

Communication difficulties and intellectual disability in end-of-life care

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Abstract

Around 1–3% of the world's population has intellectual disabilities (Mash and Wolfe, 2004). Communication difficulties are a major obstacle in providing effective palliative care to this group. Problems may arise due to a lack of comprehension and a lack of verbal skills, affecting assessment and the provision of psychosocial support. This paper maps the communication difficulties experienced by people with intellectual disabilities within a palliative care setting, drawing on several research studies carried out by the authors. These include the time-consuming nature of effective communication, and difficulties around breaking bad news. The paper explores the ways in which people with intellectual disabilities may (mis)understand verbal information. Strategies for managing communication difficulties are outlined, including ways to use clear, unambiguous language. The authors conclude that the ability to communicate effectively with people with intellectual disabilities is a useful skill that will benefit all patients.

How do we communicate with people with intellectual disabilities who are confronted with a potentially life-limiting illness? What do we say, and how do we say it? How much can the person understand? How can we use non-verbal communication more effectively?

Difficulties with communication have been consistently reported as a major obstacle in supporting people with intellectual disabilities around end-of-life care issues (Tuffrey-Wijne et al, 2007a). Communication problems can impede timely diagnosis and symptom assessment, as well as provision of psychosocial support. Amanda Cresswell's story (see *Box 1*) highlights two key barriers to effective communication around a serious illness: a failure by carers and professionals to communicate in a way that can be understood; and carers' reluctance to disclose the truth for fear that the person will become upset or unable to cope.

This paper aims to address both these

issues. It is based on our professional experience in both palliative care services and intellectual disability services, and on the following research studies carried out by the two authors:

- The Veronica Project, an ethnographic study of the experiences of people with intellectual disabilities who have cancer (Tuffrey-Wijne and Davies, 2007; Cresswell and Tuffrey-Wijne, in press)
- A survey of palliative care provision for people with intellectual disabilities in London, collecting data from specialist palliative care professionals (32 interviews and 543 postal questionnaires) (Tuffrey-Wijne et al, 2007b; Tuffrey-Wijne et al, in press)
- A study investigating practices around disclosure of diagnosis to people with intellectual disabilities in a hospice (McEnhill, in press). We will explore the challenges that arise in communicating with people with intellectual disabilities, and provide some guidelines for overcoming these challenges.

Definition of intellectual disabilities

Around 1–3% of the world's population has intellectual disabilities (Mash and Wolfe, 2004).

There are various definitions, and indeed terminologies, for 'intellectual disabilities'. Other terms include 'learning disabilities' and 'learning difficulties'. People with intellectual disabilities have 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development' (Department of Health (DH), 2001).

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Box 1. Case study – Amanda Cresswell

Amanda Cresswell is 36 years old. It is fair to say that she has had her share of difficulties in life. She was born with brain damage, leading to mild cerebral palsy and intellectual disabilities. When she was very young, her father was killed in a car crash. She lived with an aunt until her mother recovered from the injuries sustained in that crash. Amanda was bullied at school. Her beloved mother died of a brain tumour when she was 14. She was physically and financially abused by her foster carer when she was in her early 20s. She was diagnosed with non-Hodgkin's lymphoma at the age of 30, and went through an aggressive programme of treatments.

When Amanda was asked, as part of a research study, what the most difficult time in her life had been, she said without a moment's hesitation: 'That my mum didn't tell me that she was sick. I still regret it now. She never told me that she was dying... She wanted to protect me. Of course, things like that are upsetting, but it's definitely better to know. She used to be in a bad mood all the time, she used to shout at me, it was horrible. And of course I didn't understand why!'

Amanda also spoke of her experiences in hospital when she had cancer: 'They talked to me, but they were using language that I didn't understand... I didn't have a clue what was going on, and I was very, very scared.' (Cresswell and Tuffrey-Wijne, in press)

The first part of this definition highlights the potential difficulties when trying to give information about cancer or other life-limiting illness: such information is often complex, and often new (although not always, depending on the person's life experience). In addition, a reduced ability to cope independently often means that people are more dependent on others to help them manage the life changes accompanying life-limiting illness, and effective communication is key in this.

