellectual Development Disorders (hereafter CCN-IDD) obtained through a worldwide online survey developed by the NECCO-ENMI thematic network². In other words, the present study was carried out worldwide, using data provided by parents and caregivers of people with Complex

2. Red Temática NECCO-ENMI (Necesidades Complejas de Comunicación y Enfermedades Minoritarias). Málaga University (Spain). www.necco.uma.es

Communication Needs, IDD and Minority Diseases taken from the Complex Communication Needs and Minority Diseases Survey (www.Necco.uma.es). 79.5% of the participants in the online survey were mothers, 13.3% were fathers and 7.2% were professionals working with people with CCN and IDD.

Methods of Research

A global online survey was developed within the thematic network Complex Communication Needs and Minority Disorders funded by the University of Malaga (Spain). The research team was constituted of 18 professionals from different fields (psychologists, speech therapists, biologists, geneticists, computer scientists, translators, family members and caregivers). Data were collected in several countries (Canada, Germany, Spain, the USA, and some Latin American countries).

Parents or professionals provided information on 83 subjects(patients) with various diagnoses of clinical minority, complex communication needs and IDD. Of the total responses collected through the questionnaire, 50 were male subjects (60.2%) and 33 were female patients (39.8%), The age of the subjects ranged between 2 to 43 years ($M = 9.68$, $SD = 7.53$) The data came from people with minority syndromes such as Rett, Angelman, Syngap1, Prader-Willis, among others.

This survey was divided into five sections. The first section included the demographic data of the respondents (age, gender, clinical diagnosis, and relationship of the respondent to the person diagnosed with the rare disease). The second section of the questionnaire collected information on the educational modality they attend (fully integrated, partially integrated or in a specific classroom). The answers in the second section were: do not attend, have been attending this educational modality for 0-3 years, have been attending this educational modality for 3-6 years or have been attending this educational modality for more than 6 years. A third section asked about primary and secondary communication. 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-IDD-MIDE. MIDE in clinical psychology refers to a comprehensive care model for people with disabilities.

Procedure of data collection

From June to November 2019, the online survey was designed to determine the complex communication needs of people with minority diseases. The survey was sent by email and data were collected until January 2021. Respondents gave consent for the data to be used for research purposes. This study has been approved by the Ethics Committee of the University of Malaga following the ethical standards of the Declaration of Helsinki for human subjects.

Following the objectives set out in this study, the educational modality used by people with CCN-IDD-MIDE, their communication modality (primary and secondary), communication modes and functions were analysed. Given the characteristics of the study, descriptive analyses were carried out using the SPSS version 26 statistical package.

Results

Attendance at educational modality

Educational modality is defined as the method of student's participation in instruction in person, remote or hybrid. The results of this section of the survey showed that 38.6% of respondents indicated that people with CCN-IDD-MIDE do not attend mainstream inclusive schools, Those who have been attending inclusive classes between 0 and 3 years are 9.6% of the total subjects under study, between 3 to 6 years are 4.8%. Only 8.4% reported that they have been attending mainstream classes for more than 6 years.

In Spain, there is an educational modality called B, in which pupils with special educational needs are included in the regular classroom for some hours of the curriculum. In other words, they are partially included. 44.6% of respondents stated that people with CCN-IDD-MIDE have never received this type of educational attention, while the attendance with partial inclusion of 2.4% ranged between 0 to 3 years, 4.8% have been attending this educational modality for 3 to 6 years and only 4.8% stated that they have been attending the “partial inclusion” modality for more than 6 years.

In the educational modality of attending specific classrooms, 22.9% of respondents indicate that persons with CCN-IDD-MIDE do not attend specific classrooms, 16.9% indicate that they have been receiving this type of educational attention for between 0 and 3 years, 9.6% have been attending this educational modality for between 3 and 6 years and 13.3% indicate that they have been attending specific classrooms for more than 6 years.

Communicative modality

The results come from the open response phase of the survey in which family members or carers of people with CCN-MIDI are asked about which communicative modality the subjects used as primary and secondary. This analysis shows that the primary communicative modality of people with CCN-MIDI is through oral utterances (shouting and vocalisations) and physical manipulations such as hand pulling or showing the desired object. As a secondary modality, disruptive behaviour is observed when the primary modality does not meet their needs or interests.

