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COMMUNICATING WITH PERSONS WITH ID: A PRACTICAL APPROACH IN A BUSY CLINIC

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ABSTRACT

Communication barriers are one of the reasons people with ID have poor access to healthcare services. This article describes some practical ways that physicians who practice in busy primary care clinics might facilitate better communication between themselves and their patients with ID. These strategies are suggested not as the means of obtaining perfectly accurate answers to questions every time, but as a means of building a trusting relationship between physician and patient with ID over the course of the patient's lifespan. This relationship forms the foundation for deeper understanding of the patient and their health concerns.

Keywords: Communication barriers; communication strategies; primary care; physician-patient relationship

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INTRODUCTION

Deficits in communication are characteristic of people with intellectual disability (PWID). The difficulties that PWID face in understanding others and expressing themselves often pose a barrier to their access to appropriate healthcare. Making an appointment to see a health provider, registration at a clinic, describing one's health concern, accessing healthcare funding, and following through with a treatment plan are all dependent on an individual's ability to effectively receive and express information.

The majority (approximately 85 percent) of PWID have mild intellectual disability (ID). In most situations, this means that they would have basic levels of language ability. Some may live independently and therefore attend the clinic without an accompanying caregiver. However, because there is evidence1 now that language development and ability may be independent of general intellectual development and functioning, it cannot be assumed that someone with mild deficits in most areas of intellectual functioning will have equally mild deficits in language. For people who have moderate to severe levels of ID, it is expected that their language ability be more limited, and that they will likely be accompanied by a caregiver when attending clinic sessions. It is common in situations where a caregiver is present for the clinician to speak only to the caregiver, assuming that the patient with ID is unable to understand, respond or does not have the mental capacity to make health-related decisions. Often the decision to communicate solely with the patient's caregiver is based on what is deemed most efficient.

It is true that communication with a patient with ID is likely to take longer than a patient without ID. However, there are other considerations that can be argued to take precedence over efficiency. The first of these would be that speaking to the patient with ID confers dignity on and respect to the individual. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) treaty aims to "promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity."[2] These rights include the right to receive appropriate healthcare and be included in healthcare decision-making to the extent it is appropriate.

Second, attempts to engage and communicate with the patient with ID enable the physician to develop rapport with the patient. With good rapport comes trust. Trust is the foundation upon which the physician can receive accurate information and perform procedures (like blood tests) efficiently. Both steps are essential to effective healthcare. Patients with ID have the most direct knowledge about their symptoms, needs, and preferences. Relying solely on caregiver reports risks missing or misinterpreting important information. Caregivers, despite their familiarity, cannot fully represent the subjective experience and perspectives of the individual.

In a previous publication, the common language and communication deficits of PWID were described and some general strategies were suggested to overcome the communication barriers present when interacting with PWID. This article will consider the context of a general practitioner (GP) clinic or a polyclinic in Singapore to provide practical suggestions on how we might apply these strategies to improve communication between the physician and patient with ID can be improved. Recognising that GP clinics and polyclinics see a high volume of patients daily, and thus physicians often have limited time with each patient, the strategies suggested are simple, low-cost, and in most cases immediately implementable.

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PRE-VISIT PREPARATION

Communication is the exchange of information between two parties. This exchange can happen with or without words. The way an environment is structured can communicate welcome or exclusion. It can bring about sensations of comfort and safety, or insecurity and fear. What this means is that the clinic environment can be designed to communicate inclusion and safety, thus setting a positive backdrop against which other exchanges of information occur. People with ID may have sensory sensitivities or difficulties processing certain types of sensory information (visual, auditory, olfactory). This is especially if they have co-occurring autism. Choosing warm lighting or dimming the lights in the consult room may help patients who are sensitive to bright lights. Warm light also tends to communicate calm, which is important since the patient may arrive at the clinic already anxious and unwell. Strong fragrances could also be distracting or distressing for some patients. Choosing fragrance-free cleaning products and refraining from the use of air fresheners in clinics will be helpful.

Clinics are often visually and auditorily stimulating environments. Walls have signs, posters, and flashing numbers. There are people constantly moving around (more so in polyclinics than GP clinics). With constant activity is a constant background hum of people conversing, phones ringing and beeping, and machines whirring. Though easily ignored by most, people with ID and sensory processing difficulties may find it difficult to ignore the background noise, making it more effortful for them to pay attention to what is being spoken to them. While removing signs, posters, and the flashing number system may not be possible, visual and auditory stimuli can be reduced in a clinic setting by arranging for patient appointments during less busy times of the day.

ASSESSMENT

The Ministry of Health in Singapore has been advocating for Singaporeans to select a primary care physician to oversee their health for better continuity of care over the lifespan and thus better health outcomes. These benefits apply to PWID as well as people without ID. A consistent primary care physician for PWID can be said to be even more critical given the potential for complex health issues developing as they age.