Communication

Cogher (2005) asserts that 'communication occurs when two or more people correctly interpret each other's language and/or behaviour'. Most people with intellectual disabilities, even at the mild or moderate end of the spectrum, will have some difficulty with communication. This can include any one or a combination of the following (Iacono and Johnson, 2004):

- Speech that is difficult to understand
- Problems in understanding what is said
- Problems in expressing themselves because of limited vocabulary and sentence formulation skills.

Non-verbal communication

The non-verbal components of communication may be more important than we realise. Mehrebian (1971) analysed the impact of a message, and broke it down to 7% verbal (words only), 38% vocal (tone of voice, silence, inflection) and

55% non-verbal. Argyle (1988) said that non-verbal communication is five times more influential than verbal communication. Non-verbal aspects include facial expressions, touch, gestures, interpersonal spacing and posture. In a study of the way in which people with intellectual disabilities and severe communication difficulties communicate their distress, Regnard et al (2007) found a median of 24 changes in signs or behaviours per patient during episodes of distress, indicating a wide 'vocabulary' of non-verbal communication even in people who do not use words. It is likely that our own non-verbal signs and behaviours are picked up by patients who may not understand the words we speak. The difficulties of palliative care staff in coping when verbal aspects of communication are limited are exemplified in the following quotes from our research:

'Communication was basically non-existent, so if we went to talk to him he would pull the sheet over his head and that was it. I don't think he ever communicated, he certainly didn't communicate with us. His communication had always been very limited.' Doctor (acting consultant), interview

'I couldn't communicate with the person because he couldn't verbalise how he was feeling so you are dependent on the family for what he is feeling, what his symptoms are, what his likes and dislikes are.' Clinical nurse specialist, interview

Alternative and augmentative communication systems

Palliative care staff may be aware of different forms of communication, and often recognize the key role of family and carers.

'The first thing I would find out is how this person communicates; what their communication systems are, so hopefully there would be carers or relatives that you could talk to maybe first.' Clinical nurse specialist, interview

Many people with intellectual disabilities benefit from communication aids to augment their spoken language, including:

'Ascertaining this when someone has impaired cognitive abilities and often accompanying impaired social skills can be complex and may require the support of intellectual disability colleagues'

- Objects of reference (such as a cup to signify drinks, a towel to signify bath time)
- Signs (some sign languages commonly used by people with intellectual disabilities, such as Makaton and Signalong, use signs taken from British Sign Language together with short, simple but grammatically correct spoken sentences)
- Symbol-based systems (including photographs, line drawings and commercially available symbol packages, using communication boards or computer software) (Ambalu, 1997).

Assumptions on what system works best for an individual cannot be made. Many people with intellectual disabilities benefit from the use of pictures to augment communication; for example, the Books Beyond Words series can be useful (picture books designed to help adults with intellectual disabilities understand and talk about difficult issues, including cancer and death: see, for example, Donaghey et al, 2002). However, some people do not easily understand or relate to pictures. Thurman et al (2005) comment on people with high individual communication needs:

'They are unable to ask for things that are not actually present and are dependent on others to present them with the real tangible items... [they] can only react to situations as they arise. Such reactive communicative behaviour is often interpreted as challenging (for example, "He spits his food out on purpose")'.

In order to facilitate choice-making and the giving of informed consent, a demonstration of tangible items is often very helpful, particularly if the item is unfamiliar. Even people with mild communication problems benefit from being shown investigative equipment, or a hospice ward, before an intervention or change happens.

Comprehension

In our postal survey of specialist palliative care professionals in London, we asked what the issues had been in caring for a patient with intellectual disabilities. Three quarters of respondents stated that 'the patient could not fully understand his/her illness or treatment'; for 36% of respondents,

this was one of the most difficult things to cope with. Comments included:

'It was difficult to know if the patient did understand what we were telling him, or the treatment we were giving. It therefore made it difficult to know if what his mother said were his wishes were truly his wishes, or maybe her wishes.' Clinical nurse specialist, questionnaire

'If people aren't communicating in a normal conventional way, then there's always the danger that you're missing something. I'd be particularly concerned about psychological needs and understanding of disease and prognosis, and how one would get that information across.' Clinical nurse specialist, interview

Such difficulties with comprehension also affect assessment, which forms a major part of the task facing palliative care professionals. Cook and Lennox (2000) found that in their survey of 289 general practice registrars, issues around doctor-carer communication, history-taking and examination were difficult. Studies by Ziviani et al (2004) and Murphy (2006) found that GPs were concerned with aspects of communication which affected their ability to diagnose, manage and inform patients, whereas patients with intellectual disabilities were frustrated by not being included in communication between their carers and the GP.

