

sharing the true stories
Improving communication between health staff
and Aboriginal patients

STAGE 1 Report

January to August 2001

Ḳakaranhamirr yuwalk dhäwu:
Gunga'yun YolḡuYolḡuny mala ga djämamirriny mala Yolḡuw märr walal dhu
marḡithinyamirr bala-räli'yunmirr.
Dhiyaḡ djämay napurr ga Ḳarrum yuwalkku dhäwuw.




Cooperative Research Centre for
Aboriginal Health

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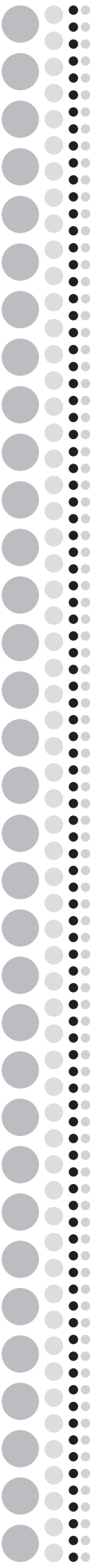
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Executive summary

Extensive research has been carried out on communication between health staff and patients, particularly in the area of doctor-patient communication. Effective communication is recognised as being crucial to achieving optimal health care, yet there have been few investigations of the extent and consequences of miscommunication in the context of Indigenous Australian health care despite the recognition that communication difficulties between health staff and Aboriginal patients are a major barrier to improving health outcomes.

This project, *Sharing the true stories*, was a response to the need to develop a more informed understanding of intercultural communication in Aboriginal health care and to identify strategies to improve communication. The project was conducted with renal staff and patients in the Top End of the Northern Territory from January to August 2001 and focused on a discrete group of Indigenous people with renal disease (speakers of the Yolŋu languages of North-East Arnhem Land). This in-depth exploration of communication issues in renal care was considered a crucial first step in ensuring that further action would be grounded in an improved understanding of intercultural communication, informed by the perspectives of both health service providers and Indigenous users of health services.

In this study communication was conceptualised, in line with Pauwels' description (1995:7), as a process in which:

- **we cooperate with each other to construct a message or meaning. The message is**
- **constructed by means of signs or symbols whose meaning is shared and agreed on by**
- **those involved in the communication process.**

Based on this construction, miscommunication then occurs when participants:

- **do not share the same system of signs (they may speak different languages) or they**
- **may not attach the same meaning to the signs because they do not share the same**
- **system of values and beliefs. (Pauwels 1995:11)**

A participatory action approach was considered appropriate for this project in which the aim was to begin a process of change through which more effective communication will lead to improved health outcomes for Aboriginal people. Stage 1 of the project was primarily an exploratory phase to inform decisions about actions to be implemented in Stage 2. Within this framework the theoretical perspectives, methodologies and research techniques selected were those considered most appropriate to achieve the aims of the research.

As a result, the study is most closely aligned with a constructivist paradigm in which the aim of inquiry is *understanding and reconstructing* the constructions that participants (including the researchers) initially hold. The aim is for increasingly informed and sophisticated constructions, moving towards consensus. Another aim is to increase everyone's awareness of the content and meaning of competing constructions. The role of the researcher is that of participant and facilitator in this process, and advocacy and activism are key features (Guba and Lincoln 1998).

The research design drew on various methodologies, which share common ground with the constructivist paradigm including ethnography of communication, phenomenology, grounded theory and discourse analysis. Qualitative research methods were employed as the most effective technique for developing a holistic and contextualised understanding of communication in a complex setting, and to provide what Higginbotham (2001:263) describes as 'a firm empirical ground for understanding the causal web and carrying out interventions'.

Five interactions were selected from a range of encounters identified by staff and patients as crucial and often problematic. The interactions included:

- two medical reviews (one with a patient on dialysis and one with a patient with chronic renal failure not yet requiring dialysis);
- two education sessions (a nurse providing a patient with feedback on blood test results and a consultation between an allied health professional and a new patient); and
- a dialysis treatment session.

Executive summary continued ...

These interactions were videotaped and provide powerful primary data, which was then analysed by participants and various research team members, as well as by experienced interpreters. From this triangulated data multi-layered descriptions of the interactions that integrated these multiple perspectives were then constructed.

After each interaction, each participant was interviewed to explore his or her perceptions of the nature and effectiveness of the communication that had occurred. Semi-structured in-depth interviews were also conducted with most participants (and in some cases family members) to develop a greater understanding of each participant's background and wider experiences in order to achieve more meaningful interpretations of the encounter.

The research approach was *inductive*, utilising techniques from grounded theory in data analysis and interpretation (i.e. building theory from the data). The data from all sources was integrated to explore:

- the extent of miscommunication;
- the cultural, linguistic and political factors influencing communication in renal services;
- the effectiveness of communication strategies currently used; and
- possible strategies for improving communication.

Categories used in analysis were derived from a variety of sources, primarily from the context, to reflect the participants' perspectives and to reduce the extent to which data is filtered through a restricted and predetermined set of codes. It also included, however, categories drawn from other related research and theoretical frameworks.

Although there were many differences between goals and structure of the interactions, as well as between the ages and experiences of the participants and the cultural and linguistic distance between them, there were also some common threads. These included:

- the high level of motivation of all participants to achieve the best possible communication within the constraints of their situations;
- the limited extent to which a shared understanding about underlying biomedical concepts and key terms was actually achieved;
- the overestimation of the effectiveness of communication by all participants;
- the limited awareness of both staff and patients of the frequency and severity of miscommunication;
- the overestimation by both patients and staff as to the extent of their shared knowledge;
- the different understandings between staff and patients about communication processes, such as how different cultural and professional conventions influence what is said and what is withheld, as well as roles and responsibilities in decision-making and care;
- the dominance of Western biomedical discourse systems and the marginalisation or exclusion of Yorl̥u discourse systems, which are unrecognised and/or uncontested by all participants; and
- the inadequacy of current communication practices in terms of prevention of communication difficulties, monitoring of effectiveness or repair of miscommunication when it does occur.

Most of the interactions between staff and patients focused on the biomedical communication priorities and constructions related to renal disease and treatment. Making sense of any information relating to renal issues requires, however, extensive knowledge from the biomedical domain—a shared understanding of the function of the kidneys, heart and the nature of the circulatory system for example. As there is no such shared understanding between staff and patients in renal care for many of these underlying concepts, the potential for effective communication is seriously restricted. In current practice, there are few meaningful opportunities for patients to access and share information about their renal care.

There were also very few opportunities for the Yolŋu patients to initiate or influence the topics of discussion in these encounters. As a result the patients' knowledge, experiences and priorities were excluded or marginalised. Most of the concerns that emerged as Yolŋu priorities—primarily through the interviews and informal discussions—were social, cultural and economic. They related primarily to relocation to Darwin, which at the time of this study was unavoidable for most Yolŋu with end-stage renal disease who wished to access the treatment essential for their survival.

A number of sources of communication difficulty were identified, including the cultural distance between participants (in terms of ideology, socialisation, knowledge systems etc.), the absence of educational opportunities for staff and patients to develop shared understandings, and communication differences in terms of:

- language systems, especially the understanding and use of terms and metaphors;
- the ways in which language is used in communication; and
- non-verbal communication.

Systemic barriers are also important and they include:

- time constraints, which inhibit changes in practice;
- the segmentation and reductionism that characterise the biomedical approach to management;
- the (often unrecognised) cultural specificity of health services;
- structural inertia; and
- the absence of processes and resources for planning and implementing change.

As well, the individual and institutional capacity required to meet the needs of Yolŋu patients is not critically assessed or addressed. There are no Yolŋu staff or speakers of Yolŋu languages employed in renal services and there is no provision for educational support for both staff and patients to enable optimal—or even adequate—renal care to occur in this intercultural context.

This study has demonstrated that renal staff and Yolŋu patients rarely achieve shared understanding of any of the key concepts in renal care. As a consequence the effectiveness of communication is seriously inadequate and this constrains patients' ability to make genuinely informed choices in managing renal disease. The quality of care is therefore inevitably compromised.

The findings suggest that any substantial improvement in communication, and consequently health outcomes, requires action in three interdependent areas:

- shifting control;
- increasing shared understanding; and
- improving communication practices.

The following ideas emerged during Stage I of this project and will form the basis of the next stage, which will further develop, implement and evaluate the strategies identified to address the three key areas of change.

Shifting control addresses the barriers to improving communication at both system and service levels by, for example:

- increasing participation of patients and families in service planning and management (patient-centred/integrated);
- facilitating involvement of staff from relevant cultural/language groups;
- accommodating Indigenous organisational and communication processes through changing institutional practices;
- increasing opportunities for patients to initiate and structure interactions; and

Executive summary continued ...

- creating conditions for patients to make genuinely informed decisions (through increasing shared understanding and improving communication practices).

Increasing shared understanding of key processes and concepts in health care involves:

- staff and patients/interpreter health workers working together to construct a shared understanding of key processes and concepts in renal care;
- ongoing educational programs between and within groups; and
- improved patient–staff collaboration in case management including better patient access to their medical records.

Improving communication practices in Aboriginal health care includes, for example, developing intercultural communication training for staff and patients (informed by Stage 1) integrated with:

- support for ongoing training for interpreters in health, with opportunities to specialise in renal care;
- evaluating and improving the extent to which current practice enables genuinely informed choice and informed consent; and
- developing, implementing and evaluating specific communication strategies to increase the capacity of staff to prevent, monitor and repair communication difficulties in interactions with Aboriginal patients.

Equity of access to health care will only be achieved when services for Indigenous people with renal disease adequately accommodate the cultural and linguistic needs of clients. Planning and implementing strategies for change requires collaboration for optimum outcomes:

- between service providers, policy-makers and patients;
- between staff from different disciplines and with different expertise; and
- between Yolŋu patients, their families, health workers and interpreters.

Such collaborations provide a powerful means to increase shared understanding. As well, this process would optimise the relevance and sustainability of any action that is undertaken. Action across all three areas needs to be coordinated and sustained, as improvement in any one area will only result in limited change in communicative effectiveness. For example, simply increasing staff awareness of miscommunication will not address the absence of the shared understanding, which is crucial to achieving effective communication. Similarly, increasing shared knowledge will have less effect if greater patient control over the timing, focus and structure of renal care encounters does not occur. A proposal to undertake this work is now under development (see Attachment 1).

This *Interim project report* relates to Stage 1 of what will hopefully be an ongoing process to improve communication in Indigenous health care. It is structured to enable the reader to access information about a particular issue without needing to read the report as a whole.¹

In the introduction (Section 1) some key concepts and terms are defined. This is followed by a brief overview of related research (Section 2) and further details from other studies are integrated into relevant sections of the report. In Section 3 the methodology is described in some detail for those that are particularly interested in the research process. Section 4 describes the case studies (two in detail, with summaries of the other three encounters) to provide a clear context for the following sections, which explore features of communication across the interactions (Sections 5 and 6). In these sections relevant information from other sources, the findings of this study and their implications for action related to each specific issue are integrated rather than segmented across the report. The conclusion (Section 7) provides a brief overview of the barriers to effective communication identified in this study. Strategies to improve communication, informed by this research and other related work, are then summarised. These ideas for action are further developed in the proposal for Stage 2 of *Sharing the true stories*, which can be found in Attachment 1.

¹ The contents of this report with additional material, such as video examples from the research, can also be found at www.sharingtruestories.com

1. introduction

Communication difficulties in interactions between health staff and Aboriginal patients are widely recognised as a major barrier to improving health outcomes. This project is part of an ongoing and collaborative process to improve intercultural communication at all stages of health care interactions and to improve both process and outcomes, from accuracy of diagnosis and adherence to treatment through to changing health-damaging behaviours.

Stage I of the *Sharing the true stories* project was conducted with renal staff and patients in the Top End from January to August 2001 and focused on one group of Indigenous patients (speakers of the Yolŋu languages of North-East Arnhem Land). The primary aim of this project was to develop a deeper understanding of communication issues in this context and to identify potential strategies for improving communication in collaboration with staff and Aboriginal patients.

The first stage of this project also aimed to generate further action to develop, implement and evaluate the strategies identified as potentially beneficial, to assess their viability for other health care settings and other language groups and, if appropriate, to facilitate their broader implementation. The in-depth exploration of communication issues in renal care reported here was a crucial first step to ensure that further action is grounded in an improved understanding of intercultural communication, informed by the perspectives of both health service providers and Aboriginal users of health services.

Definitions of terms used in the report

Communicating information about the project through this report is a process that is itself at risk of miscommunication because of possible cultural and ideological differences between the writer and the reader. To minimise this risk, there is an explanation below of the ways in which some of the common terms are used in the report. These are not offered as definitive interpretations of terms that may be conceptualised in many and varied ways in different disciplines and by different individuals, but as the constructions which have been found to be most relevant for this context.

Communication

A definition of communication, which is consistent with the theoretical orientation of this study, is given by Pauwels (1995:7), who describes communication as a process in which:

- **we cooperate with each other to construct a message or meaning. The message is**
- **constructed by means of signs or symbols whose meaning is shared and agreed on by**
- **those involved in the communication process.**

Intercultural communication

Pauwels (1995:24) also offers a definition of culture, which, although very limited, is consistent with the above definition of communication and useful for the purposes of this study. Intercultural communication is:

- **a historically transmitted system of symbols, meanings and patterns which are both**
- **regulative and reflective of a group's behaviour.**

The work of Scollon and Scollon (1995) relates specifically to intercultural communication and is also relevant to this study. They consider culture in terms of the aspects found to be most significant for understanding systems of discourse as well as major factors in intercultural communication. These include:

- *ideology* (history and world view, which includes beliefs, values and religion);
- *socialisation* (including education, enculturation and acculturation; primary and secondary socialisation; and theories of the person and of learning);
- *forms of discourse* (functions of language: information and relationship; negotiation and ratification; group harmony and individual welfare);

1. introduction continued ...

- *non-verbal communication* (kinesics (the movement of our bodies) and proxemics (the use of space; concept of time)); and
- *face systems* (social organisation, which includes kinship; the concept of the self; ingroup–outgroup relationships; Gemeinschaft and Gesellschaft).²

Based on these constructions, miscommunication then occurs when participants:

- **do not share the same system of signs (they may speak different languages) or they**
- **may not attach the same meaning to the signs because they do not share the same**
- **system of values and beliefs.** (Pauwels 1995:11)

Interpreting

There are many references to 'interpreters' in this research report and the term requires some clarification. Interpreting, as a profession, is regulated in Australia by the National Accreditation Authority for Translators and Interpreters (NAATI). NAATI establishes professional standards for interpreters and translators and sets tests by which interpreters and translators can be accredited at various levels. The designations for these levels of accreditation are 'Paraprofessional Interpreter', 'Interpreter' and 'Conference Interpreter'.

- **The paraprofessional level represents a level of competence in interpreting for the purpose of general conversations. Paraprofessional interpreters generally undertake the interpretation of non-specialist dialogues.**
- **Interpreter is the first professional level and represents the minimum level of competence for professional interpreting and translating. Interpreters at this level are capable of interpreting across a wide range of subjects involving dialogues at specialist consultations...Their specialisations may include...the law, health and social and community services.**
- **Conference interpreter is the advanced professional level and represents the competence to handle complex interpreting.** (NAATI 1997/98:A1–A5)

There are no interpreters accredited at the professional or advanced professional level in Indigenous languages. The facilitators for Yolŋu languages who participated in this research were thus either paraprofessional interpreters, who had gained accreditation after completing a short training course, or they were people assisting with bilingual communication without any prior training or accreditation.

An interpreting service for Aboriginal languages in the Northern Territory has only recently been established. The need for specialised training for Indigenous interpreters is widely recognised and is currently being addressed through a number of avenues, including Stage 2 of this project, which will support the training of interpreters and users of interpreters in both the renal and other health contexts.

² For further explanation of this framework see Scollon and Scollon 1995:127–54.

Yolŋu

The term 'Yolŋu' refers to the Indigenous people who live in North-East Arnhem Land in the Northern Territory. All the Yolŋu participants in this project come from one of the larger communities in the region or from one of the smaller 'homeland' communities nearby. A mission was first established there in the 1940s and subsequently a large number of people from different clans in the region were drawn to that location for various reasons. The past fifty years has therefore been a period of dramatic cultural, social and economic change, although many of the features of traditional lifestyle have been maintained to some extent. All children continue to learn a Yolŋu language as their first language and English has little relevance in everyday life. Although Christianity has had a pervasive effect, traditional Yolŋu belief systems, ceremonial practices and the kinship system remain central in the lives of most people. Hunting and gathering are still highly valued activities, although most people rely on the community store and take-away shops for most of their food, particularly during the week. Few salaried jobs are available in the community, and many of these are filled by non-Aboriginal people. The majority of Yolŋu receive either social security payments or participate in community development and employment programs (i.e. work for the dole), with little opportunity to move into paid employment. Serious illness and premature death are impacting increasingly on everyone in the community. The little available systematic data suggests that chronic diseases such as respiratory illnesses, diabetes, and renal disease have increased rapidly during recent years. At the time of this study, haemodialysis treatment for the growing numbers of Yolŋu with end-stage renal disease (ESRD) was only available in Darwin, which resulted in the patients—and often many of their extended family members—relocating 500 kilometres from their homes, with all the associated trauma. In this community, the average age of death (excluding perinatal deaths) in the period between 1992 and 2000 was forty-six (Knight 2000).³

Balanda

'Balanda' is one of the terms used by Yolŋu to refer to non-Aboriginal people. This is the term used in the report to refer to anyone who is not an Indigenous person from North-East Arnhem Land.

Dialysis

The term 'dialysis' is generally used in this report to refer to haemodialysis—the form of treatment received by most Yolŋu with ESRD, which requires up to five hours on a haemodialysis machine three times a week. 'PD' refers to continuous ambulatory peritoneal dialysis—a form of dialysis in which a plastic tube is permanently inserted into the abdominal cavity and a plastic bag attached several times per day so that fluid can be drained into and out of the abdomen. This form of dialysis can be carried out by patients in their own homes.

³ For a detailed discussion of Yolŋu beliefs and practices related to health, see Reid (1983) *Sorcerers and Healing Spirits: Continuity and change in an Aboriginal medical system*. Australian University Press/Pergamon: Sydney.

2. Background to the research⁴

Effective communication is widely recognised as crucial to achieving a high standard of health care. Extensive research has been carried out in other countries, particularly in the area of doctor–patient communication (Ong *et al.* 1995). A number of studies have shown a clear correlation between effective communication and improved health outcomes, such as emotional health, resolution of symptoms, function, pain control and physiological measures such as blood pressure and blood sugar concentration (Stewart 1995).

The importance of achieving effective communication between Aboriginal and non-Aboriginal people is also recognised in many reports and policies related to health care in the Australian context. For example, the Royal Commission into Aboriginal Deaths in Custody, Recommendation 247 e), states that:

- **Effective communication between non-Aboriginal health professionals and patients in mainstream services is essential for the successful management of the patients' health problems. Non-Aboriginal staff should receive special training to sensitise them to the communication barriers most likely to interfere with the optimal health professional/patient relationship.** (Johnston 1991:87)

Achieving effective communication is highly problematic, however, when the differences between the cultural and linguistic backgrounds of the service providers and the users range from minor to extreme. English is not the first language of many Aboriginal users of health services in the Northern Territory, and their ideology and socialisation may have little in common with those of the service providers. Even when Aboriginal people speak English or a dialect of English as a first language, serious communication difficulties can still occur as a result of the complex sociolinguistic, cultural and political factors that influence communication between different cultural groups (e.g. Eades 1991).

The consequences of miscommunication

The health care implications of language and cultural differences between service providers and their patients who speak languages other than English have been widely recognised in Australia. For example, the National Health Strategy Issues Paper (1993:19) stated:

- **The lack of a common language between patient and health professional can have serious implications for their communication, for diagnostic accuracy and overall quality of care. It can inhibit describing symptoms effectively, asking questions and talking about fears and anxieties, leading to further distress, dissatisfaction with care and to adverse health outcomes for patients and their families. Likewise, health providers' limitations in talking with their patients lead to frustration with treatment regimes, perceived problems with compliance and negative attitudes toward people from non-English speaking backgrounds.**

Anecdotal reports of such incidents in Aboriginal health care are common. In his book about health issues for Aboriginal people from North-East Arnhem Land (who are also the patient group in this study), Trudgen (2000) suggests that most Yolŋu are intellectually marginalised in the dominant culture's world because, for most Yolŋu, English is their fifth or sixth language. Trudgen identifies differences in cultural knowledge and world view, in addition to language differences, as the sources of communication difficulty between Yolŋu and the dominant culture. He suggests that the resulting communication failure creates immense suffering and that Yolŋu can wait years to understand what is making them sick and some never find out. According to Trudgen, these communication barriers prevent (non-Yolŋu) health service providers from being able to:

- *diagnose* patients' complaints in the normal question and answer way;
- *inform* Yolŋu patients of their condition (sometimes life threatening) and obtain proper consent before carrying out medical procedures;
- deliver *health education and prevention* information to patients in a timely and cost-effective way;
- accurately diagnose the overall problem and *develop programs* that are culturally sensitive and appropriate; and
- *evaluate* these programs and modify them so they become more effective. (Trudgen 2000:73)

The nature and extent of miscommunication in Aboriginal health care

Linguistic, cultural, social and political factors all impact on communication, and differences between participants in any of these areas are a potential source of communication difficulty. Differences in perspectives, expectations, understanding and interpretations (phenomenological differences) are one source of communication failure. As well, there are extensive differences between Standard Australian English (SAE) and Aboriginal languages, and between SAE and Aboriginal English, both linguistically and in the rules of language use (Christie and Harris 1985). Social and attitudinal factors (including power relationships and motivation), as well as the individual's specific intercultural communication skills (such as knowledge of potential areas of difficulty, ability to recognise communication breakdown when it occurs and to employ repair strategies), also influence the effectiveness of communication (e.g. Clyne 1994; Scollon and Scollon 1995; Pauwels 1995).