Thus while information gathering is usually topmost in the physician's mind when seeing a patient, with patients who have ID, it is beneficial to prioritise engagement and the building of rapport over information gathering in the first few minutes of the healthcare encounter. This is because engagement and rapport are the foundation for accurate information gathering in the long term. The goal is less about obtaining as much information as possible in the shortest amount of time, but rather to develop sufficient rapport so that the patient with ID will be willing to return regularly to the clinic. Instead of gathering information all at once, the assessment process is spread out over time. Once rapport and trust has been established, efficiency of information gathering will naturally increase.

In the case of a patient with ID who presents at the clinic with a caregiver, developing rapport and trust means making effort to first engage with the patient with ID, even if he or she is unable to provide a reliable response. Following this, it is appropriate to then inform the patient that time will be spent speaking to his or her caregiver. For a patient with ID who has adequate speech, it may mean asking generally about the patient first, and allowing him or her time to talk about what is on their mind at the time even if it might not be entirely relevant to the health issue.

Trust is also built by pre-empting the patient as to each step of the assessment process. For example, simply saying something like "First I am going to measure your blood pressure and temperature, then I'm going to ask you some questions" helps to reduce patient anxiety by removing some of the uncertainty of the health assessment. Describing procedures before beginning them and asking for their consent to proceed also helps to reduce anxiety and provides patients with a sense of control.

Routines are important in the lives of PWID since learning a new task or adapting to a new environment may take longer for them than for people without ID. Therefore, developing a clinic routine might also be helpful for the patient with ID. If each time the patient comes to the clinic, the assessment is performed in the same order, it will help the patient learn the steps more quickly. **Table 1** provides an example of an assessment flow that can become a routine for patient and physician and facilitate the process as the patient becomes familiar with it over time.

Table 1. Example of an assessment routine

Assessment routine	
Step 1	Measurement of height and weight
Step 2	Measurement of blood pressure
Step 3	Measurement of temperature
Step 4	Auscultation
Step 5	Subjective assessment in the following order: pain, sleep, bowel and bladder habits, dietary habits
Step 6	Physical assessment of relevant parts of the body

The question-and-answer process of the subjective assessment is often the most challenging for PWID and attending physician. This is particularly so with patients who have limited verbal ability. As PWID may have problems with attention, to increase the chances of the patient understanding the question asked, it is first important for the physician to ensure that the patient is attending to him and the question at hand. To do so may mean to insert the patient's name before each question. Pausing slightly after the patient's name to observe for signs of attention, like an eye gaze, before proceeding with the question may be beneficial.

"Jonathan (pause and observe for signs of attention), how are you feeling today?"

Another way to draw the attention of the patient to the question at hand is to give context to the question. This means saying something like "Jonathan, now we are going to talk about what you eat and drink" before launching into questions about dietary habits. As PWID often have difficulty with organising information in their mind, recalling relevant information to answer questions often takes more effort and time. By first stating the topic before asking the question, it might help patient attend mentally to the relevant information and assist with the recall process.

Due to longer processing times in PWID, it is important to ask questions one at a time and give the patient sufficient time (at least 10 seconds is suggested) to respond. If a response is not given, repeating and rephrasing the question is appropriate, again with time given after each repetition or rephase for a response.

Abstract questions and concepts pose a greater challenge for PWID to answer. One of the common and deemed essential questions of the subjective questioning process surrounds the issue of pain. Pain however is a subjective experience and abstract concept. It cannot be observed or objectively measured. Therefore, PWID often have difficulty communicating their experience of pain though "current evidence suggests that individuals with ID may actually be more sensitive to painful stimuli, have greater pain-evoked potentials, and be more likely to experience chronic pain compared with typically developing peers".[3] For patients with mild ID, and sufficient verbal ability, they are usually able to answer questions about pain in a similar way to individuals without ID. However, for some, describing the nature of the pain (e.g., sharp, dull, achy) and quantifying their pain severity on a scale may prove difficult. In these situations, the use of a visual scale with a series may be beneficial or the focus could shift instead to how the pain affects the patient functionally.

For patients with more severe language deficits, even expressing the presence of pain may prove difficult especially if asked in an open and general fashion (e.g., "Do you have any pain?"). It might be helpful to instead point to the patient's body parts and ask if he or she has pain in that body part, i.e., "Do you have pain in your head? Do you have pain in your chest? Do you have pain in your arm?" This line of questioning requires a "yes" or "no" answer. Once again, "yes" and "no" are abstract concepts that PWID with more severe language deficits may not fully grasp. A quick check with caregivers may be necessary to ensure the patient's "yes/no" answers are reliable and consistent. As mentioned earlier, instead of asking questions directly about pain, it may be more beneficial and helpful to approach the issue indirectly through questions about behaviour and function.