Disclosure

A lack of understanding could arise from cognitive limitations innate to the intellectual disability itself. It is important to keep in mind, however, that it may well be exacerbated by the fact that the patient's family or carers are protecting him/her from the truth. This was the case for several participants in the Veronica Project. Our survey of palliative care professionals also highlighted the issue. One respondent wrote:

'The family refused to allow the patient to be told her diagnosis or that she was dying when I first became involved. But with a lot of support and time I enabled the family to be honest with her and she then understood what was happening.'

'The advice of people with intellectual disabilities is counterintuitive to the wisdom that bad news should be given gradually, starting with 'warning shots''

She died at home very peacefully.'
Clinical nurse specialist, questionnaire

When asked, many people with intellectual disabilities (such as Ms Cresswell) want to be told truthfully and straightforwardly about what is going on. However, as with the general population, some people with intellectual disabilities prefer not to be told painful truths, and therefore professionals still need to endeavour to find out what the person 'wants' to know. Ascertaining this when someone has impaired cognitive abilities and often accompanying impaired social skills can be complex and may require the support of intellectual disability colleagues.

Interviews with people with intellectual disabilities in this situation suggest that their response to the news is conditioned not only by their cognitive ability but by their previous experience of serious illness or death; therefore, such experience needs to be checked out early. The interviews also indicate that standard models of 'breaking bad news' are experienced as confusing and sometimes alarming. The advice of people with intellectual disabilities is counterintuitive to the wisdom that bad news should be given gradually, starting with 'warning shots'. Some interviewees suggested that these 'warning shots' alerted them to the fact that there was something they were supposed to understand, but that it did not help them to understand what it was or what response they were expected to make. They said that professionals should not 'beat about the bush but get on with telling it straight'. However, they also requested that the giver of bad news should 'be kind' (McEnhill, in press).

Taking time

Extra time is often required, not only to allow for the need to establish the best way to communicate with the person, to repeat questions and explanations if necessary, and to ensure that the person understands as much as possible, but also to build a therapeutic relationship and gain trust. In our study of specialist palliative care staff, almost half of the respondents stated, 'It took a while before we gained the patient's trust'.

'I think she was just frightened. And

also the fact that I came in and tried to examine her on the first day, which I think with hindsight I should never have done. She wouldn't let me come near her, and she hit me and told me to go away...And then over the next few days, the only conversations we could have was talking about her postcards, looking at her books with her. She wouldn't talk about what was wrong with her and how she felt, and she wouldn't let us examine her at all... I actually only examined her once the whole time she was here, and that was when I was really worried about her abdominal distention and I just wanted to have a feel of her tummy, and by then we had a reasonable relationship, and she let me.' Doctor (SHO), interview

'It could take up to an hour to talk him through why he had to stay, and then it would happen again in the evening and I would have to go back again. It was just so time consuming...I did find that quite difficult.' Doctor (acting consultant), interview

Perez (2003), a woman with intellectual disabilities who compiled a list of top ten tips for effective communication (see *Box 2*), suggests offering the first appointment of the day, and double consultation time. She also stresses the importance of speaking to the person with intellectual disabilities first, before talking to the carer or supporter. Thacker (2003) points out the importance of introducing yourself clearly (name and role, as well as explaining why you have come to see the person), and re-introducing yourself at every subsequent contact.

It may take a person with intellectual disabilities longer to think about what has been said and formulate a response, so it is important not to rush on with questions if the person does not respond immediately (Royal College of Nursing (RCN), 2006).