Some of these factors have been identified in the few studies that have investigated communication in health care in the Indigenous Australian context, and all of the studies have found evidence of extensive and serious communication problems (e.g. Mobbs 1986; Watson 1987; Edis 1998; Amery 1999; Kemp 2001). Watson's study of communication with Aboriginal patients in the maternity ward of Royal Darwin Hospital, for example, reported extensive communication problems resulting from both cultural and language differences between staff and patients, inadequate use of interpreters and the staff's inadequate sociolinguistic knowledge (Watson 1987). Extensive communication difficulties between medical staff and Aboriginal patients were also found to be a source of distress and frustration by Mobbs (1986) and in a more recent study of communication in intensive care in Alice Springs and Darwin (Kemp 2001). Another study, which focused specifically on communication, videotaped simulated encounters between Indigenous patients and health staff (Edis 1998). This study identified linguistic, pragmatic and cultural sources of miscommunication and concluded that training in intercultural communication and use of interpreters was crucial for improving communication between Aboriginal and non-Aboriginal people in health care. An important finding of this study was that participants were often unaware of instances of miscommunication.

In 1997 a survey of patients conducted in Nhulunbuy for Territory Health Services (Aboriginal Resource and Development Services 1997) reported the following:

- Aboriginal patients felt that, although they were generally treated with respect, most staff members were very ignorant of key cultural understandings;
- most Aboriginal patients were dissatisfied with the level of explanations about diagnosis and treatment, which was the area in which linguistic and cultural barriers to good communication were most apparent during the survey; and
- most Aboriginal patients were totally unaware of what their medication was for.

Anecdotal evidence about communication problems in Aboriginal health care is also abundant and some of it has been documented (e.g. Brennan 1979; Hill 1994; Shannon 1994; O'Connor 1994; Campbell 1995; Trudgen 2000). Studies focusing on other Aboriginal health issues have also identified serious concerns related to communication between health staff and Aboriginal patients (e.g. Devitt and McMasters 1998; Humphery, Weeramanthri and Fitz 2001).

In their study of the social and cultural dimensions of ESRD among Aboriginal people of Central Australia, Devitt and McMasters (1998) described communication between Aboriginal patients and non-Aboriginal carers—or the absence of it—as a core issue. The extent of verbal interaction was minimal and even when it did occur there was a lack of effective communication; as a result communication associated with renal patient care was found to be 'seriously fragmented and deficient' (Devitt and McMasters 1998:164).

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⁴ This section draws on papers written as part of a review of health communication conducted for the CRAH in 1998 (Lowell 1998) as well as recent research relevant to the field.

2. Background to the research continued ...

Strategies to improve communication in Indigenous health care have been repeatedly identified and include equity of access to trained interpreters, specialised training programs in medical interpreting, training for users of interpreter services, increased awareness amongst service providers of the ethical and legal requirements for ensuring effective communication, and increased awareness by Aboriginal clients of the role of, and their right to, an interpreter (see Lowell 2001).

Although trained interpreters have been available throughout Australia for speakers of languages other than English for many years, an interpreting service for Aboriginal languages has only recently been established in the Northern Territory. However, use of interpreters in health care encounters with Indigenous patients is only slowly increasing. In the context of renal care, Devitt and McMasters (1998) identified a medical interpreting service as one measure to address a communication gap between patients and service providers, which they described as 'profound and pervasive'. Greater use of interpreters was repeatedly suggested by Aboriginal people, but was a strategy rarely employed, as illustrated by the example in which a senior renal nurse had used an interpreter only once in seven years (Devitt and McMasters 1998).

However, increased and more effective use of interpreters, although widely recognised as necessary for improving communication, is not necessarily sufficient. In an investigation into health professionals' perceptions of Aboriginal people not accepting biomedical advice and treatments, *Humphrey, Weeramanthri and Fitz (2001)* argue that the issue is not a medical one but a socio-cultural, economic and political one. Their report implicates a complex interaction of factors, including cultural and communicative factors, along with ideological and institutional factors. Not least of these is the impact of colonisation and, with it, dispossession, poverty and institutional racism.

A study of interpreting issues within health services in South Africa also emphasised the importance of addressing the broader context in which intercultural encounters in health care are situated, describing communication as:

- **a multifaceted problem that has to be conceptualized in a more global way than merely by providing interpreters, though this is clearly indicated. The language barrier may be more helpfully conceived of as occurring within a cluster of problems that overlap and need to be dealt with in a concerted way.** (Crawford 1999:32)

Crawford argued that inserting interpreters into health institutions had little success because this did not articulate with a process of transformation in the institution and did not modify the power relations within the system that operate to the detriment of patients.

The extent to which the conditions for effective communication of health information are met, and the problems inherent in achieving this, vary from context to context. Devitt and McMasters (1998:165) found that 'there is concern, there is care, but there needs also to be better reciprocal understanding that is grounded in authentic knowledge'. Lowell (1998) also found widespread concern about the effectiveness of communication between Aboriginal patients and staff members who did not share the patient's cultural and linguistic background. Miscommunication between staff and patients, as well as communication problems between Aboriginal and non-Aboriginal staff, were often identified as a source of great frustration as well as concern. Despite this concern, the extent of miscommunication and the potential seriousness of the consequences for Aboriginal patients were often not well understood by either the service providers or the patients. One of the specific suggestions, which emerged from Lowell's review, was for a research project to identify and clearly document the extent, nature and consequences of miscommunication in health service interactions. This could inform cultural education program development and encourage improvements in current practice. The study reported here, as Stage I of *Sharing the true stories*, is a direct response to these concerns.

An understanding of the range of factors influencing intercultural communication is necessary if service providers are to take appropriate action to address the serious and pervasive nature of communication difficulties in Aboriginal health care. Although assumptions about likely sources of communication difficulty can be made from research in other fields, these assumptions need to be tested within the context of health services for Indigenous Australians.

Previous studies have relied on indirect methods, such as interviews with service providers and sometimes with Aboriginal patients about their perceptions of communication. This reliance on indirect methods for obtaining information about communication is likely to understate the extent of the problem; however, as studies in other contexts (e.g. Cooke 1998) have demonstrated, miscommunication often goes unrecognised by the participants.

There have been no studies of interactions in Aboriginal health care similar to those undertaken in the context of the criminal justice system (e.g. Eades 1991; Cooke 1998) and education (e.g. Lowell and Devlin 1998), which utilise more direct methods such as participant observation and videotaping of interactions. The exception is one study in which simulated interactions between health staff and Aboriginal patients were videotaped (Edis 1998). The study conducted by Edis provided useful indicators for the development of this study. A crucial difference is that in the current study the interactions are not simulated, but are authentic encounters occurring within one health care setting. Even a single study that informs practitioners about miscommunication in their field can result in improved practice. For example, Cooke's study of communication in the criminal justice system (Cooke 1998) has directly influenced practice in Northern Territory courts (Mildren 1999). This current project, however, is intended to go beyond merely another description of the problem and intends to both identify strategies to improve communication and facilitate their implementation.

In order to identify and effectively evaluate communication strategies that result in improved health outcomes for Aboriginal people, a better understanding of the nature and extent of miscommunication, which considers the political and cultural context in which it is occurring, is clearly necessary. This is the aim of the study reported here. Changes in practice, which are intended to improve communication, can then be grounded in authentic information about the specific nature of communication difficulties within the relevant settings. Based on the findings of this project, a second stage has been planned to develop, implement and evaluate such changes and to facilitate transfer across other health services.



3. The research

The original concept for this project emerged from an earlier Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) project, which explored communication issues in Aboriginal health care through a review of the literature and extensive discussions with a wide range of stakeholders (see Lowell 1998). The purpose of the review was to identify strategic directions for research in the area of health communication, and communication between health staff and Aboriginal patients was identified as a major concern. The proposal for the project was informed by the findings of the preceding review and was developed through a collaborative process involving a range of interested people. Staff at Top-End Renal Services expressed an interest in participating in the project, so this was the context selected for Stage 1.

The aims of the project

In the early stages and throughout the project, extensive discussions occurred between members of the research team, the advisory group and other participants, both renal staff and patients, about the aims of the project and how these would best be achieved. As a result of this negotiated process, the original outline was modified and a detailed research plan was developed, with further changes occurring in response to emerging issues as the research progressed.

The primary aim of this project, as a first stage in an ongoing developmental process, was to increase our understanding of intercultural communication issues in renal health services, among them:

- the extent of miscommunication;
- the cultural, linguistic and political factors influencing communication in renal services;
- the effectiveness of communication strategies currently used; and
- possible strategies for improving communication.

There was also an intention to develop specific strategies, which the research team identified as potentially useful, either through their use in other contexts or through the researchers' previous experiences. In consultation with the advisory group and the research team it was decided, however, to restrict this stage of the project to the analysis of current practice. Rather than act on the untested assumptions inherent in the original research plan, ideas for action were drawn from the empirical data and informed by the experiences and priorities of the participants, both staff and patients. It is intended that the strategies identified through this process can then be implemented and evaluated in a second stage.⁵

The research framework

Participatory research has been defined as:

- **systematic inquiry, with the collaboration of those affected by the issue being studied,**
- **for purposes of education and taking action or effecting social change.** (Green 1994, cited in North American Primary Care Research Group Policy Statement 1998)

A participatory approach was therefore considered appropriate for this project, which aims to begin a process of change through which more effective communication will lead to improved health outcomes for Aboriginal people.

Although the broad underlying philosophy was drawn from participatory research, the theoretical perspectives, methodologies and research techniques selected within this framework were those considered most appropriate to achieve the aims of the research. As a result they are eclectic, drawing from a range of research paradigms and approaches.

⁵ A submission for Stage 2 is being developed, based on the findings of this project (see Attachment 1).

The paradigm with which this project is most closely aligned is constructivism, as described by Guba and Lincoln (1998). In a constructivist paradigm the aim of inquiry is *understanding and reconstructing* the constructions that participants (including the researchers) initially hold. The aim is for increasingly informed and sophisticated constructions, moving towards consensus, as well as increasing everyone's awareness of the content and meaning of competing constructions. The role of the researcher is that of participant and facilitator in this process, and advocacy and activism are key features of a constructivist inquiry.

Constructions are subject to revision, and multiple 'knowledges' are recognised when equally competent interpreters disagree 'and/or depending on social, political, cultural, economic, ethnic, and gender factors that differentiate the interpreters' (Guba and Lincoln 1998:212). This reflects a relativist ontology in which:

- **realities are apprehendable in the form of multiple, intangible mental constructions,**
- **socially and experientially based, local and specific in nature and dependent for their**
- **form and content on the individual persons or groups holding the constructions.** (Guba and Lincoln 1998:212)

In such an inquiry the methodology is hermeneutical and dialectical, and through such a process more informed and sophisticated constructions are formed through juxtaposition of varying constructions. Providing vicarious experience through, for example, case studies such as those presented in this report for each interaction is an important mechanism for transferring knowledge. In this approach:

- **the investigator and the object of investigation are assumed to be interactively linked**
- **so that the 'findings' are 'literally created' as the investigation proceeds.** (Guba and Lincoln 1998:207)

The research methods

Qualitative research methods were employed as the most effective technique for developing a holistic and contextualised understanding of communication in a complex setting. The focus of this study was the lived experiences of the participants and the methods were selected to provide what Higginbotham (2001: 263) describes as 'a firm empirical ground for understanding the causal web and carrying out interventions'.

Various methods of data collection and analysis were used in the study and these provided one form of triangulation⁶ to enhance the trustworthiness of the research. The primary source of data was the videotaped interactions between renal staff and patients. A number of key interactions were identified through discussions with staff and patients and five were selected for videotaping. The participants in these interactions were selected to provide as wide a range as possible of renal experience, familiarity with the culture and language of the other group, age and gender.

The videotaped interactions provided powerful primary data, which was then used to explore the perspectives of all participants in the interaction. The participants' interpretations of the videotapes then provided further data, and thick descriptions of these interactions were then constructed from these multiple perspectives. Exit interviews were also conducted with each participant immediately following the interaction, as well as in-depth interviews to contextualise the participants' experiences. Other sources of data included interpretation of the videotaped interactions by various research team members as well as experienced interpreters, as well as information from group discussions. Combined together, methods, data and observers make triangulation a powerful means of strengthening the quality of the research, which enhances the trustworthiness and authenticity of the findings.

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⁶ Higginbotham et al. (2001:251) explain that triangulation has shifted from a technique that was 'grounded in the notions of validity, reliability, objective truth, and bias, to a broad-ranging strategy which also encompasses the qualitative concerns for depth, multiple perspectives, and complex meanings'.

3. The research continued ...

The research setting

The Nightcliff Renal Unit sought to become involved in the project as a result of a strong impression by staff that difficulties in communication of important concepts and information between patients and staff seriously impaired optimal treatment for Aboriginal patients.

The Renal Unit provides dialysis and transplantation services for approximately 160 patients, of whom 80 to 85 per cent are Aboriginal. The majority of Aboriginal patients come from outside the metropolitan area and they and their families are required to relocate to Darwin for their therapy—which for most means until they die. The mortality rate of the unit's Aboriginal patients is far greater than that of the non-Aboriginal patients. While this is, in part, explained by a greater number and degree of co-morbidities in the Aboriginal group, there are also marked differences in measures of therapy 'compliance' between the two groups that undoubtedly contribute to the higher mortality seen in the Aboriginal patients. Measures of dialysis attendance, fluid intake and blood pressure control, and other parameters that have been correlated to survival on dialysis, are poorer in the Aboriginal group.⁷ While the Renal Unit has sought to provide culturally appropriate and language-specific educational materials for patients regarding such factors, it was apparent to staff members that their attempts were not dramatically affecting patient behaviour and thus were unlikely to result in improved outcomes for patients.

The Renal Unit treats Aboriginal people from at least five main language groups, with many having English as their second, third or fourth language. At the same time, there are no staff members who are proficient in *any* Aboriginal language. Before planning for this project began, there were no trained Aboriginal interpreters available to assist in staff interactions with patients. Often family members of a patient, other patients from the same language group, or non-Aboriginal people with some proficiency in the patient's language acted as interpreters, resulting in a high risk for serious miscommunication despite the best intentions of all parties.

ESRD can be viewed as one of the most complex and demanding of the 'chronic' diseases. Such diseases require an ongoing commitment to therapy by the patient. A commitment of this nature necessarily requires an understanding of the disease process, the rationale for therapy and the likely consequences of partially or not 'complying' with the required treatment. While often the patients are seen as the 'culprits' when they do not comply with their prescribed therapy, the staff of the Renal Unit felt that much of the difficulty lay in the patients not truly understanding their disease, the importance of various aspects of their treatment and the ramifications of partial or non-compliance with their therapy.

The participants

Genuine collaboration⁸ is central to a successful participatory research project. Achieving a high level of participation by all parties at all stages was a central concern throughout the project and various mechanisms were used to this end. As described above, the original concept for the research emerged from a comprehensive process of consultation with stakeholders and this concept was then developed through a collaborative process involving people from a range of backgrounds.

The research team

The research team included both Aboriginal and non-Aboriginal members and representatives from both the staff and patient groups. The participation of researchers who had in-depth knowledge of the context (renal services) from both staff and patient perspectives greatly enhanced the relevance of the study and the effectiveness of the research design. It also allows for immediate action to occur, which was informed by the emerging findings. Other team members had extensive experience in the fields of participatory research and intercultural communication, and in working with Yolŋu in various contexts.

⁷ According to the relevant data collected by the unit as part of routine patient care.

⁸ The term 'collaboration' is defined as a research partnership among equals with complementary knowledge/expertise (North American Primary Care Research Group 1998).

The Advisory Group

The Advisory Group brought together a range of stakeholders from institutions with a direct interest in the research and other groups that could inform and/or potentially benefit from the research outcomes. One of the concerns about the structure of this group was the difficulty in achieving meaningful participation of Yolŋu, as the meetings were conducted in English in a style that can be very difficult for Yolŋu to engage in. Marrŋanyin, the Yolŋu researcher, attended Advisory Group meetings and extensive informal discussions about the project also occurred with Marrŋanyin and other Yolŋu in other settings. An advantage of this group was that it created opportunities for people from very different professional and ideological backgrounds to engage in extensive dialogue. In addition to the research team members, the Advisory Group included representatives from the CRCATH, the Aboriginal Interpreter Service, Aboriginal Resource and Development Services, Nightcliff Renal Unit, Menzies School of Health Research and Batchelor Institute.

The patients and staff involved in the research

Participants were selected using a 'maximum variation sampling' approach, in which a small sample is selected to achieve maximum diversity across specific attributes (Higginbotham 2001:237). In this case the attributes were age, gender, length and quality of renal experience (receiving or providing treatment), degree of familiarity with the culture and language of the other group, and training and/or experience in intercultural communication.

The patients⁹ were:

- **Balan**, a young man with chronic renal disease who did not yet need dialysis (a pending patient);
- **Banadi**, an older man from a remote homeland, with little proficiency in English, who had recently reached end-stage and commenced dialysis;
- **Galikali**, a middle-aged woman with a high level of Western education and fluent in conversational English who was a long-term renal patient;
- **Narritjan**, a middle-aged woman with very little Western education and little proficiency in English who had recently commenced dialysis; and
- **Wurrapa**, an older woman with very little Western education and little proficiency in English who was a long-term patient.

All the patients lived in communities or homelands in North-East Arnhem Land until they needed to relocate to Darwin for treatment for their renal disease. In this region, colonisation was recent—in the community most of the patients come from the first mission was established in the 1940s. Many features of traditional Yolŋu culture continue to influence everyday life to varying degrees: hunting and gathering and other cultural practices, including participation in ceremonies, are of central importance for most Yolŋu. Yolŋu languages are used in almost all interactions and English has little relevance outside the school and clinic.

The staff members were:

- a male renal physician with extensive experience working with Aboriginal patients (referred to in the report as 'a physician'¹⁰);
- a male renal physician with limited experience working with Aboriginal patients (referred to as 'a physician');

⁹ The Yolŋu researcher discussed with each patient how he or she wanted to be identified in the report. The preferred names or māslk (skin names) are used.

¹⁰ Due to the small number of staff members working in renal care, general terms are used to refer to individuals to protect their identities as much as possible although most participants were willing to be identified by their own names.

3. The research continued ...

- a nurse with extensive experience in all areas of renal care with Aboriginal patients who was working primarily in an educator role (referred to as a 'nurse educator');
- a recently qualified nurse with long-term experience working with Aboriginal patients in other roles (referred to as a 'nurse');
- a nurse with extensive experience in all areas of renal care with Aboriginal patients (referred to as a 'nurse'); and
- an allied health professional with very little experience working with Aboriginal people from remote communities, who only recently began working in renal services (referred to as an 'educator').

The interactions

Staff and patients were able to identify key encounters in renal care in which achieving effective communication is both crucial and challenging. Not all of these interactions could be included in the study due to the limitations of time and resources. The research team therefore selected five interactions, which they considered the most relevant and practical for the purposes of the study (see Section 4 for details).

Due to a change in the location of the project from Territory Health Services to Northern Territory University, there were some delays in obtaining ethics approval and this resulted in some uncertainty during the early stages of the project. However, this had an indirect advantage in that data collection could not proceed immediately and therefore ensured that an optimal period of consultation and planning did occur. The common temptation to move too rapidly into the data collection phase was therefore avoided and this allowed for a high level of genuine participation by the advisory group and other stakeholders in deciding on the details of the research plan. This has also allowed sufficient time for the Yolŋu researcher to implement an effective consent process to ensure potential Yolŋu participants were adequately informed and had a genuine opportunity to decline to participate (a direct request for participation does not necessarily provide such an opportunity).

The specific steps followed in data collection were:

1. Staff and patients were informed about the project in their own languages by a researcher from their own culture and invited to participate. Written consent was obtained from volunteers selected according to the sampling criteria. Particular care was taken in the consent process with the patients. This usually involved a number of discussions in Yolŋu Matha between the Yolŋu researcher and the patient, as well as further discussions with the project coordinator when required (with the Yolŋu researcher acting as interpreter). Although a written consent form in Yolŋu Matha was developed, this was not considered a sufficient indicator of informed consent without ensuring extensive oral discussions with each patient in his or her own language also occurred.
2. Interactions were then videotaped opportunistically; that is, when an interaction was occurring in which both the nature of the interaction, and the participants in that interaction, fitted the sampling criteria described above.
3. Exit interviews were conducted with each participant to obtain his or her perceptions of the purpose of the interaction and its content, specifically:
 - what he or she wanted to find out from the interaction and if this happened;
 - what information he or she intended to communicate during the interaction and if he or she thought this was a successful process;
 - the overall effectiveness of the communication; and
 - its similarity to other situations.

