Sharing the true stories: improving communication between Aboriginal patients and healthcare workers

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DOCTOR–PATIENT COMMUNICATION, by creating good interpersonal relationships, allowing the exchange of information and facilitating treatment-related decisions, is fundamental to optimal medical care.[1] Effective communication correlates with improved outcomes, including physiological criteria such as levels of blood pressure and blood sugar.[2] Conversely, professional, language and cultural barriers can impede communication.[3,4]

Few investigators have studied the extent and consequences of miscommunication in Australian Aboriginal healthcare,[5] an area in which effective communication is extremely important.[6] Previous studies involving interviews with service providers and Aboriginal patients have identified significant concerns about communication.[7-9] Some researchers have identified an acceptance, as the *norm*, of a grossly deficient standard of cross-cultural communication.[8] We believe that previous studies, based as they have been on indirect reporting or simulated interactions[10] (rather than direct observation and analysis of the interaction itself), probably understate the degree of miscommunication. The communication gap may be so wide, and so ingrained in healthcare, that it is not even perceived by staff.[11] Similar misunderstandings in Australian court cases often go unrecognised by the participants.[12]

In our study of staff–patient interactions in a dialysis unit in Darwin, NT, we attempted to develop a more informed understanding of intercultural communication between Aboriginal patients and non-Aboriginal staff and to devise strategies for improvement.

ABSTRACT

Objectives: To identify factors limiting the effectiveness of communication between Aboriginal patients with end-stage renal disease and healthcare workers, and to identify strategies for improving communication.

Design: Qualitative study, gathering data through (a) videotaped interactions between patients and staff, and (b) in-depth interviews with all participants, in their first language, about their perceptions of the interaction, their interpretation of the video record and their broader experience with intercultural communication.

Setting: A satellite dialysis unit in suburban Darwin, Northern Territory. The interactions occurred between March and July 2001.

Participants: Aboriginal patients from the Yolngu language group of north-east Arnhem Land and their medical, nursing and allied professional carers.

Main outcome measures: Factors influencing the quality of communication.

Results: A shared understanding of key concepts was rarely achieved. Miscommunication often went unrecognised. Sources of miscommunication included lack of patient control over the language, timing, content and circumstances of interactions; differing modes of discourse; dominance of biomedical knowledge and marginalisation of Yolngu knowledge; absence of opportunities and resources to construct a body of shared understanding; cultural and linguistic distance; lack of staff training in intercultural communication; and lack of involvement of trained interpreters.

Conclusions: Miscommunication is pervasive. Trained interpreters provide only a partial solution. Fundamental change is required for Aboriginal patients to have significant input into the management of their illness. Educational resources are needed to facilitate a shared understanding, not only of renal physiology, disease and treatment, but also of the cultural, social and economic dimensions of the illness experience of Aboriginal people.

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METHODS

Participants and setting

The participants were patients and staff of a satellite dialysis unit in suburban Darwin. The interactions on which our study is based occurred between March and July 2001. The patients came from the Yolngu language group in north-east Arnhem Land. Five interactions were videotaped, each involving a single patient (although family members were present on two of these occasions). Four interactions involved a single staff member and one involved a doctor and a nurse. The interviews occurred at the dialysis unit and at a remote Aboriginal community several hundred kilometres from Darwin.

Design

We used qualitative research methods to reflect the perspectives of all participants. The research design drew on "grounded theory", which describes the inductive process of identifying analytical categories to describe and explain key issues as they emerge from the data.[13] Hypotheses were developed from the ground up,

rather than being defined a priori, as is usually done in *quantitative* research.

Recognising that the effectiveness of communication is inextricably connected with structural issues of poverty, dispossession, marginalisation, low educational achievement and racial discrimination,[7] we chose a "participatory action" approach. This is a style of research in which the demarcation between "researcher" and "subject" is blurred, research design is negotiated, and the participants perceive the need to change and are willing to participate actively in the change process.[14] The research process is illustrated in Box 1.