Another strategy to facilitate understanding and response when asking PWID questions during the subjective assessment process is providing binary choices. This strategy again helps the patient with attention because he or she only has to attend to two options. This then makes differentiating between options easier as well. An example of providing binary choice might be to ask, "Do you cough more in the morning when you wake up or when you are sleeping at night?"

As a general principle, when communicating with PWID, speech should be slow and the language used clear, simple, and direct, avoiding the use of medical jargon. Another general principle is that visual aids often aid the process of understanding and expression in PWID. Visual stimuli are more permanent than auditory stimuli. They reduce the need for the patient to rely on memory when processing information as the visual stimulus remains in front of them. For example, having a picture to represent common complaints like coughing, sneezing, constipation, and headaches might help the individual express their discomfort. Simply writing the options to questions on a piece of paper is also an appropriate visual aid for patients who are able to read. Diagrams to explain how procedures will be carried out are also helpful visual tools.

All of the above strategies will necessarily mean that an assessment of a PWID might take longer than a typical consult. As mentioned earlier in the article, the first aim of communication is the development of rapport through engaging the patient. Therefore, considering the nature of a busy clinic, practically speaking, in situations where the patient clearly has significant language deficits, it is the author's suggestion that a physician may attempt a number of the strategies above for the first few minutes of the consult or at intervals throughout the consult while mostly gathering information from caregivers. The PWID should be informed when turning attention to the caregiver. Also, consider what information and procedures are essential on that particular day, and what can be postponed until a subsequent visit.

COMMUNICATING TREATMENT OR HEALTH ACTION PLANS

Following assessment and diagnosis, the physician needs to communicate the treatment options and suggested health action plan to the patient. Adherence to these plans is important for good health outcomes. To assist PWID to follow through with medication regimes and lifestyle changes, they need help to understand the instructions and the reasons for them. This is another area that visual aids will come in useful. Due to limitations in their ability to organise information, PWID may have difficulty recalling detailed instructions. Organising health information visually for the PWID will help with memory and recall. For example, write instructions on medication on a separate piece of paper from instructions on diet change.

Time is an abstract concept, which means that PWID might have difficulty planning to perform tasks at regular time intervals through a day. This means giving an instruction to take medication twice a day might not automatically

translate as expected to the patient to consume the medication at two fixed times in the day. It is thus helpful when communicating with the patient with ID to attach new health-related tasks, like taking medication or checking one's blood glucose levels, to an existing habit. For example, the instruction might be to take one's medication at breakfast time and at dinner time, or to go for a walk after dinner.

In order for health education to be accessible to PWID, it would be helpful to have such information available in "Easy Read" format. "Easy Read" material is organised according to certain principles surrounding layout, font size, language use, etc., which guide the presentation of information to make it easier to understand. These materials are suitable for PWID who have basic reading and comprehension ability.

Behavioural change is not easy for any individual, with or without ID. For PWID, the challenge is increased due to their reduced ability to understand, process, and formulate plans based on new information. Suggestions for change should then be presented in small bite-sized pieces of information. Instead of suggesting dietary and physical activity lifestyle changes together, choose to focus on just one area. Within that one area, suggest one tiny habit change that is doable so that the patient has a high chance of success. For example, instead of suggesting that the patient stop snacking entirely, suggest that the patient remove just one snack from his daily snack intake in the time between the current and next clinic visit. As with any patient, it is necessary to get buy-in from the patient with ID in order for any health plan to have a chance of success. For patients who rely on their caregivers for assistance with daily tasks like meal preparation, it is necessary to explore with them what is acceptable and possible given their lifestyle and existing caregiving demands.

CONCLUSION

Providing appropriate and accessible healthcare for PWID requires that accommodations be made in the way physicians communicate with them. Overcoming the communication barriers faced by PWID is essential for developing rapport and trust with the patient with ID so that the patient might have support to monitor and maintain their health over their lifespan. This is especially desired in the primary healthcare setting where family physicians and general practitioners serve as first contacts of health services and education.

The accommodations mentioned in this article are low-cost, simple, and can be applied not only with PWID but with any individual who has difficulty with understanding and expressing information, e.g., people with dementia. Though simple, as with any skill acquisition process, these strategies need to be intentionally put into practice. Being a more effective communicator will contribute to the physician seeing more positive health outcomes in their patients with ID and even in those without.

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LEARNING POINTS

- **Effective communication contributes to developing rapport and trust with patients with ID for the purpose of improved healthcare access over the course of the patient's lifespan.**
- **Simple and low-cost strategies can be employed in busy primary care clinics to facilitate improved communication between physician and patient with ID.**
- **These accommodations include the use of visual aids in health assessment and communication of health action plans.**
- **With practice, physicians can become better communicators with PWID as well as other conditions that affect understanding and expression.**