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Overcoming communication barriers

Working with patients with intellectual disabilities

Background

Communication styles and communication difficulties may impact on the ability of general practitioners to provide best possible health care, particularly for patients with intellectual and other developmental disabilities.

Objective

To highlight potential difficulties GPs may face in consultations with adult patients with an intellectual disability and to raise awareness among GPs of the different communication methods used by people with intellectual disabilities. Current recommendations for improving communication with this marginalised group and practical issues in implementing these recommendations are also discussed.

Discussion

People with intellectual disabilities have different communication abilities, using a range of different styles as a group, as well as on an individual basis. They may use speech, augmentative and alternative communication strategies, or visual or behavioural cues to indicate their wants, needs or feelings. Improved collaboration between GPs, patients, and patients' support people, is encouraged to develop an individualised approach to communication with each patient and to promote best possible health outcomes and patient satisfaction.

Some medical practitioners may feel uncomfortable seeing patients with intellectual disabilities. This discomfort often stems from a lack of experience and training in working with people who have communication difficulties. These difficulties may affect interaction in consultations, which then affects the development of rapport and quality of health care provision.^{1,2} There may also be a reliance on patients' support people in obtaining a medical history.^{1,3} Although obtaining a medical history from support people may be necessary for patients with limited communication skills, it is critical that patients are not excluded from the communication exchange.⁴

Communicating with and without speech

Patients with intellectual disabilities often have varying communication abilities and may utilise a number of different verbal and nonverbal strategies.

Those with mild intellectual disabilities are most likely to communicate with speech. Consideration of the patient's ability to understand concepts is needed and explanation must be tailored to individual needs using language and terms that each individual patient understands.

Those with moderate intellectual disabilities may also communicate with speech, but to a limited degree, such as using incomplete sentences. They are also likely to use a range of other methods, referred to as augmentative and alternative communication (AAC) strategies, in addition to, or instead of, speech (*Table 1*).

Those with severe to profound intellectual disabilities have more limited communication skills and often rely on people around them to optimise their communication opportunities (eg. by using visual cues) and interpret behaviours that may indicate their wants, needs, and



Table 1. Augmentative and alternative communication systems

Formal communication systems	
Aided	
Communication boards and books	Pictures, symbols and/or the alphabet is available for users to communicate specific messages
Electronic devices	Electronic devices of varying complexity are used. Some have a limited number of messages, while others allow users to construct longer messages by typing words or accessing picture symbols. Access may be direct, such as through touching a key, or indirect, such as use of switch access to a scanning system
Unaided	
Key word signing (ie. Makaton vocabulary)	Signs are used to indicate needs and wants, or to formulate messages for other purposes. Skill in using key word signing may vary, and is dependent (to an extent) on motor skills and memory
Informal communication systems	
Facial expression, body language, vocalisations, gestures, eye contact	Informal communication may convey information about general feelings (ie. feeling happy, anxious, angry), or to indicate needs and wants

feelings (eg. vocalisations, facial expressions, body language). It is also common for people with severe intellectual disabilities to have physical and/or sensory impairment which further impacts on their ability to communicate.

Formal augmentative and alternative communication strategies

Augmentative and alternative communication strategies are used by people with all levels of intellectual disabilities (Table 1).^{5,6} Some formal AAC strategies are more straightforward to use and understand, thereby appearing more user friendly to those not familiar with them. For example, electronic devices allow a person to communicate with recorded speech (Figure 1). Communication books (Figure 2) and spelling boards may require some interpretation and co-construction of meaning (ie. the listener working with the individual to determine their message). Key word signs (ie. Makaton vocabulary) may be used by some people to produce single words or short messages. A number of signs are taught to enable those with intellectual disabilities to communicate their wants and needs – for example, signs to indicate that they would like to go out for lunch (Figure 3a–c). Signs that are taught typically depend on their relevance to an individual’s daily routine (each individual may know and use a different range of signs). People accompanying the patient, whether paid carers or family members, may act as interpreters or assist the person in other ways to convey his/her messages. Many people use more than one type of AAC strategy to communicate, such as gestures, signs, and a picture board; choosing which depending on the intended message and their communication partner(s).⁶