Sampling

Five clinical interactions, identified beforehand in consultation with both patients and staff, were selected. These concerned diagnosis, treatment and chronic disease management. Staff were asked to follow their usual practice regarding the use of interpreters. The interactions included two medical reviews (one with a patient on regular haemodialysis and one with a patient with chronic renal disease close to needing maintenance dialysis), two education sessions (a nurse providing feedback on blood-test results and a consultation between an allied health professional and a new patient), and an interaction between a nurse and a patient during dialysis.

We selected participants using a "maximum variation sampling approach", wherein a small sample is selected to reflect maximum diversity across specified attributes.[16] The participants covered as wide a range as possible in terms of age, sex, duration of renal experience (receiving or providing treatment), degree of familiarity with the culture and language of the other group, and experience in cross-cultural communication.

Collection of data

The five interactions were videotaped and analysed by all participants, the research team and professional interpreters. Multilayered descriptions of the interactions were constructed from these varied perspectives.

After each interaction, the participants were interviewed separately, in their first language, to explore their perceptions of the effectiveness of the communication. The post-interaction ("exit") interviews were conducted by A L (for English speakers) and B M (for Yolngu speakers). Semi-structured, in-depth interviews were also conducted with most staff and patients to develop a greater understanding of their backgrounds and wider experience.

Informed consent was obtained from all participants before videotaping. B M obtained verbal and written consent in the patients' own language.

Analysis

The data from all sources were integrated to explore the extent of miscommunication; the cultural, linguistic and systemic factors influencing communication; the effectiveness of communication strategies being used; and possible strategies for improving communication.
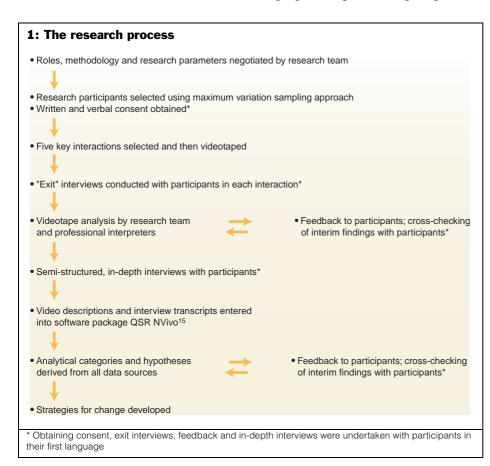
The video descriptions and interview transcripts were entered into QSR NVivo,[15] a computer software package that assists in managing qualitative data. Categories used in analysis were derived primarily from the data and through sequential analysis. To strengthen the validity of our analysis, we used "triangulation" (the comparison of results from two or more different methods of data collection) and "respondent validation" (cross-checking *interim* findings with the participants).[17,18]

Ethical approval

The study was approved by the ethics committees of the Menzies School of Health Research at the Royal Darwin Hospital and the Northern Territory University.

RESULTS

A picture emerged of serious miscommunication, often unrecognised by participants, regarding fundamental issues in diagnosis, treatment and prevention. Although there were many differences of goals and structure observed in the interactions, common themes relating to miscommunication emerged. Factors impeding communication included lack of control by the patient, differing modes of discourse, dominance of the biomedical model, lack of shared knowledge and understanding, cultural and linguistic

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1: The research process

- Roles, methodology and research parameters negotiated by research team

- Research participants selected using maximum variation sampling approach
- Written and verbal consent obtained*

- Five key interactions selected and then videotaped

- "Exit" interviews conducted with participants in each interaction*

- Videotape analysis by research team and professional interpreters ⇄ • Feedback to participants; cross-checking of interim findings with participants*

- Semi-structured, in-depth interviews with participants*

- Video descriptions and interview transcripts entered into software package QSR NVivo[15]

- Analytical categories and hypotheses derived from all data sources ⇄ • Feedback to participants; cross-checking of interim findings with participants*

- Strategies for change developed

* Obtaining consent, exit interviews, feedback and in-depth interviews were undertaken with participants in their first language

distance, lack of staff training in intercultural communication, and failure to call on trained interpreters (see Box 2 and Box 3).