Videos were analysed using an ethnographic approach (i.e. thick, layered descriptions that include the interpretations of participants and researchers). This triangulation—comparison and contrast of interpretations and, later, comparison and contrast of data from different sources—is the central strategy used to establish trustworthiness of the data.

The stages of analysis included:

- **description** of the interaction by one or more of the researchers including identifying key communication events for discussion in participant analysis sessions (e.g. effective communication strategies and instances of miscommunication) (**first level**);
- **reviews** of videos were conducted with each participant to elicit their interpretation of the interaction. This was done as soon as possible after the interaction occurred and utilised key points from the initial analysis to guide discussion (**second level**); and
- **in-depth interviews** with each participant (and a patient's family members if appropriate), drawing on key themes emerging from exit interviews and video analyses as well as eliciting information on more general communication experiences and issues.

Data analysis and interpretation

This project was *inductive*, utilising techniques from grounded theory in data analysis and interpretation (i.e. building theory from the data). Categories used in analysis were derived from a variety of sources, primarily from the context to reflect the participants' perspectives and to reduce the extent to which data is filtered through a restricted and predetermined set of codes, but they also included categories drawn from other related research and theoretical frameworks.

The process was interactive, with development of theory, data collection and analysis occurring simultaneously, and analytical categories were refined or refocused as a consequence of new data, new interpretations emerging and/or further literature review.

A qualitative data management program was used to assist with organisation and coding of the large and complex data set. The use of such software supports a more rigorous analysis and a more integrated approach in interpretation and theory development than would be possible otherwise.¹¹

An ongoing process of verification and expansion of emerging ideas occurred through discussions with members of the research team and other participants, both informally and in formal team and advisory group meetings. The aim of such participant verification at different stages of the research process is to validate the evidence, the conclusions being drawn and the theory being developed.

Considerations of quality

Higginbotham *et al.* (2001:256) suggest that the important criteria in assessing the quality of a research project such as this are:

- **the richness of the data and their ability to generate theory, their empirical groundedness**
- **in wider contexts of social life, their incorporation of multiple subjective understandings,**
- **and the reflexivity of the researcher.**

Guba and Lincoln (1998) have proposed two sets of criteria for judging the quality of a constructivist inquiry. In one set, the trustworthiness criteria of credibility, transferability, dependability and confirmability replace the criteria of internal validity, external validity, reliability and objectivity of positivist paradigms. The other set of criteria is that of authenticity and includes fairness, ontological authenticity (enlarges personal constructions), educative authenticity (leads to improved understanding of constructions of others), catalytic authenticity (stimulates to action) and tactical authenticity (empowers action).

In monitoring the quality of this research, attention was given to all these criteria.

¹¹ Although use of a data management program might be considered time-saving this is not the case if the potential of the software is fully utilised to support a highly flexible but complex and time-consuming engagement with the data.

3. The research continued ...

Dissemination and research transfer

The research findings have been disseminated through a number of mechanisms including this written *Interim project report*, journal articles (Cass A., Lowell, A., Christie, M., Snelling, P., Flack, M., Marrnganyin, B. & Brown, I, Sharing the true stories: improving communication between Aboriginal patients and health carer workers. *Medical Journal of Australia* 2002; 176:466-470, and another forthcoming paper to be submitted to *Social Science in Medicine*), and workshops and presentations with interested staff and patients and other relevant groups. Other dissemination activities have included two feedback visits to the community; four feedback sessions to renal staff; a meeting with senior Department of Health and Community Services staff; seminars at Charles Darwin University, Menzies School of Health Research, Northern Territory Institute of Educational Research, the Combined Annual Scientific Meeting of the Northern Territory Branches of the Royal Australasian College of Physicians and the Australasian Faculty of Public Health Medicine, and an Aboriginal Interpreter Training Workshop; extensive informal discussions with other stakeholders as part of the consultation process in developing Stage 2 of the project; and an item on ABC-TV's *Health dimensions*.

Most importantly, the implementation of the findings of this study in Stage 2 will facilitate research transfer within the renal context as well as more widely in other health care settings.

4. Key encounters in renal care

Due to limitations in time and resources, it was not possible to include examples of all of the interactions between staff and patients that are considered important in renal care. Five interactions were selected from a range of encounters that were identified by participants as crucial and often problematic. The practicality and appropriateness of videotaping was also considered in the selection process. The encounters were videotaped as the opportunity to do so arose during the period of data collection and included:

- a medical consultation with a 'pending patient', that is, a patient with chronic renal disease who does not yet need dialysis. The participants in this interaction were a renal physician with extensive experience working with Aboriginal people and Balan, a young Yolŋu man who was accompanied by his mother and grandmother. The patient and his family currently live in a remote community in North-East Arnhem Land;
- an education session in which a renal nurse educator provided feedback to a long-term dialysis patient, Galikali, about her recent blood test results and the implications of these results for her management;
- a medical consultation to review the progress of a patient currently receiving dialysis. There were three participants: a renal physician who began working with Aboriginal people quite recently, a renal nurse with many years of experience working in renal services in the Northern Territory and Njarritjan, a Yolŋu woman who began dialysis quite recently. Before the patient and her sister moved to Darwin to access treatment, both lived in a remote community in Arnhem Land;
- an education session addressing dietary issues with a new patient. The participants were an allied health professional, a Yolŋu man who had commenced dialysis only a few weeks earlier and his sister, a trained teacher. Both the patient and his sister are usually residents of a remote homeland in North-East Arnhem Land; and
- a dialysis treatment session in which we videotaped the interaction, during the setting up of the machine, between a renal nurse and a Yolŋu woman, Wurrapa, who has been on dialysis for a number of years.

Each participant was interviewed as soon as possible after the videotaping was completed to:

- explore his or her perceptions of the effectiveness of the communication which had occurred;
- explore what he or she wanted to communicate and wanted to find out, and whether this happened; and
- obtain his or her opinion on the extent to which this interaction had been similar to others of the same kind.

Semi-structured, in-depth interviews were also conducted with each participant (and in some cases family members) to develop a greater understanding of each participant's background and wider experiences in order to achieve more meaningful interpretations of the encounter.

To contextualise later sections of the report, the setting, the participants and some examples of key features of the communication of two of the interactions are described below in some detail. The other three interactions are also described, but more briefly. The data from all sources, including the perspectives of participants as expressed through the interviews as well as their analysis of the video data, is explored in more detail in later sections of the report.

4. Key encounters in renal care continued ...

A medical consultation: review of a 'pending patient'

The setting

This interaction took place in the physician's office in the health centre of a remote community. The renal physician, a renal nurse educator and two other members of the research team travelled to the community primarily to videotape this specific interaction. It also provided the opportunity for the renal staff to follow up other pending patients and for the researchers to inform the community about the research.

The participants

The staff member: this physician was one of a large family and grew up in a mainly monolingual, monocultural environment. He has many years' experience working with multicultural and Indigenous populations and has been working in renal services in the Northern Territory for a number of years. He has well-established relationships with many patients and is highly regarded by those involved in this project.

The patient: Balaŋ is a young man who has had renal disease for a number of years and who has in the past required treatment in Darwin. At the moment he is living with his family in his home community, where he is actively involved in community life but is not in paid employment. The primary language Balaŋ uses in almost all interactions at home and elsewhere in the community is Djambarrpuyŋgu. Although Balaŋ did attend the community school for a number of years, he does not have a high level of fluency in English and is unlikely to have more than basic literacy in either his first language or English. Balaŋ will eventually need dialysis—and therefore relocation to Darwin 500 kilometres away. The length of time before this becomes necessary depends greatly on effective management of blood pressure and other biological parameters, which are crucial in optimising his kidney function for as long as possible.

Management of the interaction

This interaction was initiated by renal staff members, who had identified medical reviews with pending patients as important encounters in renal care, although it was not part of standard management practice for this physician to travel to the community. In current practice, patients such as Balaŋ are followed-up by the visiting general physician on a regular basis. However, during the consultation the physician looked for test results in the file and found that there had been no entries since 1999, which suggests no reviews had actually occurred during this two-year period. It was later confirmed that Balaŋ had not been followed-up by the visiting physician and had had no blood tests in the community.

The primary language used in the consultation was English. No attempt was made to engage an interpreter and the physician relied on the family members to assist with communication, which is described by staff as standard practice in such consultations. When it became apparent during the exit interview that there had been serious communication difficulties, however, the researchers asked the physician to return to the consulting room and clarify the family's concerns, with some assistance with communication from the Yolŋu researcher (see below).

In the first interaction (without interpreting assistance) most of the talking was done by the physician—Balaŋ and his family did not ask any questions and gave very limited responses, if any, to the physician's questions. The few responses made by Balaŋ were almost all non-verbal. The structure of the interaction reflected the physician's goals for this encounter, that is, to gain information from Balaŋ about his current health and management of his renal disease and to provide information to the family about Balaŋ's renal management.

Perceptions of communication

Communication goals

The physician had clear goals for this consultation:

- **We've met Balaᅇ before and I wanted to reinforce a couple of things: number one—**
- **that he was at risk of progression to end-stage renal disease.**

The other key concepts that the physician wished to communicate were:

- **that he would benefit from treatment, of blood pressure in particular, to a certain goal**
- **and treatment of other things like anemia. Again, it's a message he's had many times and**
- **I still don't think it gets through that well to Balaᅇ and that may be us or it may be**
- **Balaᅇ—I'm not sure...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; so to take his treatment**
- **and get some blood tests—two things that I don't think he was doing much before we**
- **saw him.**

The expectations of Balaᅇ and his family for this interaction were not clear, but were probably few as it became apparent that they had all come to this consultation believing that Balaᅇ no longer had any renal problems. When reviewing the video data, the Yolᅇ researcher, who knew Balaᅇ and his family well, explained that the whole family thought that when Balaᅇ came back from Darwin he was completely well and had no idea he needed regular tests and medications or that he had chronic renal disease:

- **(M names all of Balaᅇ's close family)—they all thought he was manymak (fine) but**
- **bäyᅇ (he wasn't)**

The participants' assessments of effectiveness

The physician was unsure whether he had succeeded in achieving his goals for this interaction:

- **Perhaps his mother got some idea and his grandmother seemed slightly uninterested**
- **...I hope they at least understand that he is at risk of needing more dialysis, I think they**
- **now understand that he has two kidneys that aren't working so well but that he doesn't**
- **require dialysis at the moment.**

The physician also described his difficulty in assessing how much the family understood:

- **If you look at the grandmother's face it remains often pretty much the same;—often**
- **when people are trying to tell you they understand they'll smile or do something—she**
- **doesn't do that—it's always an appraising look—there are no nods of complicity or**
- **signs that (she's) understanding'...**
- **(Balaᅇ's mother) is always off and away, probably thinking—she's not distracted but**
- **she's obviously listening and thinking and the question is how much is she understanding.**
- (video analysis with physician)

After the consultation the Yolᅇ researcher talked to the family members about what they had understood from the doctor. Balaᅇ's mother told the Yolᅇ researcher that the doctor had said that Balaᅇ should come and get his medicine from the clinic and get his blood pressure taken by the health workers, and that the physician could not feel anything in the fistula. Neither Balaᅇ nor his grandmother added any further information. This was all that the family was able to recount from an interaction which had lasted seventeen minutes. During most of this time the physician was talking, explaining a range of concepts and sometimes repeating those explanations. It was clear from the questions the family members then asked the Yolᅇ researcher that they had understood very little of the information the physician had been attempting to convey.

4. Key encounters in renal care continued ...

Further exploration of communication effectiveness

The family knew that the health staff wanted Balan to have his blood pressure monitored and that the staff wanted him to take medication, but these were the only points about which some degree of shared understanding was achieved during the initial interaction (before assistance with interpreting). An analysis of the video data indicated that the family had understood, apparently for the first time, that it was important for Balan to take one of his medications with food. However, even after the extended explanation the physician gave about Balan's current status and prognosis, the family was still not clear about whether his kidneys were working. Balan's mother asked the Yolŋu researcher during the exit interview if his kidneys were all right and when the physician returned to talk further with the family, with the assistance of the Yolŋu researcher, Balan's grandmother asked if both kidneys were working or not. They were also wondering if the fistula would be removed and thought that it should be.

Two interpreters assisted with the analysis of the section of video when the physician returned to talk further with the family and they offered this interpretation of what occurred:

- **The physician said the 'kidney is working but not working normally' and they needed to ask another question because in the first place he said 'it's working' then 'it's not normally working'—the people can't understand—they can just say 'ah, his kidney is working now'—they just hear the first part.**

The physician then attempted to explain further and talked about when Balan will need dialysis and related it to the percentage of renal function he would then have. This use of a culturally specific metaphor (percentage) proved difficult for the interpreter, as there is no Yolŋu metaphor which is directly equivalent: she repeated the numbers that the physician had said—and the physician thought she was effectively interpreting this information when he heard this—but in fact it was rote repetition and not explained in a meaningful way.

There was also further ambiguity in the message that was given to the family in Yolŋu Matha, which could have been understood as 'when Balan goes on dialysis his kidneys will get really bad', that is, an understanding of deterioration as a consequence of, rather than a precursor to, dialysis.

The interpreters reviewing the video explained further why the physician's message was difficult to interpret:

- **(he is) mixing metaphors—and using in a confusing way—hands further apart—one going higher for poorer function which to us means 100 per cent but percentage is used in the opposite way—smaller percentage indicating poorer function.**

They concluded that, even with some assistance with interpreting:

- **...maybe they are understanding, maybe not; understanding just a little bit of what the physician is saying—just some of the words.**

With the Yolŋu researcher's assistance the family finally did understand that Balan's kidneys were not working well but it was unclear how much they understood about the fistula or Balan's prognosis:

- **They seem confused and are not clear about how big a problem it is with the kidneys or if he has to go to Darwin. I don't think it is at all clear how progressive it will be or what the time scale is or if he'll ever have to go to Darwin or how bad his kidneys are because they've had mixed messages. (video analysis with interpreters)**

The Yolŋu researcher is not a trained interpreter although, like many Yolŋu who have a reasonable fluency in English, she is very often asked to interpret when she is present at other medical encounters. She assisted the physician only because there was no alternative and she was concerned that the family had not understood the information given by the doctor. Her overall assessment of the communication was similar to that of the interpreters who assisted with the data analysis:

- **After this discussion the family understood that he is a sick person and that they will look at him carefully and look after him very well; when the physician was talking to them they couldn't understand a thing from him—maybe a little bit; now they understand very well; (Balan's mother and grandmother) didn't really know what was going on, they thought he was sent by the doctor to Galiwin'ku (because) he was completely well but he wasn't.**

Communicative challenges: some examples

Obtaining information

Although the physician had described his goals for this interaction as imparting information, he also wanted to *find out* information from Balan and his family about his health and what action Balan was taking in managing his renal disease. Although his training valued open-ended questions to gather all the evidence, the physician recognised the difficulties he would have if he attempted this approach with Balan:

- **I wasn't going to get much from Balan so in the interest of time and efficiency I go to structured questions which allow me to try to get an idea of the general level of activity—and use the most appropriate options (i.e. asking about hunting, fishing and sport rather than work).** (physician's exit interview)

The physician also explained that, although he is comfortable with long silences and would wait for delayed responses in some circumstances, in this case he already knew what he wanted to find out and went straight to it:

- **(it is) a follow-up of a patient with renal disease so I know there are certain problems that may occur with his level of renal dysfunction so I basically know the questions I want to ask to get an idea of how well he's functioning—for follow-up of someone with quite advanced chronic renal insufficiency certain symptoms I know they are going to get so I want to know if they've got them or if they've dropped off in terms of exercise as a marker of anaemia—so you're trying to get an idea of how well he's functioning and trying then to tailor the questions to his lifestyle.** (physician's exit interview)

The physician also wanted to know about Balan's appetite, how he was feeling and about his medications. The use of structured questions and verification strategies seems to be successful in this interchange in which at least the communication appears to proceed relatively smoothly:

- **When the physician asks Balan if he gets hungry, Balan responds rapidly and unambiguously—one of the few occasions when this occurs. The physician asks Balan if he 'feels sick like when he was on the machine or much better' (i.e. two options) and Balan shakes his head, which the physician interprets as relating to first option (feeling sick). Then the physician seeks confirmation by repeating 'much better' and Balan nods.** (Balanda researcher's video description)

Some communication strategies in use

The physician describes the techniques he uses to monitor comprehension and to provide the opportunity for the family to ask clarification questions:

- **I think they knew (the fistula) is for dialysis but I don't think they know much about it—I ask them the same question again to give them a chance if they're not really quite sure—they'll nod, then you say, 'are you quite sure, is there anything else you want to ask?' You never are (quite sure that people have understood) if you ask the question again but in a different manner which is not like you are examining them—if they volunteer that they know what it is then you'll accept it; if not, you are always in two minds—what you want to do is give them the opportunity to say, 'we're not really quite sure, tell me some more'. Now, they're never going to say that, so you ask the question in a different way, so, 'do you know what it's for?' 'Do you know how...?' So I think you're trying to give permission to say, 'look, if it's not 100 per cent clear, tell me again', or otherwise you say, 'look, do you want me to go over it again?' And they'll say, 'yes', so you offer to explain it without making them look stupid. You can do it in a concrete manner—get them to show—'what do they normally do?' (i.e. demonstration) ...there are (concepts) that you can't illustrate verbally but you can—if I said to a white person 'you put the needles in here and the blood is pumped out through the machine and through an artificial kidney where the blood is washed'— they can have a mental**

4. Key encounters in renal care continued ...

- picture of that quite easily, but I'm not convinced that these guys can, never having seen one, and the white person never having seen one can still get some idea of the sort of process you're talking about because they will have learnt about industrial pumps etc., that's why you come back to say it's like an oil filter in a car—they (Yolŋu) may have pulled a car apart and they may not have...

The physician also talks about the value in using repetition when appropriate:

- They're all a bit lost at the moment so you don't labour the point—you go over it because every time you go over it—after six or seven, they start to get some idea, something—if I talk about it all the time it's obviously important—if you talk about it once and then just ignore it, then you're never going to get the message across—the whole thing about people with chronic problems, you get lots of chance for repetition so you don't have to cure everything at once—you have to focus on what's the most important thing and just keep chipping away.

Talking about the fistula

Renal staff identified communication about the fistula as a very difficult area and this difficulty was clearly illustrated in this interaction.

During the consultation the physician realised that the family were worried about the fistula and he explained that Balan will need it if the kidneys get worse and he needs to go back on the machine. During the exit interview Balan's mother explained to the Yolŋu researcher that the physician had told her that the blood was stopped and the fistula wasn't working properly. Balan's grandmother asked the Yolŋu researcher what the doctors were going to do with the fistula. When analyzing the video the Yolŋu researcher explained that she told them 'not to worry because at that time they thought that he was nearly dying and that he had kidney failure—he has got kidney failure; the fistula is going to be there until one day he is going to be sick'. The Yolŋu researcher said the family was thinking that the fistula would be taken out and that would be the only reason he would return to Darwin. She did not feel they were aware that Balan would eventually need to return for dialysis.

Kidney function, kidney failure, blood tests, blood pressure and medications

Kidney function, kidney failure, blood tests, blood pressure and medications were key topics in this consultation and communication about each of these poses particular problems. These challenges are well recognised by the physician but, despite his high level of awareness, he was unable to overcome many of the difficulties.

During the consultation the physician asked the family if they knew what kidneys do. They shook their heads, so he explained that kidneys take the poison out of the blood, and that when they don't work the poison builds up and that the level of poison can be measured in the blood—at 800 he might start to feel sick but now he is at 400, and normal is 100. The physician gave his opinion of this discussion:

- ...no good, it's hard enough—I think people know about kidney failure—the machine and dialysis, all that, but the associated changes that go with chronic renal failure before you need dialysis are pretty hard to explain—it's hard for anyone unless they understand chemistry almost—I think it's very hard for them to understand in the English language—it's hard enough for people when English is their first language with some degree of scientific knowledge to go along with what we're talking about. It all comes to a bit of trust—take this and you'll get better—yeah, right.

A barrier to explaining this quantitative information is that it is expressed through the Western system of numbers and percentages, which may or may not be understood by Yolŋu:

- I'm never sure how numeric the people are and that's why you try and show low, high (with gesture) and I don't know how well that works either but I think the older people are more numeric than the younger ones—they seem to nod when you say 400 and 800 whereas the young ones...and that may be just the general levels of education—the younger ones are often worse (in English) you have the parents interpreting for their younger kids.