Informal communication strategies

People with severe intellectual disabilities may demonstrate limited communication skills and are more likely to communicate with informal communication such as gesturing (ie. facial expressions, eye contact) and by using body movements (ie. shaking hands, pointing, pushing things away). Those with profound intellectual disabilities often lack intentional communication. Instead, they rely on others

Figure 1. Electronic communication device



to interpret their facial expressions and behaviours as indicative of their wants and needs. The absence of formal vocabulary results in increased reliance on support people in medical consultations.

Role of support people

Depending on the severity of intellectual disability and individual communication skills, most of a patient’s medical information may need to be provided by support people, usually a family member or paid support worker. Patients with severe intellectual disabilities are often unable to convey the degree to which they understand the implications of health issues discussed in consultations. As a result, medical decisions may need to be made on some patients’ behalf. In these situations, consent for medical procedures will be needed from a legally designated ‘person responsible’; usually a family member or other appointed person.⁷

Improving communication in consultations

The principles of communication with people with intellectual disabilities are:

- assume competence: people with intellectual disabilities may understand more than they can demonstrate. Even if the person appears unresponsive, he or she may still understand and feel included when spoken to
- communicate directly: interact directly with the patient to obtain as



much information as possible. Assessment of overall functioning of the individual can be made to gauge communication skills and degree of support required in consultations

- tailor communication: the language and communication style can be tailored to individual needs. Suitable words used and the pace of the conversation may be important in ensuring optimal communication
- support communicative efforts: communication can be improved if the medical practitioner is aware of the way the individual communicates and accurately interprets communicative efforts (particularly AAC systems).

Practical recommendations for improving communication with patients with intellectual disabilities are listed in *Table 2*. These recommendations are based on the views of people with intellectual disabilities, their support people, and health and disability professionals.^{5,6,8} Ideally, applying these recommendations will optimise the effectiveness of communication within the consultation.

Inclusive practice

Patients need to be acknowledged and actively involved in consultations. Medical practitioners have been reported to focus consultations on support people and appear to completely ignore patients who have difficulty communicating.⁴ Even if some patients do not have the expressive communication skills required to participate in conversation, actively including them in the consultation conveys respect for the patient – to both the patient and their support person (*Case study 1*). In addition, many people with intellectual disabilities have stronger receptive than expressive communication skills and are likely to understand more than would seem apparent from their expressive ability.⁹ Consistently interacting with patients builds rapport and improves cooperation in the consultation, for example, during physical examinations (*Case study 2*). Strategies to actively include a patient with limited communication skills include:

- doctors introducing themselves and greeting the patient before the consultation. Even if the patient does not respond verbally, nonverbal communication is possible (eg. handshaking, smiling and making eye contact). This is essential to building rapport and is independent of the patient's ability to reciprocate
- while obtaining the patient's medical history from an accompanying support person, the doctor can share eye contact with the patient and address him/her directly to maintain their involvement in the consultation.

Maximising understanding

By adapting to a patient's communication skills, medical practitioners can encourage patient participation in consultations. Comprehension can be enhanced through the use of appropriate language at a pace that is comfortable for the patient. How the patient uses AAC strategies is also an important consideration. Medical practitioners can optimise engagement and communication within consultations through learning how individual patients communicate.⁵ Strategies to aid communication include allowing patients sufficient time to

process their thoughts and respond.⁵ The use of visual cues such as pictures, diagrams, and appropriate body language may also improve understanding.⁵ These suggestions are also applicable to patients who communicate with speech.