Lack of control by the patient

In each interaction, it was the *staff* who controlled the time, place, participants, purpose, structure, topics and language, as well as the form and style of discourse. There were few opportunities for the patients to initiate or influence the agenda. The staff decided whether or not interpreters would be required, even when unaware of the patient's fluency in English.

Differing modes of discourse

Western modes of discourse dominated, with Yolngu modes being marginalised or excluded. Question-and-answer routines, central to Western discourse, do not feature commonly in Yolngu discourse, particularly in relation to personal topics. In Yolngu discourse, the question-and-answer approach is complicated by factors such as cultural restrictions on who may ask for, or give, specific information. It is generally considered impolite to directly contradict or to respond negatively, particularly in encounters of unequal power or when the participants lack a close relationship. The patients in our study repeatedly gave responses that they believed the staff wanted to hear, a practice known in linguistics as "gratuitous concurrence".[19] Triangulation showed that these responses did not represent the patient's true feelings or experience, but were attempts to give "required" or "correct" responses, as in the following example:

> *Physician:* How much are you drinking? How much water?
>
> *Patient:* Little bit water tea, little bit ga bilin ["that's it"].
>
> *Physician:* How much each day? Water, tea?
>
> *Patient:* Three cup, two cup, little bit [said very confidently].

The physician believed that the patient had a clear understanding of the question and was describing the amount of fluid drunk daily. However, it later became clear that the patient responded this way because she knew what was expected. Her understanding of fluid restriction was that

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2: Sample interaction (A)

Setting: The doctor's office in a remote community 500 kilometres from Darwin.

Participants: Mr "A", a 24-year-old man with chronic renal disease who recently had a prolonged admission to Royal Darwin Hospital, during which he required temporary dialysis. He lives with his mother and grandmother, and is fluent in Yolngu languages but not in English. He will need relocation to Darwin within two years for maintenance dialysis.

Dr "B", a 38-year-old male physician with many years' experience working with multicultural and Aboriginal patients.

The interaction: The 20-minute interaction, in English, was initiated by Dr B, who did most of the talking. The patient's mother and grandmother assisted with communication. Mr A and his family asked no questions and gave limited, non-verbal responses to the doctor's questions.

Communication goals: Dr B had clear goals:

I wanted to reinforce that [the patient] was at risk of progression to end-stage renal disease and that he would benefit from treatment, of blood pressure in particular . . . and treatment of other things like anaemia. . . . The main thing was that he doesn't need dialysis at the moment, but that he needed to be monitored and to take his tablets.

The expectations of Mr A and his family were unclear. It later became apparent that they believed that his disease had been cured during his admission. They had no appreciation of its chronicity and of his need for regular tests and medications.

The participants' assessment: Dr B was uncertain of the outcome of the interaction:

Perhaps his mother got some idea . . . I hope they at least understand he is at risk of needing more dialysis. I think they now understand he has kidneys that aren't working so well . . .

After the consultation, the Yolngu researcher discovered that the family's understanding of the doctor's advice was that Mr A should be taking medication. Despite Dr B's extended explanation of chronicity and prognosis, the interaction did not achieve a shared understanding of the state of the patient's kidneys, the significance of test results or the importance of blood pressure control. The family had understood little. This prompted the Yolngu researcher to recall Dr B to explain further, while she provided interpreting assistance.

Consequences for clinical management: Miscommunication reduced the ability to actively engage Mr A and his family in controlling his blood pressure, in retarding progression of his renal disease and in planning for future dialysis. Lack of effective communication about the need to relocate to Darwin for treatment, away from family and community, could result in the patient's reluctance to accept dialysis in the future.

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she should drink only two cups of "fizzy drink" per day, but that drinking tea or water whenever she felt like it was acceptable. Questions requiring a "yes"/"no" response were particularly susceptible to gratuitous concurrence. A nurse made the following comment:

> I never even considered that they might be saying "yo" [yes] when they are really saying "no". I never even thought of it.