Although the physician talked extensively about blood pressure and measured it as well as stressing the importance of controlling Balan's blood pressure a number of times, this approach had limited success beyond establishing a connection between blood pressure and medication. When the Yolŋu researcher asked in the exit interview about Balan's blood pressure result, his mother told her that Balan had run out of tablets, but no one was able to comment on his blood pressure and they apparently had not understood that it was high.

The difficulties in talking about treatment were also expressed very clearly by the physician:

- ...there's too many conditionals—that's the problem; I don't really know (any alternative strategy)—that's one of the big concerns. When you're talking about a preventative treatment the whole thing is conditional—if you do this now, some time in the future you will have a benefit—hard enough for most of us to do that. Also I made the mistake of having two things in the conditional—the blood pressure and the anaemia (with the additional challenge of one result being a concern when it is high and the other when the result is low).¹²

Summary

The extent of shared understanding achieved in this interaction was limited to:

- the need for regular check-ups at the clinic;
- the need to take medication; and
- that one of the medicines should be taken with food.

Shared understanding of other key issues, including the current status of Balan's kidneys, the status and function of the fistula, his blood test results and their meaning, his current blood pressure and why blood pressure control is important, was *not achieved* between the doctor and Balan, his mother and/or his grandmother during the consultation.

This lack of shared understanding became apparent in the exit interview and the physician was called back to talk further with the family with the Yolŋu researcher's assistance. To some extent, this clarified some of these key concepts. Balan and his family became aware—apparently for the first time since he returned from Darwin two years earlier—that he was not fully recovered and that he had chronic renal disease. The extent to which they understood his prognosis and future need for treatment in Darwin was unclear, but speakers of Yolŋu Matha involved in the data analysis felt that Balan and his family did not have a clear understanding even *after* the assistance with communication.

This interaction was particularly challenging for a number of reasons, although these challenges are not uncommon. Although the physician knew the patient well, he had had little previous contact with the family members present and so did not have the advantage of an established relationship or familiarity with how they might interact in English. In accordance with his standard practice¹³, the physician did not attempt to engage an interpreter and did not seek assistance from a local health worker.

Not only did this interaction reveal extensive communication difficulties between the participants in this encounter, it also uncovered *a pervasive and serious systemic failure in communication*. The patient and his family were not aware of his chronic renal failure and the importance of regular blood tests and medication in managing his condition, which would prolong the time he could remain in his community before being forced to relocate to a distant city for dialysis. Follow-up by clinic staff and the visiting physician had not occurred and this breakdown in management had not been identified.

It is important to consider also the positive influences on the outcomes of this interaction: the physician participating was very experienced in working with Aboriginal patients and, as the above extracts from discussions with the physician demonstrate, he also had a high level of insight into the communicative challenges and his own communication practices. Yet even with such experience in intercultural communication and a high level of motivation to communicate effectively, the extent of shared understanding achieved was far from adequate to achieve optimal management of this patient's renal disease.

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¹² See Section 5 for the physician's ideas on how effective communication about blood pressure might be better achieved.

¹³ This physician explained that this was the case, as trained interpreters have been unavailable until recently and health workers are often unable or unwilling to act as interpreters.

4. Key encounters in renal care continued ...

An education session: feedback of blood test results

The setting

In this interaction, the primary purpose was education. Part of the nurses' role is to inform patients about the results of their monthly blood tests and this is viewed as an opportunity for the staff members to educate the patients. This may be done by a patient's primary care nurse or, as in this case, by the nurse educator. This interaction took place in the area in which patients wait until it is time for them to go in to dialysis. This is an open area in which the reception desk is situated and around which a number of offices are located. Interactions ranging from informal exchanges to more formal education sessions between staff and patients often occur in this area.

The participants

The staff member: the nurse educator grew up in a predominantly English-speaking, Anglo-Saxon cultural environment and had little cultural-awareness training either before coming to Darwin or since. She started working in the renal field seven years ago and has worked in a variety of roles including both staff and patient education. She explained that she had not learned much about the cultural aspects of working with Aboriginal patients during the first couple of years, as her learning focused on renal treatment. She speaks about this with regret because:

- **I didn't know the people and the language difference—a lot of them could speak English**
- **and I thought they were understanding me quite well—it wasn't until I started the self-care program and saw some of the deficit—what we thought was the knowledge base**
- **and it really wasn't...**

She has since developed a much higher level of insight into the challenges of communicating with Aboriginal patients and is continually reflecting on, and improving, her practice.

The patient: Galikali is a Galpu woman from North-East Arnhem Land who speaks a number of Yolŋu languages as well as English, which she learnt during her years attending the mission school in her community. After leaving school she worked as a teacher's assistant and then completed her teacher training through Batchelor College. Galikali started to get sick in 1990:

- **I used to go to school very tired, sometimes I used to go very late, sweat a lot and feel tired and get very thirsty; I never knew what it was that made me like that. I was worried but I wasn't thinking that I had this kidney problem; I thought I had something wrong in my back or up in my chest but I didn't know it was kidney—I didn't know what was wrong and I was frightened of the doctor.**

When doing her final year of teacher training three years later, Galikali collapsed and was hospitalised:

- **They told me straight; they said 'you've got a kidney problem' and I got very worried, it's not a good sickness to have. I thought I was the only one who had kidney (failure); I got all upset about my work—for the first time I won't be able to work. I wasn't worried about the sickness; I was worried about the poor children in the school. (My friend) took me to the hospital and I was there for one week and then I said to them 'I want to go back to Galiwin'ku' and they wanted me to stay in the hospital. I didn't know about dialysis then; they told me, 'soon you'll be getting dialysis, maybe in Darwin, maybe in Gove' and I was thinking to myself, I wonder what dialysis is...**

The nurse educator and Galikali had known each other for about five years, both expressed respect for the other, and there was no reported history of negative experiences in their interactions.¹⁴

¹⁴Following this interaction and the interviews and discussions that occurred as part of the research process, Galikali 'adopted' the educator as her daughter, a common practice for Yolŋu in the community, but one which appears to be much less common in the renal unit. As a consequence they developed a much closer personal relationship, as well as a collaborative professional one, than had previously existed.

Management of the interaction

This interaction was initiated by the nurse educator. Part of her role is to provide education to patients and she wanted to do this through feedback to Galikali of her latest blood test results. Discussions with staff had identified this kind of interaction as an important and challenging exercise in communication. The timing of the interaction was decided by the staff member: it was based on her work program and the patient's dialysis schedule. Similarly, the place in which the interaction occurred was determined by the staff member, based on her experience of where patients were most comfortable and on what her own location and time constraints made practicable.

It was taken for granted that the language to be used in the interaction would be English and the use of an interpreter was not considered as Galikali was perceived by staff to have a high level of English competence and she had also had extensive experience with renal treatment. The purpose of the interaction—feedback of blood test results including education about related issues—was determined by the staff member. The structure of the interaction reflected its purpose, that is, the passing of information from the nurse educator to Galikali about her blood test results: most of the talking was therefore done by the nurse educator and was predominantly informative or explanatory.

As a result of these factors, the control over the communication process rested almost entirely with the staff member. The features of the interaction were described as typical of such interactions by the nurse educator, reflecting standard practice in renal patient education.

At the end of the formal 'education' session, the researcher initiated a discussion with the participants about education strategies, and with their permission the discussion was videotaped. At the beginning of the discussion Galikali was asked about how such education might be improved. The change in her communication style at this point was dramatic: Galikali shifted her position, she sat up straight and focused on the materials the nurse educator was using and she asked questions, all of which contrasted with her earlier passive and non-interactive manner.

Perceptions of communication

Communication goals

To some extent there was a shared understanding between the participants about what the interaction was to cover. The nurse educator's goal was to integrate information about dialysis, medication and diet, as this related specifically to Galikali's abnormal blood test results. The nurse educator believed that explaining the links between the test results, treatments and diet was important but also acknowledged that this was not always successful, including in this case. Galikali's understanding was that the nurse educator wanted to talk to her about the medicines that she takes and about her blood test results. Galikali was particularly happy that the nurse educator had talked about all the test results, including those that were within normal limits, which Galikali said had not been done before. This explanation only occurred when Galikali asked for more information about the results but the nurse educator also agreed it was useful and explained that the reason she had initially focused only on the abnormal result was to avoid confusion or information overload.

The goals of the interaction were framed by both participants solely within the staff member's goals: what the patient may have wanted to achieve was not mentioned by either the nurse educator or Galikali. Only one 'problem' was expressed by the patient—her difficulty sleeping due to a recent personal tragedy—in response to the nurse educator's inquiry about Galikali's eating and sleeping. The problem Galikali described was not pursued further by the nurse educator either during the session or later.

4. Key encounters in renal care continued ...

The participants' assessments of effectiveness

The topics addressed in this interaction were complex. The nurse educator attempted to explain the key concepts related to the biochemical components of blood in some depth, as she believed that she could effectively communicate this level of information to Galikali. The nurse educator based this judgment on Galikali's fluency in conversational English and the fact she was a long-term dialysis patient.

Both participants were interviewed (separately) following the interaction and both believed that the communication had been effective, at least to some extent. Galikali commented on how she felt about the interaction, as well as the effectiveness in providing information:

- **...I could see it all clearly—I didn't have any misunderstanding...It was good talking with (the nurse educator)—today I had a good experience with (the nurse educator)**
- (Galikali)

The nurse educator was more ambivalent about the success of the communication. For example, although she believed that

'Galikali knows a lot about medication and dialysis treatment' and that 'she knows what medication she's on', the nurse educator felt there was some difficulty linking that knowledge with the reasons for the blood tests to be taken.

Further exploration of communication effectiveness

Neither the nurse educator nor Galikali reported extensive miscommunication and there was little evidence (e.g. through attempts to repair misunderstanding) that they were aware of miscommunication occurring during the interaction. However, through the process of video analysis involving each participant and other discussions with them, extensive evidence of miscommunication emerged.

The key terms used by the staff member in this interaction included:

- the components of blood tested in the regular biochemical analysis conducted on blood samples from dialysis patients (including haemoglobin, phosphate, calcium); and
- medications used to regulate the individual's biochemistry (e.g. Nephrex, Caltrate, EPO-Erythropoietin, iron).

In this interaction the nurse educator assumed, to some extent, a shared understanding of these specific terms, as well as of the metaphors and communicative routines commonly used in Western medical discourse. Effective communication in this interaction also depended on the extent of shared understanding about underlying biomedical concepts and processes, such as the function of the circulatory system, the action of nutrients and medications in the body and their effects on biochemistry, and the symbolic representation of the body's function in written numerical form.

Through the process of video analysis and interviews with Galikali, it was evident that she did not share the nurse educator's understanding of any of the key terms related to test results. She was unable to name most of her medications and her understanding of their actions bore little relationship to the biomedical construction. For example, when asked about her medications, Galikali responded:

- **I've forgotten all their names—I can remember one or two—Caltrate—we take two with food three times a day, morning, dinner and afternoon; the Caltrate brings down the levels of phosphate if they are too high.¹⁵**

There was then some discussion about phosphate—first, about what phosphate does to the body, and Galikali attempted to explain:

- **It makes you better again, no, it makes you bad, if we don't look after ourselves with the Caltrate, if we don't take it, the thing called phosphate will reach high levels and hit our head (headache?) no'mulkurr—mukthun' (thick-headed?)—no, give us brain damage**

¹⁵See Section 5 for more detailed discussion about communication related to medication.

—And when asked, ‘what is phosphate?’, Galikali said:

- ... medicine¹⁶, not really, something like poison or—I only heard about these medicines
- recently—I’m not really sure about the names of these medicines ...

During further discussion about her medications which, as noted above, the nurse educator believes Galikali ‘knows a lot about’, Galikali explained:

- I don’t really know what their names are—there’s Caltrate, that’s the one I know best,
- and magnum—the medicine called magnum is like this, orange—when we take that,
- it’s a separate thing for our hearts and we eat it so we can walk for long distances but
- whenever I take it my head goes a bit crazy and spins around, I become dizzy, my head
- spins around; I’m sorry I don’t know the names of the other medicines; you know—
- you’re a Balanda! (interview transcript)

There were few attempts by the nurse educator to check the accuracy of her assumptions that a shared understanding of key concepts either existed or was being achieved. In later discussions about the interaction, the nurse educator recognised this as a problem and identified the need to improve strategies to check the patient’s understanding. Similarly, Galikali did not challenge these assumptions either directly or indirectly—she did not indicate any difficulties with the content of the nurse educator’s information or the communication process and did not ask for clarification.

There is a range of factors that appeared to be influencing the effectiveness of communication between the nurse educator and Galikali. Their positive personal relationship appeared to be the salient feature of the experience for Galikali, who described the nurse educator as a ‘manymak myalk’ (good woman). The way the discourse is structured, although not challenged by either participant, constrains the interaction on many levels (see ‘Management of the interaction’ above). Differences in knowledge and language systems were also identified as an important source of miscommunication through analysis of the video and participant interviews. The following examples—related to the use of the terms haemoglobin and EPO—illustrate some of these differences.

Communicative challenges: some examples

The main focus of this session, from the nurse educator’s perspective, was Galikali’s haemoglobin¹⁷ result, as this was the only result that was outside normal limits. After the interaction, however, Galikali reported that all her results were normal (when asked specifically about her haemoglobin results she said ‘marr gangga’ (not good, not bad)). There are a number of possible reasons for this. It may simply be that she forgot until prompted or she may not have clearly understood the message.

The nurse educator began by explaining briefly what haemoglobin does and said that the result ‘should be more than 112’, but did not mention what it actually was. As the nurse educator spoke, Galikali leaned forward and looked at the results in her file.

For effective communication to be achieved in this example, there needed to be a shared understanding about how the test results were represented. Although the nurse educator had talked about why the blood tests were done and how the results were presented at the very beginning of the interaction, there was no attempt to check that Galikali did in fact understand the medical representation of components of blood, which uses quantification based on the Western system of numbers (all very culturally-specific concepts).

The nurse educator’s comment also assumed a shared understanding that the implicit meaning of ‘should’ in this context indicated (indirectly) that the actual result was not within the normal range. This could only be meaningful if the patient had been able to read numbers, interpret them through the relevant Western biomedical framework, and see clearly that the result was actually less than 112. (Galikali could read the numbers, but only with the assistance of glasses, which she was wearing at the time).



¹⁶See Section 5 for discussion about the different ways in which Yolŋu and Balanda understand this term.

¹⁷For further discussion about this term see Section 5.

4. Key encounters in renal care continued ...

It also emerged later that Galikali apparently thought that haemoglobin was some form of medication and was not aware of the association between haemoglobin, red blood cells, anaemia and EPO. Medication was also a topic about which there was considerable misunderstanding, although this was rarely identified during the interaction by either Galikali or the nurse educator. Even when a problem was noticed, the source of difficulty was not readily identified, as the following example illustrates.

Immediately following the discussion about the haemoglobin result described above, the nurse educator asked Galikali if she knew what medication she took that ‘makes that one build up stronger in the blood?’ Galikali did not respond for about seven seconds, then the nurse educator asked another question: ‘what do you have each week?’ After a couple of seconds Galikali answered, ‘EPO’; the nurse educator confirmed this was correct, then explained how EPO worked—Galikali nodded a little at first then remained still and silent until the nurse educator asked a question.

When reviewing this section of the video, Galikali explained that she had not responded to the first questions because ‘I’m trying to remember the name of the medicine—Nephrex’. Again, she did not recall that the medication was EPO until she watched the next section of the video.

In later discussions, the nurse educator suggested that Galikali didn’t respond to her first question because she used the word ‘strong’:

- **Maybe the association of ‘strong’ is with bones and not with haemoglobin, so when I asked, ‘what keeps that one strong?’, she’s automatically thought of the education she’s probably heard before about Caltrate and Nephrex.**

The nurse educator felt that Galikali only said ‘EPO’ because she prompted her and this interpretation is supported by the fact that Galikali again does not name EPO when watching the video later.

Another factor, which may have contributed to this difficulty, emerged through later discussions and video analysis and relates to the different ways in which the term ‘medicine’ is used by Balanda and Yolŋu. As Galikali explained later, when Yolŋu use the term ‘medicine’¹⁸ it does not include reference to injections. This could explain why, when asked about medications, she did not think to answer ‘EPO’, which is given by injection.

Summary

Some key influences on communication are illustrated by the examples from this interaction described above. These include the staff member’s almost total control over the management of the timing, focus and location of the interaction, as well as over the discourse structure and language used. The most important understandings about this interaction emerged only through an extensive exploration of the encounter through the interview process. The exit interview immediately after, and pertaining specifically to, the interaction and the later in-depth interview, exploring the participants’ backgrounds and perspectives in more depth, engaged both participants in interpreting and contextualising the video data.

The discrepancy between both participants’ perceptions about the effectiveness of the communication and the very limited extent of their shared understanding about the concepts addressed only emerged through this triangulation of data, drawing on multiple interpretations of the interaction. This description has provided only a glimpse of the rich and complex data related to this interaction, but it should help contextualise other features of the encounter, which are discussed in later sections of the report.

The two interactions described above involved very experienced and highly motivated staff—and are therefore likely to illustrate current ‘best practice’ in the Renal Unit. As the findings described above demonstrate, miscommunication was still pervasive. The staff participants in the other interactions were less experienced, although they too were highly motivated to achieve the best possible communication with Aboriginal patients. The other three interactions are summarised very briefly below.

¹⁸See Section 5.

A medical consultation: review of a patient on dialysis

Every two months, all patients on dialysis are seen by one of the renal physicians to review their progress. There were three participants in this interaction videotaped for this study: a renal physician who began working with Aboriginal people quite recently; a renal nurse of many years' experience in renal services in the Northern Territory; and Njarritjan, a Yolŋu woman who began dialysis quite recently. Before the patient and her sister moved to Darwin for treatment, both lived in a remote community in Arnhem Land.

Neither of the staff had undertaken any formal training in intercultural communication and both had received very little cultural awareness training. The patient spoke a number of Yolŋu languages but had very little fluency in English.

The physician had not met this patient previously, but the nurse knew her from contact when she attended dialysis. No attempt had been made to engage an interpreter and Njarritjan's sister, who is confident in English and often provided unpaid assistance with interpreting in medical encounters, did not accompany her to this appointment.

As with the other encounters, this interaction achieved very little shared understanding about key issues. Both the patient and the staff members overestimated the effectiveness of the communication and this discrepancy between perceived and actual success became increasingly evident during the subsequent interviews with participants and through their interpretations of the video data.

A recurrent feature of this interaction was the sociolinguistic phenomenon of 'gratuitous concurrence', which is the term for one person complying with what they perceive to be the expectations of another. The patient's responses to a number of questions were interpreted by staff as indicating her understanding of the discussion, but further analysis revealed this was rarely the case. For example, in response to a question about how much she drinks each day, Njarritjan responded, 'two cups'. Later discussion with Njarritjan and her friends and family indicated that she said 'two cups' because she knew this was what was expected, but she actually drinks tea whenever she feels like it. Her sister, who provides a high level of care and support to Njarritjan, particularly with understanding the medical concepts, explained that they had been told to avoid fizzy drinks but that any amount of water and tea were all right (see further discussion about 'fluid' in Section 5, p. 62).

Despite her limited proficiency in English, Njarritjan was able to convey some of her concerns to the staff, although only a partial understanding was actually achieved. This aspect of the interaction was substantially more successful than the attempts of the staff to find out information from, or provide information to, her.

As a result of the opportunity to analyse this interaction, the nurse interpreted Njarritjan's responses quite differently in subsequent encounters and both staff felt that they had reached an improved understanding of communication issues as a result of their participation.

4. Key encounters in renal care continued ...

An education session: addressing dietary issues with a new patient

The participants in this encounter were an allied health professional (referred to as ‘the educator’), a Yolŋu man who had commenced dialysis only a few weeks earlier and his sister, a trained teacher. Both the patient (Baŋaḍi) and his sister (Baŋaḍitjan) are usually residents of a remote homeland in North-East Arnhem Land. Baŋaḍi has very little understanding of English but speaks a number of Yolŋu languages. His primary language is Gumatj. Baŋaḍitjan has a high level of competence in English and has had extensive experience with medical contexts, but she does not have formal training in interpreting or previous experience with renal disease.

This interaction was very long—almost an hour—and focused primarily on the nutritional aspects of renal management, which was the educator’s primary goal for the consultation. The patient, however, had a very different goal: he wanted to talk about going home and he repeatedly returned to this topic with little success, as the educator felt unable to address his concerns within this interaction.

The educator and Baŋaḍitjan talked about how they would manage the communication before commencing and agreed that Baŋaḍitjan would interpret. This enabled Baŋaḍi to participate more actively in the interaction than had been the case with other patients in interactions where there was no interpreter present, although his attempts to participate in the discussion often went unacknowledged. For a number of reasons, the potential for improved communication from the interpreting assistance was not realised. The educator did not always provide an opportunity for Baŋaḍitjan to translate and she used a number of concepts with which Baŋaḍitjan was unlikely to be familiar, as she has no prior experience with renal care. There was often little or no explanation given about these unfamiliar concepts, so even when the information was translated there was little chance that it would be meaningful to Baŋaḍi. Again, the perceptions of all the participants about the effectiveness of communication were inconsistent with the evidence from the data: assumptions about the level of shared understanding achieved were not substantiated through comparison and contrast of the various interpretations of the interaction¹⁹ obtained through the video analysis and interviews.