Barriers to optimal communication in clinical practice

Using AAC strategies in medical consultations

The use of formal AAC strategies is further complicated by a number of factors:

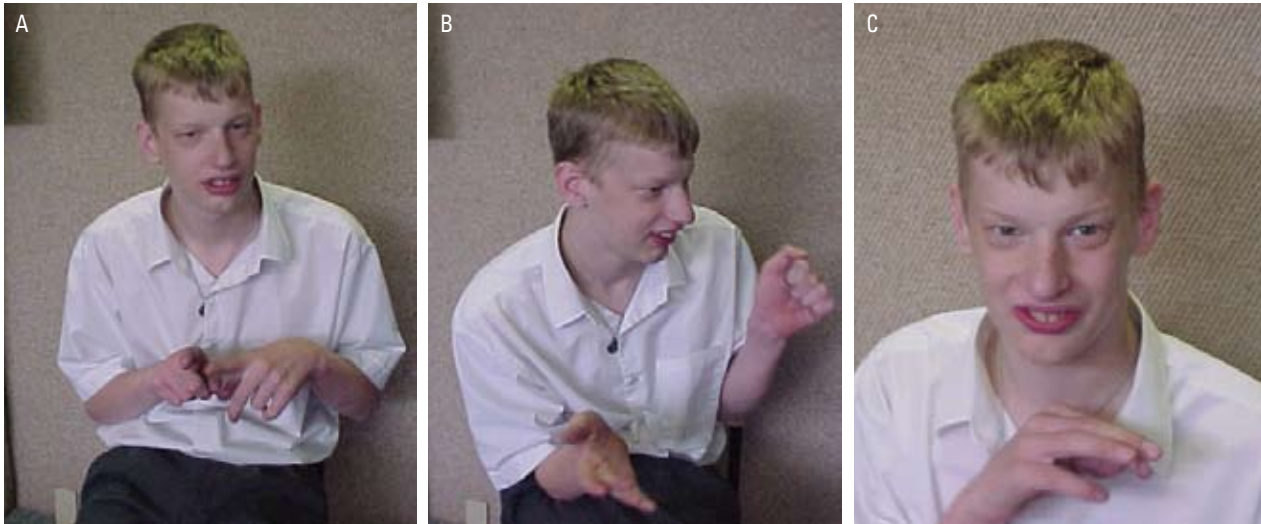
- for aided AAC strategies, the patient must have access (it is of no use if it has been left at home, or is in the bag hanging from the back of the wheelchair!)
- physical impairment may influence the patient's ability to use some AAC strategies (eg. a painful shoulder may impair the ability to use a communication device)
- the vocabulary required for medical consultations may not be available on the communication aid as AAC strategies are usually

Figure 2. Communication book





Figure 3A–C. Signing using key words: (A) quick, (B) shop, and (C) lunch



developed to address a person's most frequent communication settings and needs. These might not include the vocabulary required in a health care context (eg. to communicate symptoms such as nausea, or describe pain as sharp, crushing or burning)

- sufficient time must be made available for the patient to both understand what is being said and to formulate his/her messages.

Table 2. Recommendations for communicating in consultations with patients with intellectual disabilities

Medical practitioners may improve communication by:

- Speaking directly to patients, regardless of the severity and aetiology of the disability
- Using short sentences and clear age appropriate language – treating adult patients as adults and not using child-like or patronising tones
- Encouraging patients to be actively involved – either verbally or nonverbally – regardless of communication difficulties
- Providing clear explanations and checking regularly that they have effectively communicated key points to the patient (eg. by asking him/her to repeat key points in their own words or answer specific questions about the issues discussed)
- Using pictures and diagrams to clarify their explanations
- Checking that they have understood what the patient has meant by repeating the key points back to him/her and asking for affirmation or correction
- Making good use of the patient's health records to support good information exchange
- Ensuring adequate time is available for the consultation
- Obtaining information from other sources where necessary – after obtaining appropriate permission

For patients who communicate with an AAC system, medical practitioners can:

- Ensure that the patient has access to his/her AAC system
- Find out how the patient's particular AAC system is used

Time constraints within the medical consultation

Many areas of Australia are currently facing shortages of health care professionals, resulting in often multiple pressing demands on doctors' time. Limited time for consultations is one reason patients with intellectual disabilities fail to receive the best possible care.^{1,3} General practitioners estimate that consultations with patients with intellectual disabilities take approximately 19.5 minutes, about 6 minutes more than for other consultations.¹ Many people with intellectual disabilities also have several health related issues including medical, psychological, social, financial, and service related concerns. While these factors further contribute to the consultation time, regular review and double appointment bookings can assist. When people have complex needs the contribution of a number of health professionals may be required.

