

OVERCOMING COMMUNICATION BARRIERS TO FACILITATE HEALTHCARE ACCESS FOR PEOPLE WITH INTELLECTUAL DISABILITY

Joy Teo

ABSTRACT

Communication barriers are one of the many reasons why People with Intellectual Disability (PWID) are prevented from accessing appropriate healthcare services. As a result, the health of this population is poorer than the general population in many countries around the world. Understanding the nature of the limitations faced by PWID in language learning and communication forms the basis of creatively developing strategies to overcome them. Building bridges of understanding between the clinician and the PWID increases the chances of accurate diagnoses of health conditions, effective treatment, and an overall improved quality of life for the patient.

Keywords: Overcoming Communication barriers; Facilitating communication; Intellectual Disability; Language; Communication; Communication Strategies

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INTRODUCTION

Imagine a typical healthcare encounter between doctor and patient. The doctor asks questions, and the patient provides the relevant answers. Based on those answers, the doctor then proceeds to examine the patient and potentially orders more tests. Only after obtaining and analysing sufficient information is the doctor able to come to a diagnosis. He will then need to inform the patient of this diagnosis, explain its implications, and the treatment options going forward. The patient asks questions to clarify information, and the doctor responds accordingly. Now imagine what might happen to these processes if the patient is unable to understand what the doctor is saying, and neither is he able to express himself clearly. This is what the patient with ID faces.

Communication refers to the process of exchanging information, ideas, thoughts, or messages between individuals or groups. This exchange might occur through speech, gestures, facial expressions, and even technology. As described above, quality healthcare is dependent on effective communication between doctor and patient. Often, a large amount of information needs to be exchanged and

processed by both parties before a treatment plan can be agreed upon. Any breakdown in the expression, reception, or processing of information has the potential to affect the diagnosis of the medical condition and the treatment plan for the patient.

The evidence demonstrates that many health conditions in PWID are unidentified and thus remain untreated.¹ An inability to accurately describe one's symptoms on the part of the PWID in conjunction with the inability of the clinician to understand and interpret the information being delivered by the PWID contributes greatly to this situation. A breakdown in communication also affects healthcare when procedures cannot be performed and there is poor compliance with health interventions due to the PWID being unable to understand the information being delivered by the clinician. Therefore, overcoming the communication barrier is essential for accurate diagnoses to be made and for effective healthcare interventions to be delivered. To overcome this barrier, it is helpful to understand in some depth the intricacies involved in communication, especially as it involves language and speech.

This article will first provide a brief overview of communication, language, and speech, defining each and describing the abilities required to master them. Next, the article will describe the language impairments that PWID face. The last section will describe some communication strategies that might be employed to overcome communication barriers and provide practical tips for improving communication about health.

COMMUNICATION, LANGUAGE AND SPEECH

“Whatever else people do when they come together – whether they play, fight, make love or make cars – they talk.”²

Talking comes so naturally to people that most do not consider how humans learn to speak, and the abilities required to maintain speech. Most people rely so heavily on talking that it is synonymous with communication. However, the use of language is merely one form of communication. Language is a complex system of communication that consists of a set of structured and standardised symbols, words, or signs used by individuals or communities to express meaning. It includes both spoken and written forms. Spoken language is thus the system of sounds, words, and an infinite number of possible sentences used to express meaning. Speech refers to the verbal expression of language using sounds produced by the vocal tract.

Fromkin writes that language is a “biologically based ability rooted in the structure of the brain”.² To learn to

JOY TEO

Training and Research Manager
Happee Hearts Movement

communicate effectively via spoken language requires the physical ability to hear sound and then to organise the facial and vocal muscles to produce meaningful sounds that form words and sentences. In addition to these physical abilities, the use of language requires numerous cognitive abilities to process the information that they receive through sound and/or sight. Information processing can be divided into four steps. These are: attention; discrimination; organisation; and memory or retrieval.³

Being able to attend to stimuli in the environment is prerequisite to discriminating or deciding which stimuli are like or different from the mental models already existing in the brain. Someone who has deficits in attention may miss important stimuli in the environment. The process of attending to stimuli and discriminating between them is the responsibility of an individual's working memory.

This information then needs to be coded and organised for storage within the long-term memory system. Organisation involves categorising the information. The more well-organised the information is within the brain, the easier it will be to retrieve. As an individual matures, the capacity for storage increases, as does the speed and accuracy of retrieval. The retrieval process, also known as memory, is dependent on a variety of factors, such as the frequency of retrieval and presence of environmental cues.

Not part of the information processing sequence, but important to language learning, is the ability to translate the use of it into contexts that are novel from the one in which it is learnt. In addition, social skills such as developing joint attention are also necessary to use language effectively. Such skills are part of learning the pragmatics of language, that is, how language is used in social contexts and in relation to others.

Considering the synergy between the physical, intellectual, and social abilities required for effective speech to occur and the deficits that PWID may present within all three of these spheres, it is no surprise that PWID face significant barriers in understanding others and being understood.