Soon after this interaction Baŋaḍi did go home for a visit and returned to Darwin for treatment before going home again. At the time of writing he had been back in his community for a number of weeks and from discussions between the Yolŋu researcher, Baŋaḍi and some of his family it seems they were unaware of the consequences of his withdrawal from treatment. It seems they also believed that the tunnelled haemodialysis catheter he has in his chest is a form of treatment and that he no longer needs further intervention in Darwin.

¹⁹The videotape of this interaction was analysed by two of the researchers and the staff member, as well as another Balanda fluent in Yolŋu Matha; the patient and his sister did not have the opportunity to provide their interpretations of the video as they went back to their community.

A dialysis treatment session: 'on the floor'

'On the floor' is the context in which most of the communication occurs between staff and patients in renal care. In this interaction the process of setting up the machine and commencing dialysis was videotaped. The participants were a renal nurse who has worked in the unit in various roles for a long time and a long-term renal patient, Wurrapa. Wurrapa is an older Yolŋu woman from North-East Arnhem Land who was educated in the community and worked in the preschool for some years but is not confident in communicating in English. The dominant feature of this encounter was how little verbal interaction actually occurred. One of the interactions occurred when the nurse told the patient about the procedure she was about to perform, a situation where, implicitly at least, there was an assumption that the patient was giving 'informed consent' for the procedure. However, when analysing the video later, the nurse said that:

- **I think if I asked Wurrapa she would have no idea what I was talking about—she agrees that it's okay that we're going to do a test but if I'd asked her what the test was I think she would have said 'I don't know'...I don't think anyone has really sat down and said to Wurrapa 'this is why we are doing this to you'; we might have said 'we're doing this test to see how your blood flow is going', but I really don't think she's got any comprehension about it...if I had more time I would have sat down with her and did it and talked to her just to see if she knew—I think I would have needed...someone else there to interpret, to speak with her first.** (video analysis with renal nurse)

This was also the only encounter in which the participants reported that the videotaping substantially influenced the interaction. In this case, both the staff member and the patient said that the nurse talked far less than was normal for her in this situation. The most useful information from this interaction actually emerged through the interviews and the discussions that occurred during review of the videotapes. These discussions involved the participating nurse and another experienced renal nurse in one case, and the patient and Yolŋu researcher at another time. Some of the points to emerge from these discussions include:

- communication about procedures as they are occurring is highly valued by patients;
- personal relationships between staff and patients are a central factor in the patients' dialysis experience;
- patients are concerned about nurses' concentration when they talk to other staff while carrying out procedures;
- proficiency of staff (e.g. in placing needles) is highly valued by patients;
- extensive opportunities for increasing shared understanding exist but are rarely utilised; and
- the staff assumed the patient understands far more English than is likely, given other evidence about her level of English competence.

Summary

Although there were many differences between the interactions in terms of their goals and structure, as well as the ages and experiences of the participants and the cultural and linguistic distances between them, there were also some common threads. These include:

- all participants were highly motivated to achieve the best possible communication within the constraints of their situations;
- shared understanding about underlying biomedical concepts and key terms was actually only achieved to a very limited extent;
- all participants overestimated the effectiveness of communication and failed to recognise the frequency and extent of miscommunication;
- both patients and staff assumed a greater extent of shared knowledge than was warranted;

4. Key encounters in renal care continued ...

- patients and staff had different understandings about communication processes—what was said and what was withheld, roles and responsibilities;
- participants failed to recognise and/or contest the dominance of Western biomedical discourse systems and the marginalisation or exclusion of Yolŋu discourse systems; and
- few attempts were made to prevent communication difficulties, and effective strategies to monitor effectiveness or to repair miscommunication were rarely utilised.

Only a few examples of issues that emerged from the analysis of the interactions and other data have been described above. These issues, as well as many others, are explored further in the following sections, which integrate information from all sources relating to the key features of communication emerging from the study of these renal care encounters.

5. Key features of communication in renal care encounters

Effectiveness of communication

In all the interactions explored in this study, there was a high level of goodwill by all participants and a shared intention to achieve the best possible communication. This is unlikely to be the case in all interactions at all times between health staff and Indigenous patients. The findings of this study are not presented as 'typical' but rather as snapshots of current 'best practice' in intercultural communication in the renal treatment setting. As such, they are likely to understate the extent and severity of miscommunication.

Even where participants were attempting to achieve the best possible communication, miscommunication was still extensive and the barriers to effective communication were multiple and pervasive. This section explores the effectiveness of communication in the studied encounters by examining the participants' initial perceptions and the difficulties subsequently uncovered through comparing and contrasting the various interpretations of the data.

Lack of awareness and an acceptance of 'a grossly deficient cross-cultural communication standard as the norm' have been described in Central Australia (Devitt and McMasters 1998:147). In this project, a similarly 'grossly deficient' communication standard has been clearly demonstrated in the context of renal care in the Top End. This standard, based on the participants' descriptions of their other experiences of communication, also appears to be the norm. The extent to which this remains unchallenged, either due to lack of awareness or to acceptance, is unclear. It seems likely that both factors are relevant for both staff and patients to varying degrees, depending on the individual's experience and attitude.

The extent to which effective communication was achieved, as well as the barriers to achieving effective communication, has been illustrated many times in earlier sections of this report. Communication effectiveness was overestimated by the participants—both staff and patients—in all the interactions. A brief exit interview was conducted with each participant as soon as possible after the interaction occurred. Most of the patients gave favourable accounts of the quality of the communication and the extent of shared understanding that was achieved. There was more variability in the staff assessments:

- **...I'm pleased, looking at it now—I suppose when you see yourself on video you think you're not going to like it but I don't think I'd change that—I'm fairly happy with the way that I've delivered that information and happy about the whole process and how it's been interpreted—it was a long interview but I think I would still do the same again because I'm taking my time with each message and that's what's taking the time—getting one point across then translating it so it probably should take twice as long as doing it in English.** (interview with educator)

When analysing a particular interchange, the educator qualified the above interpretation of effectiveness:

- **even though watching the video I feel happy with this and Baḡaḡi feels happy as well, there is still—being from a scientific background—there is still no evidence to say that that message has been perceived—the body language looks good and he looked at the pictures and he's interested but how do I know, when mango season is next on, that he'll know that mangoes are high potassium?**

The patient gave an unqualified—but very limited account—of the communication, although for sociolinguistic reasons it would be very unlikely for Baḡaḡi to be at all critical of the staff member in this situation:

- **... good, she talked about good food and wrong food—good story...**

In contrast to the interpretations of the staff members and the patient, two interpreters who also analysed this videotape commented that too much information was covered and only a fraction of the information given by the educator was actually translated by B. As the educator did not employ any comprehension-checking strategies, the extent of Baḡaḡi's understanding could not be verified from the videotaped data but, from the available evidence, the interpreters suggested it was very limited.

5. Key features of communication in renal care encounters continued ...

The most experienced staff member to participate in the project gave a more cautious interpretation of the effectiveness of communication in the interaction with Balan and his family:

- **...I never know if I've communicated anything all that much with Balan over the years, quite honestly. Perhaps his mother got some idea and his grandmother seemed slightly uninterested—probably not uninterested but she was looking completely the other way so I never knew what her reaction was. That may be the way she interacts in that setting. I hope they at least understand that he is at risk of needing more dialysis. I think they now understand that he has two kidneys that aren't working so well but that he doesn't require dialysis at the moment. The other thing was that he would benefit from treatment, of blood pressure in particular, to a certain goal, and treatment of other things like anaemia. Again, it's a message he's had many times and I still don't think it gets through that well to Balan and that may be us or it may be Balan—I'm not sure; he's one of the less animated and less engaged of the Yolŋu people that we have to deal with, which seems more common with the younger males** (interview with physician)

In this interaction, the staff member's feeling that very little shared understanding was actually achieved was consistent with the other interpretations of this interaction.

In other cases, staff attributed lack of understanding to a conscious choice by the patient. In discussing the interaction with the new patient, the educator said:

- **...I don't think that we realise it enough—I think it's there but it's only when you do something like this that you actually get to the bottom of what people really understand—that you find those common occurrences that this is what people really think like, 'I've been good—can I go home?', and there's a certain element of 'what do they want to understand?', you know, that selective information—they don't want to think about not going home.**

One of the staff members reviewing the interaction on the floor talked about her perception of the participating patient's (Wurrapa) English competence:

- **...I think she understands—I just think she's quiet.**

However, when Wurrapa talked to the researchers, the Yolŋu researcher consistently translated anything said by the Balanda researcher in English and Wurrapa replied in Yolŋu Matha, using just a few isolated English words. This suggests it is very unlikely that she understands English at the level the nurses assume.

About another patient, the same staff member said:

- **...B doesn't (do it) because B doesn't want to learn. B knows how to do it but she just doesn't want to do it ...**

The suspicion that patients' understanding was greater than it appeared was often voiced in informal discussions with staff members who reported that such assumptions are common. However, analysis of the videotaped interactions provided an effective means for challenging such assumptions. The staff member above was also involved with another interaction and she described how her perceptions changed through her participation in the research process:

- **...just from looking at that video—I just learnt so much from that; I never even considered that they might be saying 'yow (yes)' when they are really saying 'no', I never even thought of it; it was really, really interesting that they say they are understanding and they haven't got a clue. I'm sure a lot of people would think exactly the same as I have—that they didn't know it was so vast—the extent of misunderstandings and possible misunderstandings.** (interview with renal nurse)

The description in the earlier sections of the encounters clearly illustrates that differences between perceived and actual communication effectiveness were common and often extensive. These discrepancies were evident for all the interactions but varied in extent. A far more informed picture of effectiveness emerged through the comparison and contrasts of the participants' perceptions and the interpretations of the participants and researchers of the video data. In the following sections the nature of the miscommunication that was uncovered and some of the factors, both positive and negative, that influenced the communication are explored in more detail.

Barriers to effective communication

Many barriers to effective communication were evident in these interactions or were identified through the interviews with participants. At the broadest level, there were systemic factors that prevented even the most experienced and motivated staff and patients from achieving effective communication. These included the location of control over all aspects of renal care encounters, primarily with staff, and the absence of appropriate training for staff to ensure they have the capacity to provide optimum services to Yolŋu patients. These political and systemic barriers were compounded by the extreme cultural and linguistic differences between participating staff and patients, which are reflected in their very different ways of communicating and learning. These and other sources of miscommunication are explored, integrating all forms of 'data'—the multiple interpretations of the videotapes, interviews with participants, relevant literature and other information from participants—to reach a deeper understanding of the complex and various experiences of staff and patients as they work together to achieve their shared goal of improving health outcomes.

Competence in intercultural communication

Predicting and preventing miscommunication

As the previous section illustrated, the potential—and actual—effectiveness of communication was almost invariably overestimated by both staff and patients. To ensure effective communication, it is first necessary for participants to consider the potential for *miscommunication* in any specific interaction and to take appropriate preventative action. This requires a high level of understanding of, and expertise in, intercultural communication. However, in these interactions few strategies were used to predict, prevent, identify or repair miscommunication.

There was little indication that either staff or patients had considered the level of risk for miscommunication before engaging in these encounters. Even if this had been attempted, there were no tools or guidelines available to health staff to use in making such an assessment, such as the test of English proficiency used in legal contexts. As well, there has been until recently no alternative to attempting the best communication possible with the participants at hand. In the past, in the absence of an interpreter service for Indigenous languages, family members have been used as interpreters in all areas of Aboriginal health care. Although an Aboriginal Interpreter Service now exists and speakers of Yolŋu languages are readily available, changes in practice are only slowly occurring. None of the participants—staff or patients—sought the assistance of a registered interpreter in these encounters.

Monitoring and repairing miscommunication

Just as there was little apparent awareness of the level of risk for miscommunication, there was also little recognition of miscommunication when it occurred—by either staff or patients. Often neither participant was aware that a misunderstanding had occurred. These instances of miscommunication became apparent only through comparison of data from different sources, including the video interpretation by the participants as well as the researchers, and the exit interviews.

This lack of recognition of instances of miscommunication was due to a number of factors. One of the challenges in monitoring communicative effectiveness is the extent to which instances of miscommunication are 'masked' for various reasons. For example, Yolŋu consider it appropriate for the listener to respond in a way that is consistent with the expectations of the speaker and to avoid any direct confrontation, and as a result their responses may not reflect their own understanding or opinions (see Cooke 1998). Yolŋu patients also used various strategies, such as scaffolding their responses through repeating some or all of the speaker's words, in an attempt to keep the communication flowing even when they do not understand.

5. Key features of communication in renal care encounters continued ...

As well, when patients are fluent in conversational English, staff members sometimes assume—often incorrectly—that they will share an understanding about a wide range of concepts and topics. As one experienced staff member explained, she was unaware of how little shared understanding was achieved until she was directly assessing patients' understanding of important concepts through the self-care training program:

- ...a lot of them could speak English and I thought they were understanding me quite well— and it wasn't until I started the self-care program and saw some of the deficits that what we thought was the knowledge base and it really wasn't. (interview with educator)

Inaccurate assumptions by staff about the patients' levels of English proficiency can also lead to judgments that the patients' apparent lack of understanding is sometimes deliberate. For example:

- ...there's a certain element of 'what do they want to understand?', you know. (interview with educator)

Just as strategies to predict miscommunication were not employed, few strategies were used to monitor the effectiveness of communication. All the participating staff expressed concern about the difficulty in assessing the patients' understanding in these interactions. Concerns about the staff members' understanding of the patients' messages were rarely expressed by anyone, however, which again illustrates the staff-centred nature of these interactions and the centrality of the biomedical perspective and information.

The need for improved strategies for assessing communication effectiveness was very evident from the analysis of the interactions, and is recognised by staff. Although no simple solutions emerged, a number of techniques were identified, which could be further explored and developed. For example, one experienced staff member described some of the strategies he uses:

- I ask them the same question again to give them a chance if they're not really quite sure—they'll nod, then you say, 'are you quite sure, is there anything else you want to ask?' You never are (quite sure that people have understood). If you ask the question again but in a different manner which is not like you are examining them— if they volunteer that they know what it is then you'll accept it; if not, you are always in two minds—we all say 'yes' to things politely that we don't understand or we don't want to look stupid—what you want to do is give them the opportunity to say,—'we're not really quite sure, tell me some more'. Now, they're never going to say that, so you ask the question in a different way, so, 'do you know what it's for?' I think you're trying to give permission to say, 'look, if it's not 100 per cent clear, tell me again' or otherwise you say, 'look, do you want me to go over it again?' and they'll say, 'yes', so you offer to explain it without making them look stupid. You can do it in a concrete manner—get them to show what they normally do. (interview with physician)

Given the extent to which instances of miscommunication are 'masked', as described above, accurately assessing the effectiveness of communication is a complex and almost impossible task without the assistance of a trained interpreter and remains a challenge even when an interpreter is involved. Development and evaluation of practical techniques to enable more accurate assessment will be an important focus of Stage 2.²⁰

²⁰See www.sharingtruestories.com to access guidelines for improving communication between health staff and Aboriginal patients, as well as information on other relevant resources.

Training in intercultural communication

These limitations in intercultural communication practice are inevitable within the current system, which does not address the institutional and individual capacities required to meet the needs of Yolŋu patients. None of the renal staff speak an Aboriginal language and none of the Yolŋu patients (nor indeed many other Aboriginal patients) speak English as a first language, but none of the participants have received formal training in intercultural communication.

Even general cultural awareness training, which is readily available to staff, had been accessed to a very limited extent and with limited effectiveness. One staff member recalled his only cultural-awareness training experience:

- **...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...**

Yet he found that intercultural communication was:

- **...an incredibly difficult aspect of working there, that I knew that there was next to no communication between me and many other people, which means the patients, which had obvious impact on what happened.** (interview with physician)

The barriers to accessing formal training identified by staff were described as organisational, for example:

- **I haven't done a cross-cultural course at all—when I first came up it wasn't compulsory and I've tried to get in several times over the years and it was either booked out or Renal wouldn't relieve me because they didn't have enough staff at the time.** (interview with renal nurse)

The consequences of this lack of training were described by one of the nurses:

- **...(the) first couple of years was coming to grips with renal focus on the treatment at first rather than the person, so getting that culture thing comes in later, sadly, and because I didn't know the people and the language difference—a lot of them could speak English—and I thought they were understanding me quite well and it didn't come out until later when I was doing the self-care program some of the concepts...(that they were) not understanding...**(interview with nurse educator)

For most of the staff learning occurred 'on the job', but this had serious limitations:

- **You become aware of the issues just through doing what you're doing. Which is poor ...It's a slow way and you learn by obstacles and by, you know, some people might learn by causing affront and problems and whatever, and by finding that things that they want to do can't work and for a whole variety of reasons.** (interview with physician)

Informal education provided by the Aboriginal Liaison Officer on general cultural issues was one source of support identified by staff as useful. Another was learning from more experienced staff, although this has both advantages and disadvantages:

- **It was the experienced staff in the unit, what they thought, how they communicated, how they got to know people—sometimes (it works well) if the knowledge is correct sometimes it works really well, sometimes it doesn't.** (interview with renal nurse)

Participation in the research was also found by some staff to be a powerful learning experience:

- **I felt it was fascinating looking at the analysis of the interaction. It certainly stimulated me, I mean I had already wanted to read more, but it certainly stimulated me to read more and think more, and looking at the way in which people who are experts in analysing communication look and analyse things I think is fascinating. I enjoyed it immensely.** (interview with physician)

5. Key features of communication in renal care encounters continued ...

The opportunity for staff members to analyse their own practices through looking at the videotapes of their interactions with the patients was particularly effective and directly influenced their practices:

I actually learnt from looking at it (the tape) on Wednesday for how to deal with it (assisting physician during medical reviews) today; I actually associated what I'd learnt in my dealings today; so it was really helpful because I wouldn't have thought of that before...just from looking at that video—I just learnt so much from that (interview with renal nurse)

I think I became more aware of how (the nurse) and I were interacting in that interview, that's something that we always do...I mean I do try an ...do miss having someone there if they're not there, but maybe I'll make sure they're always there. And go out and get them if they're not. And our talk about pause times...I'm a bit happier with silence and having time to think about things, I think I was more aware of that having talked about it. I think I'll try and take that on board—stop myself jumping in. So there are a few things and then I think if there are some concrete outcomes, I think they might be things that we can all talk about and try and deal with it. (interview with renal physician)

Provision of appropriate training for staff—and patients—in intercultural communication emerged very strongly as a priority for action and the potential for effective training to improve communication was illustrated in the changes that occurred in practice as a result of participation in the research. The incentives, and the opportunities, for developing capacity in this area are great and are areas of focus in Stage 2 (see Attachment 1).

Communication beyond the encounter

Communication between staff and between service settings, for example between Nightcliff Renal Unit and the Renal Ward in the Royal Darwin Hospital and between renal staff and remote community clinics, was also identified as problematic. These aspects of communication were not the focus of this research and will not be explored in detail here, but some examples will be described to illustrate the importance of attending to the broader systemic barriers to improving communication.

One of the participating staff members is employed to work primarily with patients who are 'pre-dialysis' and effective communication with the renal ward and community clinics is especially important in this role. She describes some of the challenges:

At the moment especially in my job there is that follow-up—the communication between the communities and Darwin Renal Unit—that is one of the issues as well, our patients come in and have a fistula made then go back out on the communities, so bridging that gap as well from the communication from the communities where they come from—I'm setting up a formal mechanism at the moment; prior to that it has been ad hoc with the doctors—they send a letter out to the community about the patient's status—that they've had a fistula and that they should be seen in another three to six months, but a lot of patients have fallen through that loop and have come back in end-stage and quite sick and that's no fault of the community or ours...what we'd like to do is keep them off dialysis as long as possible, so we should be involved in their care to prevent them coming in on dialysis, so we should be communicating with the clinic to see if they've come in for bloods, if there are any problems, what medications are they on, do they need any changes, so we are setting that process up now but it is still in it's infancy—so that is another huge communication issue—the follow-up of patients. (interview with nurse educator)

Communication beyond the clinical encounter was also important amongst Yolŋu themselves and similarly ineffective in terms of communication between patients and their families about biomedical information. This is discussed further in Section 5.

Power and control in renal care encounters

There is a complex reciprocal relationship between power and communication: power relationships between the participants in an interaction play a crucial, but often unacknowledged, role in communication and communication itself is an important influence on the dynamics of power between groups and individuals. In the context of Aboriginal health care, Weeramanthri (1996) suggested it should be self-evident that communication of information is critical in addressing the imbalance of information, and therefore power, between policy-makers, practitioners and community members. It is also crucial to consider communication in the context of the power relations operating within the health system as a whole. An understanding of the relationship between communication and power is not often reflected, however, in practice.

An important theme to emerge from this study was the influence of location of control on communication and particularly on management of communication, access to information and decision-making about treatment. In each of the encounters, control over every aspect of the communication was located primarily with the staff. The time, place, participants, agendas, structure, topics and the language, as well as the forms and styles of discourse used, were controlled by the staff and generally accommodated by the patients, as much as they were able to do this.