Dominance of the biomedical model

The discourse in the interactions focused on renal function, renal failure, monitoring of and adherence to dialysis, and dietary and medication regimens. Non-medical aspects were excluded or marginalised. Yolngu priorities, which emerged in subsequent interviews and informal discussions, were social, cultural and economic, relating primarily to

(currently) unavoidable relocation to Darwin if patients wished to access necessary treatment. One patient illustrated her problems with living in Darwin:

> I told her [the staff member] the truth . . . that I wasn't getting enough [food]. When I get my allowance, they take all the money for accommodation and leave only $30 for food — that's not enough.

Yolngu priorities, which directly affect clinical management, were rarely raised, and, when raised, were either not pursued or were brushed aside. Patients had no explicit opportunities to discuss their own approaches to managing their health. For example, in two interactions, they attempted to talk about Yolngu knowledge and management practices (related to traditional foods), but their contributions were either not understood or not acknowledged.

3: Sample interaction (B)

Setting: The open waiting area at the dialysis unit.

Participants: Ms "C", a 50-year-old woman who had been on dialysis for five years. She speaks Yolngu languages and is fluent in conversational English. She has graduate qualifications as a teacher.

Sr "D", a 31-year-old female nurse with 10 years' experience in renal services, both as a nurse and patient educator, but with little formal training in cultural awareness.

The interaction: The interaction, in English, was initiated by Sr D. She determined the timing and location to fit in with her work program and with the patient's dialysis schedule. The nurse did most of the talking and the patient asked few questions.

Communication goals: Sr D aimed to provide education through feedback and discussion of routine monthly test results. She aimed to integrate information about dialysis, medication and diet, specifically related to the test results.

Neither participant mentioned what Ms C might have wanted to communicate.

The participants' assessment: Both believed that the communication had, to some extent, been effective. Ms C said, "I could see it all clearly. . . . I didn't have any misunderstanding."

However, through analysis of the video with each participant and with further discussion, evidence of extensive miscommunication emerged. The nurse had emphasised, during the interaction, that Ms C's haemoglobin level was low and had discussed its significance in terms of her health and the use of erythropoietin. In the exit interview, Ms C indicated that she believed that all her results were normal.

Sr D had discussed results of biochemical tests and the use of specific medications. She said, "[The patient] knows a lot about medication and dialysis treatment. . . . She knows what medication she's on."

However, at exit interview, it became clear that Ms C had not understood key issues relating to the results, that she was unable to name most of her medications, and that her understanding of their actions was completely different from the biomedical explanations she was given. The absence of shared understanding of key concepts relating to results and medications was seen as an important source of miscommunication.

Consequences for clinical management: Both participants had perceived the communication to be effective. The discrepancy between perception and reality became evident only through triangulation of the data. Standard assessments of quality of care by the measurement of staff and patient satisfaction, in this case relating to education and staff–patient interaction, would not have revealed the miscommunication. This has important implications for clinical management. Best outcomes in the management of end-stage renal disease require adherence to a complex treatment regimen of regular dialysis, repeated tests, dietary restriction and daily medications.

Lack of shared knowledge and understanding

Extensive prerequisite knowledge is essential for making sense of information about the management of end-stage renal disease. A shared understanding of kidney and heart function, and of the nature of the circulatory system (including, for example, the components and function of blood), is necessary for meaningful discussion about medication, fluid restriction and dialysis. As shared understanding of many of these concepts does not exist, effective communication is seldom achieved.

Cultural and linguistic distance

The vast cultural and linguistic distance between staff and patients in these interactions impeded communication. Staff use of culturally specific terminology was one difficulty. For instance, quantification was a constant problem. Key biomedical issues were expressed quantitatively, including percentage of renal function, number of drinks consumed, amount and frequency of medications, length of visits home, length of time without dialysis, high and low blood pressure, and blood test results. But litres, kilograms, hours, dates and percentages have little, if any, meaning for most Yolngu, while Yolngu ways of expressing quantity and spatial and temporal concepts were completely unknown to staff.

Lack of staff training in cross-cultural communication

None of the staff speak an Aboriginal language and none of their Yolngu patients speak English as a first language. Furthermore, none of the staff had received any formal training in intercultural communication. Even general cultural awareness training, which is increasingly available to staff, had been utilised to a limited extent and to minimal effect. One physician recalled his only training experience in cultural awareness:

In Alice Springs, I probably had a day's training. It would have been a standard thing, and it was brief, and I have no memory of it.