Using simple language

It is clearly important to avoid jargon and to use plain language. Many professionals find this a challenge:

'I think the difficult thing was knowing how to phrase things. Instead of saying,

Box 2. Top ten tips for effective consultation (Perez, 2003)

1. Offer the first appointment to someone who has intellectual disabilities
2. Offer double consultation time
3. Speak to the person with intellectual disabilities first, and only then check out with the carer if something is not clear. Be sensitive to the person's feelings and be encouraging
4. Try asking open questions or changing the question round to check out if you still get the same response
5. Explain the process of the consultation before you start
6. Use language that the client understands at a simple level, or use a communication aid, i.e. pictures or symbols
7. Sometimes it may be useful to get information from supporters as well.
8. Always check out that the client has understood by asking them to explain to you in their own words
9. When you are talking about time, use events that the person might understand
10. Do not assume that the person will understand the connection between the illness and something they have done or something that has happened to them

"Are you getting any symptoms", I had to say, "Does it hurt you anywhere?", kind of phrase things in really simple terms; "Are you feeling sick?", "Are you eating your food?" and just kind of keep it really simple.' Clinical nurse specialist, interview

Vincent (not his real name), a participant in the Veronica Project, was a man in his 40s with mild intellectual disabilities. He had lung cancer and was visiting the consultant at the hospital for a routine check-up. Here is an extract from the field notes of the Veronica Project, written by IT who was the participant observer.

'The doctor asks, "Do you get breathless?". Vincent doesn't quite know what the doctor means. His hesitation prompts the doctor to qualify, "How far can you walk on the flat?" [This is not very clear either; I thought, at first, that he meant 'walking around your flat]. "I'm OK", says Vincent. "I'm not good with hills. I get out of breath then." "Would you have breathing problems if you were sitting still?" "I'd rather keep active", says Vincent. He clearly has no clue about what this questioning is all about [...] The doctor peppers his talk with words like "instigate treatment" and "correlate how you are feeling with the X-ray results". Vincent looks blank, as if he has switched off, staring at the

floor in front of him [...] They are not on the same wavelength. They speak different languages.' Veronica Project, participant 7, field notes

How can we ensure that communication is effective? Sentences should be simple, with only one concept being introduced at a time. Communication aids (pictures and symbols) can help, and it is always useful to have pen and paper to hand, both for yourself and for the patient.

It is important to remember that people with intellectual disabilities, even if they seem to have understood, may actually not have understood at all. Many people with intellectual disabilities are eager to please, and will tell you what they think you want to hear. It is also important to bear in mind that people with intellectual disabilities often answer 'yes', regardless of the question. Closed questions ('Have you understood what I said?', 'Do you have any pain?') should therefore be used with care. In addition, when presented with a choice, some people with intellectual disabilities tend to repeat the final option ('Tea or coffee?', 'Coffee'). It is useful to check out whether the patient has understood by asking him/her to explain things back to you in their own words.

Abstract concepts are more difficult than concrete ones. Concepts of time, for example, can be very difficult. Sentences like, 'How long have you had the pain?' or, 'You are going home next week' may be hard to comprehend. It is helpful to mark the passing of time by using 'index events' that the person will understand; for example, 'Did you have the pain at Christmas?' or 'Take one tablet with your breakfast and one tablet when you go to bed' (rather than 'twice a day').

Some people with intellectual disabilities, particularly those on the autistic spectrum, may take words literally. Saying, 'We have lost Grandpa', rather than, 'Grandpa has died', may leave the person wondering why we don't start searching for Grandpa. This can be particularly relevant when discussing treatment options. It is possible that even a person with a relatively mild learning disability may misunderstand terms such as 'side-effect', taking it literally and believing that it affects only one's sides; or, as

has been reported in younger children, think that a radioactive 'dye injection' will actually lead to their death (Myerscough and Ford, 1989). Staff, therefore, should not only think about which words they will 'say', but how these will be 'heard'. Using non-euphemistic language is a skill that needs to be learned, particularly given our understandable avoidance of blunt communication in this area of practice. With practice it is possible to be clear, truthful and sensitive; but this requires time, patience and a tentative checking out of what is being understood at each step of the process. Distress in patients with intellectual disabilities need not be a sign of a failure to communicate, but may be the inevitable result of having clearly communicated the seriousness of the situation.