The time and place

All the interactions that were included in this study were initiated by staff. Medical reviews, for example, occur regularly every two months. In theory, the patients are informed when their review is due (on a non-dialysis day) and they are picked up by a bus driver either early in the morning or early in the afternoon. They may then wait for a number of hours to see the doctor, as there are no specific appointment times. In general, the patients appear to accommodate the institutional system without question, but there are exceptions. One patient recounted an incident in which she attempted to take some control over the process when she felt she had not been appropriately informed about her review appointment, and the only way she could do this was to withdraw in protest:

- **If they don't let me know the day before I don't have to come here²¹ because they didn't let me know—they just come and pick us up—while we are still sleeping they drag us out ... the driver came on Tuesday about 7.30 and asked, 'wanha B? She's got an appointment at the NRU', and I said, 'what for?'" "Doctor's visit", and I said, 'I'm not going because they didn't let me know—they should have let me know yesterday'. (renal patient)**

The importance in the community of adequate notification about appointments was also stressed by one participant:

- **it's very important when the doctors are going to (communities) to see kidney patients**
- **that they give notice about what time and what day they are coming to see these**
- **people so that the family knows and can get ready for it. (interview with family member)**

Just as medical encounters are initiated by staff according to the institutional routine, education sessions are also generally initiated by staff according to their perceptions of the patients' need for information. This is structured primarily around blood test results for patients on dialysis and as part of the management routine for new patients.

Participants

In some of these encounters family members were also present. In one case, the patient's sister assisted the staff member with interpreting, but there was no attempt made to consult the patients about who they wanted present and in what roles. In general, most patients attend the medical reviews alone. Although this is not imposed, it is normal practice within this—and many other—Western medical settings. This presupposes that the patient is the primary, and only, decision-maker about his or her own health management, which for Yolŋu is not necessarily the case.

²¹ When Yolŋu use the construction 'I don't have to...' it can mean 'I won't (do something)...' as a consequence of some other factor.

5. Key features of communication in renal care encounters continued ...

When another Yolŋu was present and provided assistance with interpreting, as occurred in two of the encounters, there was a marked—and beneficial—shift in control:

- **I think they get to ask their question and get it answered better through an interpreter, for sure; and it's probably not less threatening but they are more in control of the interview when there is a third person there; when I'm there I do most of the talking either because I talk too much or because if I don't talk nothing is said because everyone is either too shy to ask me or doesn't really know—they know what they want to ask but they don't ask; I think they get more control with interpreters; I talk about the same but I answer their actual question.** (interview with renal physician)

The potential value in providing opportunities for appropriate family members and interpreters to participate in renal care encounters was recognised by staff and patients, and strategies to do this more effectively will be implemented in Stage 2 (see Attachment 1). These strategies will include finding ways for patients to spend time together in a comfortable and supportive setting, where they have a chance to talk informally with each other and with health professionals where possible. Promoting possibilities for patients to share understandings together is the first step towards promoting the development of shared understandings between non-Aboriginal health professionals and their patients.

Communication goals, style and structure

In every interaction the language used was English, which was not the first language of any of the patients. None of the staff members are fluent in the language of this group of patients and even those who had worked with Yolŋu patients for many years were not familiar with frequently used words such as 'manymak' (good). Yet no attempt was made by staff members in any of the interactions to engage an interpreter. The patients were therefore forced to accommodate the linguistic preference of the staff members even though four of the five patients had very limited proficiency in English and little experience of the Western biomedical cultural context.

The staff members' goals for the interactions were the main determinants of the topics covered, and the preferred communication style of the staff members structured the ways in which these are talked about. For example, the question and answer routines common to biomedical encounters dominated the medical review. Similarly, a 'transmission model' of communication structured the education sessions in which 'information' was 'given' by the staff member to the patient. In the two education encounters and the interaction 'on the floor', the talk was dominated by the staff member, with few opportunities for the patient to initiate or respond. In the medical encounters there were more frequent attempts to elicit responses and questions from the patients but with little success, which was not surprising given the barriers to patients participating as active communication partners in these interactions.

The effectiveness of these encounters was also restricted by the compartmentalisation, which is inherent in a biomedical approach. This separation of the physical dimensions of the patient's experience from the social, emotional, political and economic context in which they occur has been widely challenged—and, in many health care contexts, modified—but remains a dominant feature of this setting.

The following example illustrates how this compartmentalisation and the dominance of staff communication preferences and priorities are manifested in the context of renal care. In this encounter between a staff member and a new patient from a remote homeland, who speaks very little English and is unfamiliar with the communicative routines and roles in Western medical encounters, their very different expectations were unresolved even with interpreting assistance from the patient's sister:

- **Baŋađitjan (the patient's sister) explains that Baŋađi (the patient) is telling the educator what he wants to eat. She responds, telling him that bush food is good, then without waiting for this to be interpreted she asks him, 'what do you think the machine does for you?' Baŋađitjan interprets this and Baŋađi responds, 'manymak (good)', then immediately asks if there is any way that he can go home for two weeks. The educator says two weeks is too long, so Baŋađi offers 'one week' and the educator says he needs to talk to the doctor about it. The educator then switches the topic back to her main focus.** (researcher's video description)

When reviewing this interaction on video the staff member acknowledges the conflicting communication goals for this encounter:

- **My needs are to talk about dietary interventions and his needs are to talk about when he can go home, and he said two weeks and I said, 'no, and I'm not the person to talk to', and he said, 'okay, one week' (laughs) and it's something we'll go back to with him—he needed to get that out...he's quite controlling of the interview in a subtle way and he's got back on to the fact that he hasn't missed a dialysis session and that he's been good and that he'd still like to go home.** (interview with educator)

Again and again in this interaction, Baḡadi—and his sister—try to actively participate, accommodating the educator's topic preferences and offering information from their perspective, by talking about Yolḡu foods, for example:

- **(the educator) explains that Baḡadi's protein level is too low then 'Baḡaditjan asks her to clarify. The educator then says what Baḡadi should eat. Baḡaditjan translates and discusses this with Baḡadi then she repeats and expands on the foods the educator said he needs; the educator then tells him to eat protein food twice a day and gives examples, which Baḡaditjan translates. The educator then talks about hunting, Baḡadi's skill and who he will go hunting with, and Baḡadi talks about goose eggs, but the educator does not pursue this topic.** (researcher's video description)

Baḡadi returns repeatedly to the topic about which he is most concerned—going home:

- **Baḡadi then tells the educator he wants to go home and asks about who pays airfares and Baḡaditjan translates for the educator, who says he needs to talk to the social worker about it and the educator encourages them to 'postpone' going home until he is stronger. (this is not translated by Baḡaditjan)** (researcher's video description)

The staff member gives her interpretation of this part of the interaction:

- **It's toward the end of the interview now and B has come back to Baḡadi's original question, 'can he go home?', and she seems like she's negotiating on his behalf—B was saying he'd like to go home and she also then said because he's a new patient and she sort of suggested that it would be better to leave it a little while, so I don't think she actually wants him to go home so early yet, and so your comment about not translating that back may have come from her not wanting to tell him that he can go home yet—that's my impression.**

This interaction highlights a number of differences in expectations and understandings related to the discourse structure of such encounters, a structure which more experienced patients become increasingly familiar with and attempt to accommodate. This patient expected to discuss his priority concern and he was unaware that this topic was not considered appropriate by the staff participant for this encounter. His apparent attempts to 'bargain' with the staff member about going home also illustrate his perception that he has little power in the decision-making process. While the presence of the interpreter may have presented an opportunity for a collaborative approach in Baḡadi's renal care, the staff member did not take advantage of this. The marginalisation or exclusion of Yolḡu perspectives and knowledges—and their perceived and actual lack of power in the decision-making process—are features of all the encounters.

The educator talks about how different understandings about the organisational culture contribute to the communication difficulties:

- **Within the first five seconds of the interview Baḡadi's aim of the conversation was to talk about going home, and I think the problem's set up in that patients see interviews like what I'm conducting as a chance for them to sort out all their problems, whereas Balanda people see their roles as quite separate, and so my needs were to talk about dietary issues, his need was to talk about going home for two weeks because he sees other people going home and he wants to know when he can go home, so but for us it's inappropriate for me to say you can't go, so I still said to him two weeks is too long, not knowing the guidelines.** (video interpretation with educator)

5. Key features of communication in renal care encounters continued ...

This staff-centred and compartmentalised approach to management, based on the roles and priorities of staff rather than the concerns of the patients, was again illustrated in the medical review. The patient, Njarritjan, wanted treatment for diarrhoea and, despite her limited English, she was able to clearly communicate this to the physician. However, at the end of the consultation, when the nurse summarised their discussion, she did not mention the diarrhoea because 'I was looking for dialysis (issues) rather than the overall health' (interview with renal nurse). The patient's health concern was outside the focus of the review, which was management of renal disease, and at the end of the consultation Njarritjan had to ask again for medication for the diarrhoea, which had been forgotten.

In other encounters, patients rarely attempted to influence the focus of discussion or introduce any non-medical concerns and, even outside these encounters, the opportunities for patients to control information-sharing processes were limited. For example, control over information such as test results was also located very much with staff for a range of reasons. The patients have little access to this information and although it is documented in their files few patients are able to interpret the data in the way it is presented. There is an intention that this information is to be shared with patients, but usually—although not always—only abnormal results are discussed with patients. In one example, a patient was told during her medical review that all her results were normal, but according to the file her haemoglobin level was low. Another staff member explained what might have occurred:

- **...even though her haemo is low it's not in the critical low to change anything—the (staff) perception is, 'okay, we'll monitor it', so they probably won't say to the patient, 'well, it is low but we'll keep watching it'; they'll say, 'oh, no, everything is looking good', but they know in their head they're still watching it carefully.** (interview with renal nurse)

Although the standard practice is to inform patients of abnormal results, one of the patients insisted she wanted to know all her results and assumed that staff actually withheld bad news but wasn't sure why this was done:

- **I don't know what they're thinking: if they tell us the truth we might think hard, maybe they don't want to tell us yuwalk dhāwu (true story)? If they've got bad news for me, I want them to tell me straight. I won't get upset if they tell me 'you've got bad blood' or 'a big heart' or 'a bad liver' if they tell me straight.** (interview with Galikali)

Some staff members do recognise the inadequacy of current strategies for sharing information, particularly as they affect the patients' levels of participation, although some beneficial changes have recently been implemented:

- **I feel there is a lack of feedback of information to the patients at the moment and I'd like to see them have more involvement in their health and their outcomes and the dialysis therapy, and it is moving that way in the unit—there is bi-monthly clinic reviews where the patients come whether they are sick or not, whereas we used to find only a certain amount of patients would see the doctor and the others who stayed well would never see them—to say—'even though you are healthy and well, you should still know about your dialysis—there might be little things that come up that you can talk to the doctor about and generally have a chat and see how everything is going', so it's feedback for the patient—and I think they enjoy that and we involve the dietitian on that day and (she) is going to do a cooking class and we have food provided for them on that day so it is a social thing as well— so they are more involved in their dialysis treatment and their options and their family as well.** (interview with educator)

Beyond management of communication: controlling behaviour

Devitt and McMasters (1998:165) suggest that the less patients understand what it is they must do and why, 'the more compliance itself becomes simply an issue of "obedience"'. This was also clearly illustrated in this study, where the rejection of treatment was a common strategy described by patients, which seemed to be directly related to control, often in the context of being told what they should or should not do about their health. Because of the politeness conventions, power dynamics, limited English proficiency and limited understanding of Western biomedical cultural knowledge that influence Yolŋu discourse in clinical encounters, it is unlikely that patients will directly challenge or reject information or advice they are given. Their responses might not be verbalised but, instead, might be realised through their actions.

Dietary advice, particularly related to diabetes, is one area in which Yolŋu resist what some see as attempts by Balanda to control their actions:

- **I was thinking that they were lying to me (about sugar and diabetes); I won't worry**
- **about it—it doesn't matter if I eat sugar, I won't believe them: see where I am now.**
- (interview with Galikali)

Another Yolŋu also described how she and her sister (both diabetics) rejected the advice they were given about 'healthy food' by the nutritionists:

- **You know that Yolŋu don't eat good food all the time, we eat junk food at the same**
- **time, like that—we like to eat any kind of food—it's what we want to eat.** (interview with
- Njarritjan's sister).

In the context of haemodialysis, control issues were also evident in the patients' views of staff decision-making as based on reward and punishment and, as in this example, are discussed in terms of winning and losing:

- **if they're (other patients) early and I'm late and I can see these people sitting on their**
- **chairs already dialysed and I say to (the staff) 'I'm going to get 4 hours—leave one**
- **out'... they can—if it's a bad tempered women they don't listen but I always win.**
- (interview with Galikali)

It is recognised by staff that some Yolŋu withhold information that is relevant to their renal care, either intentionally when they are concerned about how staff will respond or unintentionally because they are unaware of the significance the issue might have for their health.

One staff member explained that, although staff might recognise the importance of understanding the patients' perspectives, they are unsure about how to engage patients in such discussions:

- **The other communication problems are when patients are not turning up to dialysis**
- **you want to know why not, but how do you make that non-judgmental and non-**
- **threatening...but I think the non-judgment needs a lot of work as a lot of patients feel**
- **judged if they don't come; judged on their medication if the dosette box has tablets left**
- **in it, so there are those issues of communication: how do you ask someone is there a**
- **problem without being judgmental and especially with fluid and alcohol and those issues**
- **as well; (how do you do it?) be truthful to them—I'm just trying to find out the**
- **medications that you do take, if you don't take them that's okay because we are looking**
- **at your bloods and we want to see if the medication is strong enough...telling them the**
- **truth, why you're trying to find out, but it's very hard especially about the fluid, where**
- **the fluid comes from, that's very hard—because the word—'drink' has been associated**
- **with alcohol; certain types of English words are quite demeaning to Aboriginal people,**
- **so don't say 'drink' when you're trying to ask them for tea, coffee, coke—a lot of people**
- **get upset and say, 'I don't drink alcohol'...when you say, 'what do you drink?', there is**
- **an immediate association.**
- **Asking about food is a problem as well because you don't get the whole story because**
- **either they feel embarrassed or the way they've told it, 'yes, I get enough food', or if**
- **they're eating the wrong food they think they'll get told off again...(interview with educator)**

5. Key features of communication in renal care encounters continued ...

Power and agency in biomedical discourse: verbalisation as cause

In Yolŋu epistemology (theories of knowledge), truth is something negotiated in a context where the meanings of signs and significations are agreed upon. In some contexts (like the secret/sacred) the negotiating power of ordinary Yolŋu is suspended and those in control exercise a special constitutive power through language. Some Yolŋu, assuming the same to be the case for English speakers, suspect that there is a secret English, which Balanda withhold from Yolŋu (Christie and Perrett 1996). Similarly, in the context of biomedical health systems, some Yolŋu identify a special and dangerous power in the language of medical practitioners. For example, in discussions with one of the researchers during this and other projects, some Yolŋu have expressed a belief that verbalising a diagnosis can in some way bring the sickness into being. This is an extreme effect of lack of control and absence of shared understandings.

Some time ago, a Yolŋu woman explained to one of the researchers that when health staff provide warnings—or even statistics—about potential health problems this could be construed as a—‘threat’, as prior knowledge of future illness can imply involvement in causing the illness through sorcery. Similar perspectives were evident in informal discussions with Yolŋu during this project and this generated some more specific exploration of the phenomenon involving both Yolŋu and Balanda participants in the project.

A very experienced physician noted that Aboriginal people are reluctant to talk about how they feel although they will talk about their sicknesses after they have passed, which may be related to this avoidance of ‘naming’ their illnesses:

- **...if you say to a whitefella, ‘how are you feeling?’, you’ll get every complaint under the sun, whereas not infrequently an Aboriginal person will not tell you a thing even when they are really sick—(but) if they have been sick and they are better most people can tell you that...**

These ideas are very tentative and much more investigation is needed to clarify Yolŋu beliefs about the consequences of being told about their illnesses and how they interpret warnings about potential health problems through health education programs. A greater understanding of these beliefs could be crucial for improving communication and could explain some Yolŋu resistance to accessing and utilising medical services. Even this partial picture illustrates the importance of a higher level of pre-existing shared understanding between the patient and health professional to minimise these problems within clinical encounters.

What's in a name?

One area in which Yolŋu accommodate the linguistic limitations of the Balanda staff is in the use of names. Most Yolŋu have a minimum of three names: an English name, a ‘registered’ Yolŋu name (recorded on the birth certificate and/or in the community clinic records) and often numerous other Yolŋu names as well as a (patrilineal) family name. Most Yolŋu have a Yolŋu ‘calling name’—it may be their registered name or one of their other given names—and this calling name can often change when a person of the same name dies, as cultural protocol dictates that the name then cannot be used for a number of years.

Few Yolŋu are addressed within their own environment by their English names, although all Yolŋu do have one. With a few exceptions (e.g. when someone with the same Yolŋu calling name dies), the English name is used for Balanda administrative purposes only, in places like the school roll, the hospital records, bank accounts and so on.

In the early stages of this project the research coordinator frequently had communication difficulties in discussions with renal staff about patients' names as she knew many of the patients by their Yolŋu names—some for many years—and often had never heard their English names used. The health records often record only the English name (often unfamiliar even to family and friends) and the family name (which is shared by a large number of people). The most important and reliable identifiers, the patient's registered and/or Yolŋu calling names, are often not recorded on their files. This can result in serious mistakes in identity or difficulty in making or maintaining contact with patients, as well as confusion for family members. Many minor instances occurred during this project and many instances probably remain unidentified. For example, during a community visit by the research team, an old lady participating in a group discussion told the physician that she had a fistula and yet a search of all available renal records for her Yolŋu name was fruitless.

The cultural complexity related to individual identity—the significance names hold of connections with people and places; the use and avoidance conventions related to kinship, context, and death; the use of *mälk* (skin names) and *gurrutu*—(relationship terms), rather than names in interaction—is generally invisible to staff, although the consequences of breaking conventions may be very evident. Asking people to state their own names, or a brother to name his sister or to use the name of someone who has died are just a few instances that can result in discomfort or even distress.

Most staff expressed a willingness to use the name preferred by the patient and it was suggested that this needed to happen from the first contact to establish the pattern. Most Yolŋu participants were very encouraging about staff using their Yolŋu names but stressed it should be the decision of each individual as to what name he or she preferred to be called. As a result of discussions about this issue amongst the research team during the project, some staff talked to patients about what they would prefer to be called and a number of patients were very keen for staff at least to attempt to use their Yolŋu names. This occurred increasingly during the period of the project and the patients often responded to these attempts with enthusiasm and encouraged the interested staff with other informal language-learning assistance. Institutional change in the ways in which patients are identified in health records is essential, however, if this accommodation of Yolŋu practice and preference is to achieve the optimum benefit in improving patient care.

5. Key features of communication in renal care encounters continued ...

Contrasting discourse systems and the consequences of difference

The effects of political and systemic factors on the effectiveness of communication are intensified through the extreme disjunction between the Yolŋu and biomedical discourse systems. This disjunction goes beyond differences in language and includes the many other dimensions of communication that interact in complex ways in these encounters.

The influence of cultural differences on communication in addition to, or independently of, language differences has been extensively investigated (e.g. Clyne 1994). In the context of renal services, Devitt and McMasters (1998:164) have described the communication problem between Indigenous renal patients and carers in Central Australia as 'one that resulted from a deep cultural gap, both profound and pervasive'.

A number of studies (e.g. Christie 1994; Cooke 1998) have explored the influence of such contrasting ideologies or paradigms, such as ontology (ideas about the nature of reality), epistemology (including concepts of time, space and causality) and methodology (how we construct knowledge), on communication between Aboriginal and non-Aboriginal people.

Most of the participants in this study had some awareness, but little in-depth understanding, of the actual level of risk for miscommunication, which is inherent in interactions between people from such different cultural and linguistic backgrounds. Most were unaware how little cultural knowledge they shared with the other person or how culturally specific their own discourse systems are.

An understanding of how both biomedical and Yolŋu perceptions of health and sickness are culturally constructed is essential to ensure effective clinical and educational interactions. Beliefs about causation are just one cultural feature that can critically influence health communication (e.g. Berndt 1982; Weeramanthri 1996), particularly the way in which information is interpreted. The cultural specificity of communication routines and organisational structures are other sources of difficulty about which there was limited understanding. For example, there was no explicit recognition by staff that question and answer routines, such as those used in the medical reviews, might be quite unfamiliar to Yolŋu. Balanda staff members are also unlikely to know that in sharing information Yolŋu use other forms of discourse, such as the event-focused narratives which predominated in the interviews with Yolŋu participants. Similarly, the patients did not always accommodate the compartmentalised nature of the biomedical approach to renal care in which certain topics are the domain of specific staff members. For example, patients' attempts to discuss going home (to their home communities) with the educator, or to discuss medical problems not related to dialysis with the renal physician, met with limited success.