And yet he found that intercultural communication was

. . . an incredibly difficult aspect of working there. I knew that there was next to no communication between me and the patients, which had an obvious impact on what happened.

There were organisational barriers to formal training, as a renal nurse related:

I haven't done a cross-cultural course at all. When I first came up [to Darwin], it wasn't compulsory and I've tried to get in several times over the years and it was either booked out or Renal couldn't relieve me because they didn't have enough staff at the time.

For most of the staff, learning occurred "on the job", but this had serious limitations, as a physician reflected:

You become aware of the issues just through doing what you're doing. Which is poor. . . . You learn by obstacles and by . . . causing affront and problems.

Limited use of interpreters

Until recently, there was no alternative to attempting whatever communication was possible through the assistance of whoever was available. In the absence of professional interpreters, family members had to suffice — a seriously inadequate practice.[20] Although an Aboriginal Interpreter Service providing Yolngu language speakers now exists, changes in practice are occurring only slowly. In the interactions observed in our study, the closest any of the staff or patients came to seeking the assistance of a professional interpreter was to call on the assistance of a family member who had some informal interpreting experience.

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4: Strategies for improving communication between non-Aboriginal healthcare staff and Aboriginal patients

■ Train staff in intercultural communication. It is the staff's responsibility to make this accommodation to enable Aboriginal people to make informed choices in the context of their own language and cultural environment.

■ Train Aboriginal interpreters to prepare them for work with healthcare workers.

■ Promote strategies to monitor the effectiveness of communication and to repair miscommunication.

■ Develop educational resources to facilitate a shared understanding of (a) physiological processes and treatment options; and (b) cultural, social and economic realities confronting Aboriginal patients and their families.

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DISCUSSION

Our study demonstrates that renal staff and Yolngu patients rarely achieved a shared understanding of key concepts. Consequently, communication was seriously limited and quality of care compromised. There was little indication that either staff or patients had, before or during these encounters, considered the potential for miscommunication. Even if this had occurred, staff had no tools or guidelines for assessing its extent. Our findings suggest that any substantial improvement in communication, and in ensuing health outcomes, requires fundamental change in the delivery of healthcare — in particular, in constructing a shared understanding, from the perspectives of both staff and patients, of physiological processes, renal disease and treatment options.

Previous research has been based on interviews with service providers, and sometimes with Aboriginal patients, about their perception of communication issues. Our study, by contrast, involved direct observation of interactions, and then, with the input of all participants, sequential analysis. We have shown that miscommunication can easily go unrecognised.

While previous studies of communication breakdown have usually focused on the clinical interaction, we looked beyond this. Our findings enabled us to understand both sides and to see the clinical interaction within the social, cultural and political context relevant to the delivery of healthcare to Aboriginal people.

We believe the qualitative research methods we used were appropriate. It could be argued that our findings may not be generalisable to staff–patient communication in the entire renal unit in which the research occurred, nor transferable to other patient-care settings. However, we believe that the methods of triangulation, respondent validation and maximum variation sampling strengthen the validity of our findings.

Videotaping the interactions did not appear to fundamentally alter the communication strategies used by staff. In any case, we would expect any bias, arising through participants' knowledge of being observed, to be towards *more* effective rather than *less* effective communication. Our results support similar findings of miscommunication in other Aboriginal health research[8,11,21] and in international cross-cultural research.[1,3] We believe that our research findings are both credible and relevant to the delivery of healthcare to Aboriginal people, and that similar miscommunication problems are likely to exist in other healthcare settings in which there are people whose first language is not English.

Fundamental change is required to achieve effective communication with Aboriginal patients who have renal disease. We will not be able to deliver optimal care without striking a balance between the staff's medical priorities and the patients' social needs. Some strategies for improving communication are set out in Box 4. Planning and implementing such strategies for the Yolngu will require collaboration between staff, patients and patients' families. We are currently developing such a project. Short of such radical change, attempts to improve communication can meet with only limited success.

COMPETING INTERESTS

None declared.

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