In summary, communication comprises all verbal and nonverbal methods used to transmit information between individuals, including language and speech. Language involves conveying information through the form, content, and function of symbolic systems according to specified rules. Speech is the oral production of language. The use of language is a highly cognitive process. Due to deficits in intellectual functioning as well as possible co-occurring physical and social skill deficits, PWID often have difficulty communicating with others in a variety of settings, including the healthcare setting.

LANGUAGE CHARACTERISTICS OF PWID

“Language is often one of the most impaired areas for a child with ID and may be the single most important characteristic of the disorder.”³ The language deficits in PWID vary

greatly and are interestingly not always commensurate with intellectual or cognitive functioning. It is interesting to note that existing evidence indicates that language ability may be independent of general intellectual abilities. This means that it is possible for a PWID to be able to speak well but have deficits in cognition or intellectual functioning unrelated to language that prevent him or her from living independently.

The variety in language abilities among PWID means that it would be prudent for us to not make generalisations about their communication ability. At the same time, it is helpful to be aware of some common language traits that this population demonstrates. This section will also highlight the general language characteristics of people with Down syndrome (the most common genetic syndrome associated with ID) and autism spectrum disorder (ASD). According to the CDC, the prevalence of co-occurrence of ASD and ID is approximately 37.9 percent⁴ with significant impact on communication.

The four stages of information processing is a useful way to structure our understanding of the language abilities and limitations in this population. Beginning with attention, PWID have difficulty in scanning the environment and language stimuli to select what needs to be attended to. However, their ability to sustain attention is comparable to mental-age-matched typically developing (TD) peers. People with severe or profound ID have limited attentional capacity.

Next, because PWID have difficulty with selecting salient and important stimulus cues, their ability to discriminate and compare them with stored information is impaired. Discrimination can be taught, and PWID are able to apply this skill as well as TD individuals. Again, there is a positive relationship between ID severity and the speed and accuracy of discrimination.

When it comes to organisation of information, TD individuals often rely on associations between words or concepts to aid this process. Persons with mild-moderate ID have appear not to use these strategies or do so less effectively. Since the information stored is more disorganised, PWID thus retrieve information more slowly and demonstrate poorer recall. The retention of information for future recall is achieved through rehearsal, something that PWID do not spontaneously do. They also require more time for rehearsal. Again, the more severe the ID, the poorer the memory skills.

When it comes to generalising information, PWID struggle, whether the contexts are similar or dissimilar to the one in which the information was originally learnt. This could be due to their difficulties in discrimination and organisation. Generalisation cannot be learnt. This has important implications on how information is delivered to PWID, and this will be discussed in the next two sections.

Finally, another common trait of PWID is that they tend to process auditory information more poorly than visual information. Additionally, between linguistic and non-linguistic auditory information, PWID respond better

to the latter. For example, they might respond better to a car horn indicating that they should stop walking rather than someone shouting for them to stop. This again has implications for the communication strategies selected to facilitate understanding in this population.

The variation in language and communication abilities between PWID also depend on physical and social environmental factors such as whether the individual had the opportunity to attend school, the method of communication used at home, and the attitudes of caregivers. It is not uncommon for PWID to have been taught one method of communication in school but use another at home. If caregivers do not believe that their children can understand information and express themselves, they will not encourage communication, thus limiting the development of language and communication skills.

Down Syndrome

The most consistently reported language profile in the Down syndrome population is that of expressive ability being weaker than receptive.⁷ On the receptive end of things, compared to people with other types of ID, auditory deficits in people with Down syndrome are greater. Expressively, people with Down syndrome generally have a smaller vocabulary, speak in shorter utterances, and have more verbal perseveration.⁴ The latter refers to remaining on one topic for an excessively long time, repeating things unnecessarily. Another factor that influences the expressive ability of people with Down syndrome is the intelligibility of their speech, which is often poor.⁷

The reduced verbal expressive ability in people with Down syndrome may be compensated partially by their use of gestures and sign language as they have strengths in visuo-spatial memory. Thus, the use of gestures and social cues may also support comprehension and learning of new information. People with Down syndrome may be able to read; however, the ability to read words does not indicate that they understand what the words mean. This is important to be aware of and assess for because individuals with Down syndrome are also less likely to signal non-comprehension or request for clarification.⁷

Individuals with Down syndrome have strengths in the pragmatics of language. Even at an early age, many children with Down syndrome demonstrate more social-interactive behaviours than their TD peers. They often show good ability to initiate and sustain conversation, as well as to narrate an event or story.⁷

Autism Spectrum Disorder (ASD)

Communication problems are often one of the first indications of a possible diagnosis of ASD.⁴ Great variation exists in the language profiles of people with ASD from non-verbal to language profiles that are the same as TD individuals.^{4,7} For those who are verbal, their speech is often wooden and robot-like, lacking the inflections that are heard in the speech of TD individuals.⁴

Due to the nature of their disability in the socio-communicative domain of speech, the difficulties that people with ASD face with language and speech mostly fall in the category of pragmatics.⁷ They have difficulty initiating conversation and maintaining the back-and-forth, turn-taking nature of conversations. The range of contexts in which people with ASD may choose to initiate communication is narrower than that in the TD population, and they may express their intentions in an idiosyncratic manner.⁴ For example, an individual may choose to repeat a list of MRT stations as an indication that they want to go to school because he takes the MRT to school daily. In addition, they may have outbursts of inappropriate, irrelevant, or even bizarre utterances in conversation.