Cultural and linguistic distance is not simply a matter of ethnicity, however. There was considerable variation between the Yolŋu participants' familiarity with Western cultural constructs depending on their experiences of Western health services and their educational backgrounds. Differences between Yolŋu participants, in the extent of their Western cultural knowledge, were also a source of miscommunication. For example, while interpreting for a renal physician in a discussion on renal function with a patient and his family who have little experience of Western health care, the Yolŋu researcher used the Western metaphor of percentage (which has no direct Yolŋu equivalent) without any explanation.²²

Nursing staff also talked in some detail about the differences in communicating with Aboriginal patients from different language groups, suggesting that regional differences are stronger than individual differences and were related to the extent of Westernisation:

- ...Tiwi talk, Yolŋu use more 'facial conversation'—it's cultural—that's the way they are; depends how long the church has been there;

and greater fluency in English:



²² However, although the Yolŋu researcher may have assumed a shared understanding about percentage, it may simply have been that she had no alternative than to simply repeat the doctor's metaphor in this situation. She may not have felt it appropriate, or possible, to give the extended explanation required to clarify this concept.

- **...that's just due to longevity of contact and also proximity (to Darwin).** (interview with
- renal nurses participating in the project)

In every encounter between staff and Yolŋu patients, the complex interaction between different ideologies, systems of knowledge, language systems and communication routines was evident at many levels. Some of the most salient influences—the absence of shared understandings about key concepts, terms and metaphors used in renal discourse, the differences in forms and styles of discourse, and differences in ideology, education and socialisation—are now discussed.

Key concepts in renal care: the biomedical priorities

Most of the communication between staff and patients in renal care presupposes an understanding of renal function. Information about renal disease, renal failure and renal treatment only makes sense if there is a shared understanding of renal function.

There is, however, extensive prerequisite knowledge from the biomedical domain, which is essential for making sense of any information relating to renal function. It is essential, for instance, to have a shared understanding of the function of the heart and the nature of the circulatory system, including the components and function of blood. As such shared understanding does not exist for many of these concepts, effective communication cannot be achieved in so much of the interaction between staff and patients in renal care. In the following sections, the differences in understandings about some of these concepts, and the consequences of these differences for quality of care, are discussed in more detail. First, the concepts most common in the biomedical discourse related to renal care are explored from both the patient and staff perspectives. This is followed by a similar exploration of concepts related to renal care that were more prominent in Yolŋu discourse.

Renal function

There appears to be considerable variation in the extent to which Yolŋu share the biomedical understanding of renal function. A long-term patient, who would be expected to be very familiar with the medical story about kidneys, explains that:

- **...(the kidney) washes the bad blood; it gets the rubbish and makes it clean by making urine.** (interview with Galikali)

When talking about healthy kidneys, she said:

- **It means you can walk to far away places, go hunting, you can go everywhere and still be fine.**

When the physician asked other Yolŋu who had little experience with renal services, they said they did not know anything about the kidneys. It may have been that they did not know what the term 'kidney' was referring to. Yolŋu sometimes use the English term 'kidney' even when talking in Yolŋu Matha and it is possible that some Yolŋu do not connect the term 'kidney' with the Yolŋu term 'diny'tiny'. Most Yolŋu are familiar with the diny'tiny of animals but they do not necessarily realise that 'kidney' refers to the same thing, or that humans have kidneys, as most Yolŋu are unlikely to have any direct knowledge of human internal body parts. As well, an awareness of what a kidney looks like does not guarantee any understanding of kidney function, which cannot be understood from dissecting (and eating), for example, wallaby kidneys.

According to renal staff, there are no adequate educational resources that are appropriate for Yolŋu and which tell the whole story:

- **...what kidney function is, what happens when that function starts losing—what happens to the body, what treatment you need and then what happens when they stop working completely; there are some materials down south—but they are not probably appropriate for all the Aboriginal communities.** (interview with nurse educator)

5. Key features of communication in renal care encounters continued ...

Some initial attempts to address this serious lack of resources are currently being made by renal staff and by an Aboriginal student working with this project:

- **so that is what I'm trying to develop—that story from the beginning to that treatment option video²³; and from there, once they're on dialysis there's that information they need to know, that continual (information) about their medication, about pathology** (interview with nurse educator)

The absence of shared understandings about all these concepts—from kidney function to failure to treatment—was illustrated repeatedly in the videotaped interactions and the interviews with participants.

Renal failure

As the patients' understanding about the medical view of kidney function is so limited, it is inevitable that their understanding about kidney failure also shares little in common with the medical story.

Renal disease—at least diagnosis and treatment of renal disease—is a relatively new experience for Yolŋu as a group. Galikali was one of the first Yolŋu to start haemodialysis, so when she was diagnosed in the early 1990s she had no prior knowledge of this kind of sickness:

- **I thought I was the only one who had kidney disease...they didn't tell me, those people (about what was wrong)...I don't really know (what goes wrong)—I know how it functions but I don't really know the story about how the kidney works; if a Yolŋu is healthy his urine goes straight but if the kidney is not working he won't urinate so much.** (interview with Galikali)

Understandings about the causes of kidney disease are similarly unclear and variable. Galikali had recently been warned that her grandchild could get kidney problems because of his scabies and she wondered if this might have been the cause of her renal disease. Although she was diabetic, she did not (even now) have a strong understanding of the links between her diabetes and renal disease. She talked about how, when her diabetes was first diagnosed, she had not taken it seriously:

- **because I love sugar, I was still eating sugar—as much as I wanted; they told me (to keep sugar down) but I didn't want to...I was thinking that they (the clinic staff) were lying to me; (I thought) 'I won't worry about it—it doesn't matter if I eat sugar, I won't believe them'— see where I am now.** (interview with Galikali)

Galikali took action only after she experienced serious complications, which she describes in detail:

- **...I went blind; I was asleep on a Saturday night, and then on Sunday at daybreak I heard the children and the older people talking outside and I tried to open my eyes but I couldn't see anything—it was still dark; so I called out, 'hey, is it daytime or nighttime?', and they said 'daytime' and I said 'no, it's nighttime', and then I said to my mother, 'Mother, I can't see anything, I'm blind'. She said, 'Is that true? Let me have a close look at your eyes', and she looked and she said, 'you can see, daughter' but, no, I was blind ...**
- **It was Sunday, and I said to my mother, 'see if you can find that paper with the doctor's phone number on it'... rang him up, I was dialing the number. 'Hello,' he said, 'who are you?'...'I'm Betty'. (He asked)'How are you?' 'I'm fine but I can't see.' 'What!' 'I can't see, come down here.' He came and he saw that it was true so he immediately called for Airmed²⁴ and we went straight to Darwin.** (interview with Galikali)

By the end of that year she was on dialysis and, as a consequence of her renal disease, she has been forced to live in Darwin since that time (1993).

²³ A video about the treatment options for ESRD has been produced in a number of Aboriginal languages.

²⁴ Airmed is the Government-funded medical evacuation air service for remote communities.

Galikali had not foreseen the consequences of not managing her diabetes, and even now, after many years on dialysis, she is still unclear about the connection with renal failure. This partial understanding about cause, as well as resistance to dietary change and medication for managing diabetes, was also expressed by other Yolŋu. Njarritjan (now on dialysis) and her sister are both diabetic, and her sister explained why they had not changed their behaviour when both were diagnosed with diabetes:

- **You know that Yolŋu don't eat good food all the time, we eat junk food at the same time, like that—we like to eat any kind of food—it's what we want to eat.** (interview with Njarritjan and her sister)

They had not changed their behaviour even though the doctors had told them:

- **Njarritjan's kidney wasn't any good because she was eating bad food—lots of sugar in tea and in food—that's why your kidney was not working, that's what the doctor said, that's why both your kidneys are not working.**

The role of diet was also emphasised by Galikali when talking about Yolŋu ideas about causes of anaemia:

- **(Yolŋu) say 'this is what all the Balanda brought—all the bad food to feed us'. We should have been staying at the bush all the time or along the coast eating wild food—food from the sea, food from the bush...we were healthy people (for a) long time.**

Galikali was adamant that renal disease, too, was new:

- **in the past Yolŋu didn't get this terrible kidney disease.**

Another long-term dialysis patient, Wurrapa, attributed her renal disease to a combination of factors including emotional stress. Although she acknowledged she had diabetes, which was not controlled, she did not see this as the cause of renal failure but believed that they had common origins. When asked about what Yolŋu generally think about causes of renal failure, Wurrapa and Galikali talked in great detail about food:

- **...wanting to eat too much sweet food—Yolŋu thinking—missionaries brought the bad food—Yolŋu had good food and there were no kidney problems, people lived on the beaches and when the place got smelly we used to move to a new spot...**(interview with Galikali)

They then listed all the healthy Yolŋu foods and explained that people did not get fat but were always slim.

Wurrapa went on to explain further about what she considered was another causal factor, describing an incident when she was young in which she was electrocuted by a kettle:

- **the power went up my arm and now it's dried out—there are no veins, they dried out, no blood is moving; I kept working even after all my veins dried up, I kept working then I was sleeping and a voice was talking to me, 'Wurrapa, you have no veins, you have to go a get the needle', maybe Jesus; I heard the story and I accepted it, I realised that I had to go to hospital and stay there, then I felt good (because on dialysis the veins regenerated)** (interview with Wurrapa)

Yolŋu ideas about non-biomedical factors influencing renal disease were not expressed in the encounters with staff—at least not to the staff member—but were often referred to in interviews and informal discussions. Some of these ideas, for example regarding supernatural agency in the context of renal disease, are discussed below.

The difficulties in explaining to patients about kidney function and kidney failure are recognised to some extent by staff, although the level of understanding achieved is often overestimated. For example, in the medical review of a pending patient (Balaj), the physician attempted at length to explain to the patient and his family about these concepts:

5. Key features of communication in renal care encounters continued ...

- **The physician talks about where the kidneys are and that they take the poison out of the blood; when they don't work the poison builds up and that level of poison can be measured in the blood—at 800 he might start to feel sick but now he is at 400 and that normal is 100—then the physician explains that the good thing is that his kidneys have been the same for the last couple of years, then talks about how the treatment has helped and what will happen if he doesn't take it.** (researcher's description of videotaped interaction)

When reviewing this section of video later with one of the researchers, the physician acknowledged the difficulties:

- **...I think people know about kidney failure— the machine and dialysis, all that, but the associated changes that go with chronic renal failure before you need dialysis are pretty hard to explain...**(interview with renal physician)

When the researchers talked to the family after the consultation it was clear they had not understood the explanation. Even with further discussion and assistance with interpreting, the Yolŋu participants were still unclear about Balan's current status and prognosis as it was difficult for the interpreter to translate information which had no direct equivalent in Yolŋu Matha.

As the extent of the problem of achieving a shared understanding about renal function and renal failure became increasingly apparent during the research process, considerable discussion occurred with various participants about how to address this. Galikali had one suggestion about how to better explain to new patients about renal disease and treatment:

- **...it's good if I can tell them about my own story and what happened to me and how I went on to start getting dialysis at Nightcliff; and so those Yolŋu sitting there all look at me and some are actually frightened—they think dialysis might be anything at all, they might get it and die; and so when I tell them, their heart and their emotions settle down and they're not frightened.**
- **People, when they get sick the first time, they like to ask questions like 'how did I get this kidney problem?' If we talk to people in the community about kidney problems they will ask 'how did it start?' If we go to the communities we should take lots and lots of pictures to show them.** (interview with Galikali)

Management of renal disease

Some years ago a number of renal staff members visited a remote community and one of the nurses described what she learnt from that experience about Yolŋu understandings of renal disease and treatment:

- **...we went to do some education and the dietitian, myself, the doctor and the charge nurse went and all the community came and it was a wonderful day and we sat underneath the tree with pictures and things about the machine but they all thought their people were coming home—they didn't understand that it was a life-long treatment and so it all hit us then—that people didn't understand that it is a permanent treatment that they have to stay in Darwin for, and that is why people end up going home and missing dialysis; so the thing that we see—people coming on to dialysis and they have a lot of trouble accepting that, so we can virtually do a pattern...they come in and have dialysis and feel a little bit better, go home, get sick again, it might be a couple of months if it's really early in their renal disease, then come back; and then when they are really established on dialysis they still go back and, depending on their health, how far they can waver until they get quite sick again—sometimes it can go from a week to three weeks—and then slowly by the end of the year, they know they can go away for a couple of days or a week at the most and that's because their renal function has totally gone so they've got no reserve left—that's quite a clear pattern. Especially if they've got means of getting home they go home more frequently and (then) they don't have any means of getting back.** (interview with nurse educator)

This inadequate communication between staff, patients and family members about the permanence of renal failure and life-long dependence on treatment (without a transplant) emerged as a crucial barrier to effective management. The staff participants explained some of the reasons that they believe contribute to this communication difficulty:

● **...A lot of people think that if they come to dialysis all the time for twelve months or so their kidney is going to grow back and they're going home—they don't have to stay; this is why a lot of them, when they come in and they start feeling better, then they go home again and then they get sick—a lot of it is communication and unless you can visually see what's going on it's very hard for them to realise that their kidney is not going to grow again and nine times out of ten this is the only way that they are going to stay alive...it's a very complex matter; even (a long-term dialysis patient) who is educated still has misconceptions about her dialysis even at this stage—it's not that she doesn't understand, it's just that she can't figure it out and— a lot of Europeans are the same—it's very complex.** (interview with renal nurse)

● **I think they are so sick when they come in, they have dialysis and they start to feel really better and I don't think the education is appropriate at the time—because they are so sick they're not going to retain the information anyway...and it might be in the wrong language so a lot of that doesn't sink in, that this is life-long, and because we've never previously had a well-established education program before they've come on to dialysis, so that education is not there beforehand; so then they get better and they think that they're cured so then they go home...they think they're cured and they go back, get sick again, then come back in until they then understand.** (interview with nurse educator)

The importance of achieving effective pre-dialysis education²⁵ and its inherent challenges are described by one of the staff members:

● **...it's more financially viable because the person's understanding before they come onto dialysis is greater so therefore the uptake of treatment is greater—or not if they chose with a solid choice of knowledge that they don't want dialysis. We'll still probably get that not attending but not as extreme as with no education or understanding—that's a huge (issue) that uptake of dialysis at the beginning of treatment, their understanding of what it actually is—not a cure but a treatment and there is no easy answer and the hardest thing is establishing the education program—how do you establish an education program with one person in an urban centre and they live 800 kilometres away and have once come in for fistula education, go back out in the community and there is no reinforcement?** (interview with renal nurse educator)

These are just an indication of some of the communicative challenges and the consequences of inadequate communication about renal disease and its management. Such consequences are not surprising given the extent of communication difficulties that were evident in many different areas relating to management ranging from diagnostic and monitoring procedures to all aspects of treatment. Some specific concepts, which were particularly problematic, are described below.

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²⁵ See Section 6 for further discussion about education issues.

5. Key features of communication in renal care encounters continued ...

Monitoring

Blood tests

Although blood is a crucially important concept for Yolŋu, their understandings about the nature and significance of blood are very different from biomedical constructions. From a medical perspective, blood is central in renal care: as the primary function of the kidneys is to clean the blood, the build up of poisons and fluid in the blood is the most immediate consequence of renal failure.

Blood tests are therefore an important tool for monitoring the progress of patients with chronic renal failure as well as ESRD. Blood is taken from dialysis patients every month and, in theory, patients are informed about the results by their primary care nurse and/or the doctor at their bi-monthly medical reviews. As well, other staff may become involved in education activities with a patient who has abnormal results.

Different understandings emerged about both the communication process and the biomedical concepts related to blood test results. In fact, every aspect of communication relating to blood was a source of difficulty, from the function and components of blood to the relationships between blood and diet, fluid, medications and dialysis. A number of issues about feedback of test results emerged, which related to different understandings about how and when tests are done and differences between actual and intended processes.

The nurse educator explained that the patient is informed about the results of monthly blood tests when there is a problem:

- **...bloods are taken each month and primary nurses write down the result and what should happen then that they're reviewed and the primary nurses should speak to a group of their patients, go through the results and any trouble spots they might get in the dietitian, if they're having trouble with eating food or their balance is out in some way and also myself if there is something like (abnormal) haemoglobin she'll get me in to review the patient; so that should happen every month, each individual patient should get some education and then every two months they see the doctor in the clinic review where everything is looked at—dialysis adequacy, nutrition, medication review.**

One patient, however, assumed that when she was not told the test results it was because the staff were protecting her from bad news:

- **we want to know, I don't know what they're thinking: if they tell us the truth we might think hard, maybe they don't want to tell us yuwalk dhäwu (the true story) If they've got bad news, for me, I want them to tell me straight. I won't get upset if they tell me 'you've got bad blood' or 'a big heart' or 'a bad liver' if they tell me straight. (interview with Galikali)**

This is in direct contrast to the intention of staff members, who explain why they feedback only abnormal results:

- **...it's hard because there are so many things that we can educate on but it gets too confusing sometimes—any of us can only take so much information in—we take blood every month and there are a lot of results that come out and this is why we focus on the ones that are out of limits because we need to get them back to normal...(interview with nurse)**

The purpose of the medical review is also to discuss abnormal blood test results:

- **...what I try to do in this situation is use the blood tests results and records of them on dialysis and try to discuss what might be issues from that...(interview with physician)**

A concern from patients about why blood was being taken had been identified in the past and a strategy to respond to this concern was implemented—but apparently has not been sustained:

- ...it's semi-informal—the nurses have a concept that each time a blood test is taken we should say, 'this tube is for checking haemoglobin, this one's to look at your dialysis'; that should happen automatically but I'm not sure that it happens a lot; because there were issues years ago that we were just taking bloods and chucking it in the bin and people were not getting any results back; it came about that we should be really certain that the patient knows the reason why we are taking the blood; but I'm not sure—because dialysis can be so mechanically automated that ... the verbal communication of what they're doing (when taking samples) gets missed because you're in that kind of mode. (interview with nurse educator)

In one of the videotaped encounters the main focus of the communication was the feedback of blood test results. Both the participants in this interaction had extensive experience with renal care, one as a provider and one as a recipient. Both could therefore be expected to be well informed about the other person's perspectives and understandings. This was not the case, however, and extensive differences in understandings about many of the concepts became evident through the process of video interpretation and interviews. This interaction, despite its limitations, was viewed by the Yolŋu patient as a great improvement on her prior experiences with feedback of test results:

- ...they haven't gone through all the numbers with me before—when they get our blood test and take it to Darwin hospital we don't even hear the result until we see the doctor. (interview with Galikali)

In this interaction a number of difficulties were revealed, many of which were also found to be problematic in other encounters. These included a lack of shared understanding of key concepts; representation of information in a form that was not accessible to Yolŋu; and different understandings about the processes of information-sharing related to test results, as described above.

Frequent education sessions over many years had achieved only a partial understanding of the medical purposes in testing blood, even with a very experienced patient who is fluent in conversational English:

- ...they get the blood and they look for worms or sickness or bugs and they count the cells inside our blood—white and red and how are the red and white working—which ones are dangerous and which ones are safe. (interview with Galikali)

Further analysis of communication about specific biomedical concepts illustrates the extent of pervasive misunderstanding in renal care encounters. The greatest barrier was the different understandings about the components of blood, but these are embedded in different understandings about underlying concepts such as the structure and function of the circulatory system. For example, Yolŋu have only one term for both arteries and veins—gurrkurr—and Galikali suggested that 'some Yolŋu think that blood is moving and some people think it is just sitting there'. A discussion about pulse also revealed important differences in understanding:

- ...they (Yolŋu) don't think (the pulse) is blood—they think it's air— they don't think wisely or very far, they just think that there is some kind of air inside. (interview with Galikali)

Galikali is likely to be more familiar than most patients with many of the terms used in the interaction but even she had very little understanding of their meanings:

- ...they find the haemoglobin in the blood—they'll look and say who's got lots of blood or whose blood is getting less—I don't know (how it gets less)—must be something he's been eating; a long time ago what we used to hear from those nurses and health workers—they used to tell us we'd get weak blood if we eat too much gundirr (white clay)²⁶ -people think that gundirr is no good.

²⁶ White clay is used extensively by dialysis patients. See 'Stingray and white clay: Yolŋu ways of managing their renal disease' in this section.

5. Key features of communication in renal care encounters continued ...

When asked about what haemoglobin is, Galikali responded:

- ...you Balanda know all about this—red cells are dangerous, they hit...the white cells—
- they are the protecting ones—they prevent trouble; the red cells, they won't be able to
- go and kill the white ones, maybe or what do they do? Do they eat the blood—the red
- cells?

When this confusion about anaemia, haemoglobin and red blood cells became apparent the participants discussed ways of improving communication about these biomedical concepts. Galikali explained that Yolŋu check their blood by looking at the inside of their lower eyelids or the palm of their hands, and if they are pale or if they get tired when walking Yolŋu 'know they have got not enough blood on them'. During further discussion Galikali explained that when they are told they are anaemic, Yolŋu think that they have 'Bäyŋu (no) blood—maybe all the blood's gone—that's what they think'. Informal discussions with other Yolŋu indicate that this interpretation by Yolŋu of anaemia as an inadequate quantity of blood is quite common.