Oral-verbal communicative attempts for 71.2% of the study-population were hardly or not at all intelligible, and only 15% showed comprehensible production for people outside the immediate nucleus (most of the time or always). According to the respondents, only 36.5% of people with CCN-MIDI

showed personal speech that could be correctly interpreted by their immediate environment.

According to the informants who responded to the survey, 53.9% of people with CCN-MIDI do not speak, their interactions are based on laughter, crying, and facial expressions. These people use delayed echolalia (23.9%), immediate echolalia (27.14%) and stereotypes, i.e. repetition of words, phrases or melodies (33.3%). 29.48% use single words and 22.22% use up to 4 oral-verbal productions.

According to the mode of communication based on AAC, 22.53% of this group can communicate almost always using picture communication boards, 26.61% can interact with two-dimensional pictographic symbol communication boards and 28.76% use natural manual signs in communicative attempts.

Communicative functions

From the survey responses, it appears that 91.25% of people with CCN-MIDI can make communicative attempts to obtain an object or perform an action at least half of the time. 75.3% initiate communicative attempts with the intention of asking for help. 67.9% of people with CCN-MIDI say 'hello' at least half of the time. 50% of the population can ask questions, 51.6% can answer a question, 50% is able to share their interests, 53.84% can give instructions to others, and 74.35% can affirm or reject an option at least half of the time.

Conclusions

The results show that regarding the educational modality they receive, 13.2% of the respondents indicate that their relatives or persons with CCN-IDD-MIDE have been attending the full inclusion modality for 3 to 6 years or more, 9.4% have been attending classes in the partial inclusion modality for at least 3 years or more and 39.8% have been receiving educational attention in specific classrooms for at least one year or more.

Regarding the communicative modality, more than half of the patients with CCN-IDD-MIDE under study do not speak and use, as their main modality, oral emissions (shouting and vocalisations) as well as pulling the carers' hands to achieve the desired object or action. Only 29.48% can produce isolated words and 22.22% have a repertoire of up to 4 words. As a secondary modality they resort to disruptive behaviours. These behaviours are not desirable, but they must be interpreted through the prism of communicative intentionality. These behaviours express frustration at not having been understood with the primary modalities.

From the data obtained, very low intelligibility of spoken utterances by their immediate environment has been observed.

To communicate, they use AAC such as natural manual signs (28.76%), drawings (26.61%) or pictures (22.58%), which forces the interlocutors to play an active role in the communicative exchanges. Therefore, the patients must have an in-depth knowledge of the natural manual signs as well as the communicative repertoire represented by pictograms or pictures.

The results of this survey show that people with CCN-IDD-MIDE perform various communicative functions. Specifically, 91.25% of the subjects use communicative acts to obtain objects or perform an action, and 75.3% can ask for help from the people around them with the usual means of communication. From the data collected we can say that half of the population is competent to ask and answer questions and 74.35% can affirm or reject an option at least half of the time. More elaborate communicative functions are very rare.

The diversity of profiles demands the need for a personalised design of support. Inclusive communication implies knowledge of the communicative modes and functions, as well as the specific profile of each user to address their limitations. It also aims at enhancing, improving and increasing the opportunities for the person with CCN-IDD-MIDE to be understood by

the broadest number of people and in the largest number of possible scenarios. We all have communicative intent, what we lack is the interpreting skills of the interlocutors. By improving the skills of the interlocutors, the possibility of giving a response more in line with the real needs increases. Detecting communicative intentionality in the most non-specific behaviours (such as pulling the hand towards an object) is the step towards the inclusion of people with severe cognitive impairment.

Teachers and caregivers of this group must be actively involved so that non-specific communicative attempts can be fruitful and thus lead to the implementation of communicative competence.

Limitations of this study are that the information comes mainly from parents of people with CCN-IDD-MIDE, which means that the data may be biased by over-interpretation. Future directions would involve the assessment of communicative modes and functions by professional speech therapists.

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