Immediate or delayed echolalia is also common in this population. An increase in the intensity of the echolalia may sometimes be an indication of stress or an inability to comprehend. In some situations, immediate echolalia might be a means of expressing agreement or assent, instead of saying “yes” or “I agree”. Finally, individuals with ASD may often interpret speech concretely, and find figurative language difficult.⁴

COMMUNICATION STRATEGIES

With some understanding of typical language development as well as how that development might be disturbed in PWID, it is now appropriate to share some strategies that can be taken in a healthcare setting to overcome these communication barriers. The information processing steps will again structure this section.

Facilitating Attention

Reducing the number of stimuli that an individual needs to attend to will help the individual focus on what is salient. In clinic, this can be done by reducing clutter in the room, or even just on the surface immediately in front of the patient. Face the patient directly when speaking to him or her, so that he or she can focus on your facial expressions and what you are saying. Speaking in short phrases instead of long sentences also reduces the number of auditory stimuli that the patient must sift through. For example, instead of saying, “How can I help you today? Do you have pain in any part of your body?”, say “Where pain? I help you.” Providing visual aids helps provide a concrete object to focus on when filtering auditory information is difficult. Pictures of clockfaces showing the times at which medicine must be taken each day is an example of this.

Facilitating Discrimination

Assisting the patient to attend to salient stimuli will facilitate the discrimination process. Giving the ID patient more time than you would with TD to respond to questions will also help. Using accurate labelling of body parts and avoiding vague terminology ensures that the patient knows exactly what you are referring to. This is especially so when it comes to talking about what is commonly referred to as

“private parts”. Pointing to the part of the body in question or using a visual body chart may help with the patient’s understanding.

Facilitating Organisation

Providing information about treatment and procedures to the patient in chunks or steps will help with organisation and memory. It can also help reduce anxiety in patients who have difficulty transitioning between activities. Again, visual aids help with this. The colours, choice of symbols, and position of the symbols in the aid help structure the information for the ID patient. For example, medication could be colour-coded to indicate whether it is to be taken at breakfast, lunch, or dinner. The “my healthy plate” visual guide⁵ developed by the Health Promotion Board is one way of helping individuals remember how much of each food group should be eaten at each meal.

Memory or Recall

As information might be stored in a disorganised fashion, more time should be given to patients with ID to respond to questions. Ask one question at a time and take longer pauses between questions. If the patient does not respond, it might be helpful to try rephrasing the question or breaking it down into multiple questions. For example, instead of asking where the patient feels discomfort, the clinician could point to different parts of the patient’s body one at a time and ask if it is feeling good or bad. A thumbs up or thumbs down gesture could be used to complement the question.

It would by now be obvious that visual aids are useful in every stage of the information processing pathway. Understanding that in general PWID tend to receive and process visual stimuli better than auditory makes the use of these tools even more encouraged. Visual aids not only assist clinicians in communicating to the patient with ID, but they can also provide a way for the patient to express themselves to the clinician. Patients with ID should be encouraged to bring the communication aids that they use at schools, day activity centres, or at home to the clinic. Bringing along health documentation from other healthcare institutions will assist the process of information collection as well.

Another strategy that facilitates multiple stages of the information processing pathway is providing binary choices. Having to choose between just two options reduces the attentional demands of a task, which will then improve the discriminatory ability of the individual. Organising and manipulating just two pieces of information is also less demanding than juggling three or more.

Attempting first to communicate with the patient with ID demonstrates respect for the individual and confers dignity. However, it is appropriate and beneficial to speak to the patient’s caregiver when he or she is present to clarify and corroborate information. Caregivers are often the best people to assist the clinician in interpreting the communication intentions of their care recipients. Respecting and taking seriously their knowledge and understanding of the patient is important. Many a patient with ID has suffered unnecessarily because the voices of their caregivers and advocates were ignored.⁶

CONCLUSION

It cannot be overly emphasised that each PWID is unique and will show differences in his or her communication and language profile. This article has hopefully caused the reader to be more cautious about interpreting the communicative intentions of PWID and stimulated ideas as to how limitations in language ability might be mitigated. Ultimately, the clinician’s goals are to obtain the most accurate information possible to make a diagnosis and provide information in a such a way that the treatment plan can be adhered to for best results. A bit of curiosity and extra attention to the ID patient’s unique way of communicating can go a long way towards this endeavour.

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LEARNING POINTS

- **Communication barriers prevent access to healthcare for PWID.**
 - **Language and communication profiles vary greatly in PWID.**
 - **Visual aids are one of many strategies that can facilitate communication between clinicians and PWID.**
 - **Value the knowledge of caregivers of PWID.**
 - **Taking time to be curious about and paying attention to the ways the PWID communicates will go a long way towards facilitating better healthcare for this population.**
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