Case study 1

Judy, 35 years of age, is a woman with autism and a severe intellectual disability. She attends the consultation accompanied by her key worker, Mary. The GP knows Judy does not speak and so directs his attention to Mary who points to a wart on Judy's finger she would like the doctor to remove. The GP takes a history from Mary while Judy sits in a chair humming, seemingly uninterested in the conversation. The GP leaves the room and returns with the liquid nitrogen. He resumes his conversation with Mary as he approaches Judy to treat her wart. Judy looks up as he approaches, yells, jumps from the chair, and shoves him out of the way. She then runs out the door screaming, with Mary in pursuit. When staff try to bring Judy back to the medical clinic she refuses.

Comment

When the patient is overlooked and not actively involved and engaged as much as possible a relationship of trust cannot be established. When a situation engendering fear is experienced it can be very difficult to re-establish a therapeutic relationship.



Case study 2

John, 28 years of age, has come to see his GP for a health assessment, accompanied by his mother, Anne. John has autism, a moderate intellectual disability and communicates with speech. During the consultation, the GP speaks to John to involve him more actively in the consultation. John, however, responds with only single words and simple phrases and does not seem interested. His GP decides to speak with John's mother about his overall health, and asks John for permission to do so. John does not answer but looks at his magazine while the doctor speaks to his mother.

The GP asks about John's health since the last consultation and hears that John has been well apart from having frequent back and/or neck aches, possibly related to postural problems. The GP then shifts his focus back to John, demonstrating to him several exercises to help with his back pain. During this part of the consultation, John gives his GP his full attention, mimicking the GP's actions, but goes back to looking through his magazine immediately after.

Comment

Demonstrating respect and involving the patient builds trust. Showing the patient what is being recommended can help to engage the patient and supports understanding. A collaborative partnership between doctor, patient and carer optimises health outcomes.

Other barriers

Baseline cognitive deficits, difficulty concentrating and acute problems such as anxiety or depression may compound communication difficulties. Some patients may not want to be actively involved in consultations, preferring their family members or support workers to speak and make decisions on their behalf. Patients with autism spectrum disorders may have difficulty initiating and sustaining conversation; a problem inherent to their disability. Communication in consultations may thus require a balance between:

- involving patients in a way that is practical in terms of the communication skills they use
- obtaining information from other sources (ie. support people, patient health records) to arrive at the right diagnosis and appropriate treatment/management plans
- meeting the expectations of patients and their support people.

Individual expectations

Expectations will vary from one consultation to the next, as each patient, their support people, and the GP, bring different ideas of what is and what is not appropriate behaviour and conversation within consultations. The best strategy is to build collaborative relationships over time, enabling continuity of care between the GP, patient, family members and support workers. Building familiarity allows all parties to become more comfortable with each other, making it easier for those involved to work together in the patient's best interests. Medical practitioners learn over time how best to communicate with any particular patient. Expectations of doctors, patients and support people can be discussed openly, facilitating understanding and providing opportunities for individual expectations to be met while ensuring the best possible health care is provided.

Summary

The effectiveness of applying specific recommendations in clinical practice has yet to be determined. However, specific issues have been raised and may be addressed with an individualised approach. In addition to recommendations made in previous literature, GPs may take the following steps to improve communication and health care provision for patients with intellectual disabilities:

- build knowledge and familiarity with patients, and those supporting them, to learn what their expectations are so these can be addressed appropriately
- develop the ability to include patients in the consultation, verbally and/or nonverbally, regardless of the severity and aetiology of disability
- establish effective collaborative partnerships with a patient's family members and/or support workers and other health professionals involved to obtain relevant health information, and to implement treatment/management recommendations.

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