Conclusion

In this paper, we have highlighted some of the communication challenges for people with intellectual disabilities, and presented strategies for dealing with these. Specialist palliative care professionals are usually highly trained in communication issues. We believe that it is possible for most staff to adapt their existing communication skills to include people with intellectual disabilities.

We also believe that the principles of effective communication can be used in working with any patients or relatives, regardless of whether they have intellectual disabilities or not. They often go through very worrying times, and benefit from clear and unambiguous communication. For example, remembering to introduce ourselves, stating what our interaction is about, using plain language rather than complicated sentences or jargon, and taking time, can all contribute to effective therapeutic relationships. As such, there is much we can learn from people with intellectual disabilities in our efforts to become effective communicators.



Key words

- Intellectual disabilities
- Palliative care
- Communication
- Disclosure
- Information giving

Ambalu S (1997) Communication. In: O'Hara J, Sperlinger A (eds). *Adults with Learning Disabilities*. John Wiley & Sons Ltd, Chichester: 44-60

Argyle M (1988) *Bodily Communication*. Methuen, London

Cogher L (2005) Communication and people with learning disabilities. In: Grant G, Goward P, Richardson M, Ramcharan P (eds). *Learning Disability: a Life Cycle Approach to Valuing People*. Open University Press, Maidenhead: 260-84

Cook A, Lennox N (2000) General practice regis-

trars' care of people with intellectual disabilities. *J Intellect Dev Disabil* 25(1): 69-77

Cresswell A, Tuffrey-Wijne I (in press) The come back kid: I had cancer, but I got through it. *Br J Learn Disabil*

Department of Health (DH) (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. DH, London

Donaghey V, Bernal J, Tuffrey-Wijne I, Hollins S (2002) *Getting On With Cancer*. Gaskell/St George's Hospital Medical School, London

Iacono T, Johnson H (2004) Patients with disabilities and complex communication needs. The GP consultation. *Aust Fam Physician* 33(8): 585-9

Mash E, Wolfe D (2004) *Abnormal Child Psychology*. Thomson Wadsworth, Belmont

McEnhill L. Breaking bad news of cancer to people with learning disabilities (in press). *Br J Learn Disabil*

Mehrebian A (1971) *Silent Messages*. Wadsworth, California

Myerscough P, Ford F (1989) *Talking with Patients: Keys to Good Communication, 3rd edn*. Oxford University Press, Oxford

Murphy J (2006) Perceptions of communication between people with communication disability and general practice staff. *Health Expect* 9(1): 49-59

Perez W (2003) Top ten tips for effective communication. www.intellectualdisability.info/how_to/top_10.htm (accessed 2 April 2008)

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C (2007) Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disabil Res* 51(4): 277-92

Royal College of Nursing (RCN) (2006) *Meeting the health needs of people with learning disabilities: guidance for nursing staff*. RCN, London

Thacker A (2003) Clinical communication. www.intellectualdisability.info/how_to/clin_comms.htm (accessed 17 April 2008)

Thurman S, Jones J, Tarleton B (2005) Without words - meaningful information for people with high individual communication needs. *Br J Learn Disabil* 33(2): 83-9

Tuffrey-Wijne I, Davies J (2007) This is my story: I've got cancer. 'The Veronica Project': an ethnographic study of the experiences of people with learning disabilities who have cancer. *Br J Learn Disabil* 35(1): 7-11

Tuffrey-Wijne I, Hogg J, Curfs L (2007a) End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature and available resources. *J Appl Res Intellect Disabil* 20(4): 331-44

Tuffrey-Wijne I, McEnhill L, Curfs L, Hollins S (2007) Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care providers in London. *Pall Med* 21(6): 493-9

Tuffrey-Wijne I, Whelton R, Curfs L, Hollins S (in press) Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals in London. *Pall Med*

Ziviani J, Lennox N, Allison H, Lyons M, Del Mar C (2004) Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *J Intellect Dev Disabil* 29(3): 211-25

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