The staff member involved in this interaction was aware that these terms are particularly difficult and she also explained that some patients think that the machine washes away red blood cells, not only fluid and toxins, and that is what makes them weak.

When asked what concepts are the most difficult to explain the nurse educator said:

- ...everything! Probably what I mostly concentrate on now, which is the biochemistry—
- the patient's pathology bloods are taken every month so explaining what haemoglobin
- is, what sodium is, what calcium is, which they go through but again what do they
- understand of the actual meaning when I say calcium, phosphate or magnesium or
- haemoglobin?

One of the strategies the nurse educator and Galikali implemented was to work together to construct a story about phosphate and calcium in Yolŋu Matha, which they both found extremely useful. According to the nurse educator this activity was:

- ...excellent, getting (Galikali) to write it down in her language and the story—it just
- worked so much better and she seemed to understand and she was asking me questions
- then translating back into English, saying 'is this what you're saying?', so she actually
- was getting the story so I could see then that it was exactly what I wanted to get across
- and it worked for me to actually plan out a story because when I've explained it to
- patients before you get confused and you start one way and if you see they're not
- comprehending then you change the story line and can get mixed up, but sitting down
- with (Galikali) and going through it I've got a better plan in my head of how to tell the
- story, rather than get too complicated, to get the message across. I'll write it down
- and get it established in English then use the Interpreter service to get it translated
- into other languages. I've been talking to (clinical nurse consultant) about it so that the
- other nurses (can use it); ideally what I'd like to do is have a story for each pathology
- part of the blood that we take each month and then get it translated into languages
- from that. (interview with nurse educator)

In addition to the use of unfamiliar concepts and language, the ways in which the test results are represented are also inaccessible to Yolŋu, even to patients who are literate in English and can read numbers. For example, Galikali said it was helpful to look at the blood test results and was positive about her interpretation:

- ...I understand the numbers, when they go up that's good and when they go down
- that's bad.

This is true for some of the tests such as haemoglobin. However, this is not true for all the tests: a high phosphate result, for example, is not good. This illustrates the importance of a shared understanding about the nature of the quantitative representation that is not assured by an ability to 'read' numbers.

Phosphate, potassium and calcium are also recurring concepts in the biomedical discourse in renal care. These are discussed in the context of feedback of blood test results, discussions about medication and dietary education. In every instance they were a source of often-unrecognised difficulty (see below).

Blood pressure

Understandings about blood pressure were also highly variable and in most of the interactions communication about blood pressure was not effective. In three of the interactions the patients had their blood pressure checked but no one was able to accurately report the result. In one case, Wurrapa was found to have high blood pressure and the nurse felt that she had made this clear to her. However, in later discussions about her blood pressure, Wurrapa said she was not told it was high and, although she talked confidently about the numbers she thought related to blood pressure, these numbers actually referred to her weight.

In another interaction, with the pending patient, the physician did tell the patient and his family that Balan's blood pressure was high and talked at length about the importance of managing this problem. After the consultation, however, none of the Yolŋu participants were able to respond to the Yolŋu researcher's questions about Balan's blood pressure result. They had understood—apparently for the first time—that it was important for it to be checked regularly and were intending to ensure this happened. The physician involved in this consultation explained the problem when asked if he believed the Yolŋu understood the concept of blood pressure:

- ...no, the visual blood pressure monitors (are good) because they can see a number
- whereas when we do it (this way)—it's all just witchcraft—you can say this is where you
- are and this is what it should be and they can actually see the number flashing—they
- can read the number and that's much better.

Another staff member suggested there is variable understanding about blood pressure:

- ...and the blood pressure—all they know about that is that the blood pressure cuff
- pumps up every hour while they are trying to sleep on the machine and I don't know
- that they really know (about) blood pressure—I'm talking generally—some of them do.
- (interview with nurse educator)

According to the Yolŋu researcher, many Yolŋu think that blood pressure is a sickness. Once again, without some understanding of the biomedical story about the circulatory system, familiarity with the metaphors of quantitative measurement, and consistency in the way the term is used by staff, there is little possibility of effective communication occurring about this very crucial aspect of renal management.

Fluid

Fluid is one of the most important, but also most problematic, biomedical concepts in the context of renal management. Fluid overload as a consequence of renal failure is a source of constant struggle for many patients and between staff and patient.

One staff member explained some challenges in talking about this concept and strategies she has attempted:

- ...I developed a tool called the water story—calling it water because I thought water
- was something they could relate to and they had a word for it whereas fluid was a
- better word in our language—it covered more things but it didn't really mean anything;
- so I talk about water and then I give examples 'when you drink water or tea or coca
- cola or orange juice or beer or whatever, that's fluid, and that's what you need to
- control'; that's tied in with counting—I'd like people to have an idea of how many drinks
- they have a day but there all different kinds of cups and pannikins that they use and I
- talk about four drinks, trying to get a very basic message across—talk about four drinks.
- (interview with educator)

5. Key features of communication in renal care encounters continued ...

She also talked about the importance of understanding the consequences of fluid overload:

- ...you need to explain to them why fluid overload is so dangerous. The main things that happen with fluid overload is that you get short wind, you might have to sleep propped up at night, you might get swelling on the ankles, high blood pressure and you feel tired and dizzy—but they get all those symptoms anyway...short of breath, swelling and they're often tired. Another problem with fluid overload is that if they don't have those symptoms then they're not really interested—but I know they're fluid-overloaded and I know that their heart is working harder pumping all that fluid around their body and they're at risk of a heart attack— if they don't have those symptoms of short wind and they don't really understand high blood pressure—and they all have high blood pressure if they are fluid-overloaded—but they don't realise because you can't feel it, then if you don't have it, why would you relate to it? (interview with educator)

It is not only communicating the concepts of fluid and the consequences of fluid overload that is challenging, but also communicating related concepts in English using culturally specific constructs:

- ...The other thing is that you can't talk about cutting fluids without talking about salt intake because when you have salty foods you drink more—and a lot of people'...they put salt on the food, they use salty additives, they love those noodles, they eat lots of pies...to change your taste buds takes about four to five weeks— to adapt to low salt—that's the other thing I say to them, is that salty food or salty ones, they make you thirsty but I don't think the word thirst is good as it doesn't really describe—I say dry throat and I use other things to try and get around because you can drink without being thirsty but when you've had a really salty meal you get that parched and you want to drink but I think they are so used to salt that they don't realise it. (interview with educator)

The difficulties faced by patients in responding to medical concerns, even if patients do share these concerns, are acknowledged by some staff:

- ...And then I think there are lots of issues not just in people who come here, in the type of life style they need to maintain to stay well. I think it's very difficult for anyone, and more difficult up here where it's hot, you are expected not to drink much, because it makes you sick if you do and particular diets are thought, you know, ways of eating and drinking and living, are thought to be of benefit and they're hard to explain and hard for anyone to really understand and adhere to even if they do want help. (interview with physician)

The issue of fluid was discussed in the medical review with Njarritjan as standard practice in such encounters, although she was not experiencing fluid overload at the time. The different interpretations of this exchange, as well as a description of the exchange, provide a stark illustration of the complexities of this area of management:

- (the physician) asks Njarritjan how much she is drinking, then immediately asks more specifically, 'how much water?', and Njarritjan says, 'little bit water ga (and) tea, little bit ga bilin (and that's it)', then (the physician) asks, 'how much each day? Water, tea?' and Njarritjan says, 'Three cup, two cup, little bit', very confidently. (videotape description by researcher)

In the interview with the physician after the interaction, he gave his interpretation of their discussion about fluid:

- ...I did try and talk to her about fluid intake although she's not putting on too much fluid between dialyses and we asked her and she explained quite clearly. She seemed to have quite a clear understanding about how much she should drink; I asked her how much water and she said she also drank tea and she went into some discussion of the amount she drank. (interview with physician)

This was discussed further when he reviewed this section of the videotape:

- ...the way she talks about fluid is quite detailed compared to other people—that's amazing—when she's talking about the size of the cups and she's talking about tea and water and the numbers.

A very different picture emerged from discussions with the patient and later with her sister. When reviewing the videotape with Njarritjan and some other Yolŋu, the researchers asked her if she really drinks only two cups a day and she replied:

- **...Maybe really two cups (laughs); the whole night we drink tea (lots of laughing). They told me to have two cups of tea—I have one cup of tea but it’s a long day so how can I just have two cups of tea? I have one cup of tea then another one and drink it, then another one and drink it, then another one...**(interview with Njarritjan)

In a later discussion with Njarritjan’s sister, she explained her understanding about fluid when asked what the doctors had told her about this issue:

- **...if they drink fizzy drink the fluid goes up and they’ve got too much fluid on them... she’s supposed to have fluid—just right for the kidney—everyday to drink is water, lots of water only or tea; if we make tea with sugar, too much fluid comes in to the body and it gets too big, that means they are carrying too much fluid on them. Water is all right because water can give them strength— drinking water is good, that’s what they said, too much (i.e. a lot) water to keep the kidney flowing, (the doctor) explained—they’ve all explained about the kidneys and fluid. I know that if she gets sick I’m going to take her straight into the hospital if too much fluid has built up. I don’t know (how it builds up)—they haven’t explained that to me.** (interview with Njarritjan’s sister)

This family member would be expected to be more informed than most Yolŋu about the biomedical issues: she has worked extensively in a health field with non-Aboriginal staff and describes how she actively seeks information about renal issues and asks questions to clarify anything that is unclear. She was quite confident that she shared a common understanding about fluid with medical staff. Similarly, some staff also believed there was a shared understanding about fluid and that fluid overload was a result of conscious choice rather than inadequate knowledge about how and why it should be controlled:

- **...they know—they know that it’s important— they know that it’s bad for their heart—they do know that—it has been an ongoing problem.** (interview with renal nurses participating in the project)

Another long-term patient indicated one source of the such confusion:

- **...this is the story I heard a long time ago—that if there is somebody who has got a sick kidney you should drink a lot of water, but now it is a different story, if your kidney is sick drink a tiny bit of water.** (interview with Galikali)

Even this long-term patient with extensive renal experience seems to think that the biomedical story has changed over time, and is apparently not aware that the advice remains current but for different conditions. It is not surprising that such apparently contradictory messages—which are both common in biomedical discourse—are highly confusing for Yolŋu if the different contexts to which they relate are not effectively communicated.

Diet

Diet and the association between diet, medications and biochemical levels in the blood were central in the biomedical discourse, particularly in the education encounters. Misunderstandings—and missed opportunities for increasing shared understandings—were abundant.

The challenges in communicating about diet—and acting on any understandings that are achieved—were described by one of the physicians:

- **...And then I think there are lots of issues—in the type of life style they need to maintain to stay well. I think it’s very difficult for anyone, and more difficult up here where it’s hot, you are expected not to drink much, because it makes you sick if you do and... particular diets are thought, you know, ways of eating and drinking and living, are thought to be of benefit and they’re hard to explain and hard for anyone to really understand and adhere to even if they do want help.**

Many other examples of communication difficulties over nutritional concepts—including cultural knowledge and values relating to food, food preferences and access—are described elsewhere in the report.

5. Key features of communication in renal care encounters continued ...

Treatment

'Treatment' as 'cure'

Not surprisingly, given the limited shared understanding of underlying biomedical concepts related to renal function and failure, there is little shared understanding about treatment of renal disease.

One of the common misunderstandings with potentially serious consequences is the interpretation of 'treatment' as 'cure' by Yolŋu patients. For example, some Yolŋu believe that the fistula is a form of treatment that will cure their renal disease:

- **...I thought (the fistula) was going to make me well again.** (interview with renal patient)

Another patient's family asked when the fistula was going to be taken out. The family had thought it was a form of treatment and that he no longer needed it, as they believed he was completely well following a period of dialysis in Darwin (this patient has chronic renal failure).

The expectation that haemodialysis can cure renal disease is common—and dangerous—as one of the nurses explains:

- **...A lot of people think that if they come to dialysis all the time for twelve months or so their kidney is going to grow back and they're going home—they don't have to stay; this is why a lot of them when they come in and they start feeling better, then they go home again and then they get sick. A lot of it is communication and unless you can visually see what's going on it's very hard for them to realise that their kidney is not going to grow again and nine times out of ten this is the only way that they are going to stay alive—it's a very complex matter.** (interview with renal nurse)

The limitations in current patient education practice were also identified as contributing to confusion about treatment:

- **...I think they are so sick when they come in, they have dialysis and they start to feel really better and I don't think the education is appropriate at the time—because they are so sick they're not going to retain the information anyway...and it might be in the wrong language so a lot of that doesn't sink in, that this is life-long, and because we've never previously had a well-established education program before they've come on to dialysis, so that education is not there beforehand; so then they get better and they think that they're cured, so then they go home.** (interview with renal nurse)

Haemodialysis

Even attempting to find out what the patient understands about his or her treatment is a challenge. In the education session with the new patient, for example, the staff member attempts to do this, but her attempt fails even with assistance in interpreting her question:

- **...The educator asks, 'what do you think the machine does for you?' His sister translates this and responds, 'Manymak (good)'. (researcher's video description)**

When viewing the videotape later, the staff member explains her interpretation of what happened:

- **I've opened the interview trying to establish how much he knows about dialysis and what the machine does for him and I think that when she translated she might have said, 'how does that machine make you feel?' I thought his response indicated that he had a pretty poor knowledge of what the machine did—so instead of the question being, 'what does it do for you?', and I wanted a scientific answer, it was translated as, 'how does it make you feel?'**

This was confirmed by an interpreter who analysed this interaction:

- **...When (the educator) asks about what he thinks the machine does, his sister says:**
- **‘nhaltjan nhe ñuli dhäkay ñäma?’.** There is no real talk about the function of the machine
- **or its effects -it’s interpreted as ‘how do you feel about it?’** (video analysis by interpreter)

In the medical review with a patient who has been on dialysis for some months, the use of the English term ‘dialysis’ was also problematic. The patient did not respond to the physician’s question about whether she had any problems on dialysis but did respond when he rephrased the question using the term ‘machine’. When she talked about dialysis with the Yolŋu researcher later, she referred to it in Yolŋu Matha as ‘when we sit on the chair’.

The way Yolŋu talk about dialysis can also be confusing for staff and for other Yolŋu unfamiliar with renal care, as the English word ‘medicine’ is often used (although with Yolŋu pronunciation, i.e. *mititjin*) to refer to dialysis.

One patient recalled her first health service contact related to renal disease:

- **...they gave me medicine through the pipes, not dialysis—I didn’t know about dialysis**
- **then; they told me,—‘soon you’ll be getting dialysis, maybe in Darwin, maybe in Gove’**
- **and I was thinking to myself, I wonder what dialysis is...**(interview with Galikali)

She described her current understanding, many years later, about dialysis:

- **Whenever I get dialysis it washes our blood; and it goes down the pipe and walkulum**
- **(drains out); through one of them it goes down and it cleans it that little kidney thing,**
- **and what happens to the rubbish—it is walkulum (drained out) down the other pipe, it**
- **goes off because it’s bad; and then we drink water and it gets more, like that.**

When a shared understanding is achieved the outcome can be very positive, as one family member described:

- **...when we came to Darwin it was good communication with the doctors and nurses at**
- **the hospital because they were telling me everything about (my sister) and what was**
- **going to happen in the future about the machines, if she’s going on the machine everyday**
- **it will help her, if she doesn’t go on the machine, if she misses it, something’s going to**
- **happen, like dying, that’s what the doctors said. They told us that the fistula was for the**
- **machine, twisting two gurrkurr (blood vessels) to put her on the machine because**
- **there are only two pipes to go into her arm—one is to get the blood out into the**
- **machine and one is to get the same blood, her clean blood, to come back into her body;**
- **that’s what the doctor explained and she said that was good, she wanted to have dialysis.**
- (interview with patient’s relative)

Achieving an integrated understanding of all the biomedical concepts related to renal care and how they interrelate is a challenge but essential so that patients can make an informed choice about treatment:

- **...they need to know how the results relate to dialysis because some people think that**
- **it only removes fluid not toxins, so if they haven’t got extra fluid they think they don’t**
- **need dialysis.** (interview with renal nurse)

Achieving a greater shared understanding about the Yolŋu perspectives of treatment is also essential for achieving optimal provision and uptake of treatment. The Yolŋu discourse about dialysis focused predominantly on the proficiency of staff in inserting needles, not surprisingly since this a potentially very painful procedure that patients have to endure three times a week, every week, probably for the rest of their lives. Yolŋu also expressed their concerns that, when nursing staff talk to each other when carrying out dialysis procedure, they may not be concentrating sufficiently on what they are doing.

Another important aspect of the Yolŋu experience of dialysis is their relationships with the nursing staff. This was a common topic in the interviews and informal discussions about dialysis. For example, some patients fondly recalled staff members who had left the unit many years ago and talked in great detail about their relationships with current nursing staff. The other Yolŋu priority in discourse related to dialysis was their strong and often quite desperate desire for dialysis to be available in their communities (see below).

5. Key features of communication in renal care encounters continued ...

Another area of communication difficulty concerned the reasons why patients might miss dialysis. There appears to be little opportunity for the depth of discussion to occur between staff and patients that could enable them to develop a shared understanding of issues affecting treatment uptake. Some of these issues have been discussed in other sections and include fear of the treatment itself; fear of staff recriminations, for example when a patient has been drinking alcohol; withdrawal from treatment due to distress over a death in the family or protest over lack of family support; or simply organisational barriers such as transport problems:

- **Narritjan is missing a lot of dialysis because the gate isn't open for the bus to come in. Sometimes the driver just sits there without going in— to say the name of the person aloud so the person knows—he just bips the horn; sometimes she is fast asleep and can't even hear the horn or anyone saying her name—that's why she misses dialysis.**
(interview with family member)

Peritoneal dialysis

Peritoneal dialysis (PD), an alternative treatment to haemodialysis, is available but few Yolŋu take advantage of PD, even though it could theoretically allow them to go back to their communities. Two extracts from the interviews—one with a renal nurse and one with the only patient involved in the study who had experience with PD—are presented below to illustrate the different perspectives on the advantages and disadvantages of PD:

- **...a lot of people don't like the PD—the other treatment option which would then allow them to actually go home and dialyse at home. There is a story around there that it gets infection and you die straight away and we can't establish where that story comes from. To our knowledge there haven't been any Yolŋu on PD who died.—Galikali went on it and she got a few infections but that's not why she changed. She changed because she wasn't getting enough dialysis—she wasn't getting enough regular bags, she had a lot of family, children and grandchildren around when she first moved to Darwin so she was getting very tired, so she wanted to go back on the machine, which was fine. Other than that when (another Yolŋu patient started on PD) a lot of people came to her and said she was going to die, that she's not going to stay well and she'll get sick; so there is that, which is a sad option because if in their culture they believe that is a really bad option for them—at the moment that is the only one that is financially available that could get them home if they want to dialyse in community; they just need a clean house, supplies get flown in; they just need a sink to wash their hands and they could live at home.** (interview with nurse educator)

The Yolŋu patient described the PD process in great detail and then explained some of her concerns and difficulties with this treatment:

- **...I got it in 1995. I changed the bag every four hours, four times a day, everyday: 6.00 in the morning and 12.00 and maybe 3.00 and, later, 9.00, then sleep, then wake up at 6.00 next morning—hard work; one woman got (PD) and took it to (her community) and she died. I don't want my stomach to be cut, cut all the time—I had it for PD and I don't want anymore; maybe she missed the machine—maybe she went visiting and hunting and camping and missed using the machine...**
- **...then one day I forgot to change my bag and then I started to get crook—my feet were swollen, my face was swollen, I had to crawl—problem with my children—we were all staying in that house and also two old ladies (including) my mother and they said, 'why are you crawling around?' and I said, 'I forgot one bag and now I'm sick', and my mother said, 'how about you change back to normal dialysis', and then I rang one man who speaks good Yolŋu Matha (we taught him). I told him and he told the boss and I told (the renal physician) I would like to go back to dialysis and I wanted the bag taken out.**

I had it for three months and it was going well until that one day and also I had to sit there at home looking after my body without going hunting; if I had that for a long time and forgetting it sometimes it would have got worse and worse because it was hard to remember because I was interested in playing cards and going hunting—it made my life more difficult than (haemo)dialysis.

...they wanted me to go back (to the community) when I had learnt the system properly, then they would have let me go home.—They sent one man back to (his community) on PD and now he is back on dialysis; a lot of people on bags come back to dialysis.... (PD) made me heavy—I didn't feel as well as on dialysis—that's my experience with that bag; no other Yolŋu (tried it) only myself and yapa (sister)—others don't want it—I don't know why, it's their decision.

She then talked about some of the barriers to returning to the community with PD:

For people going back to (the community) the problem is the housing. If they build a new house for that person to go back—but only the person with the bag and the spouse and children could stay there, and the house would be kept clean, and not too many people using the toilet. If the brother goes and lives in that house it would be difficult for the woman to do the work she needs to do—if it is only the woman, her husband and her children, that's okay, but if there's mirriri²⁷ (woman's brothers) then it's too hard—anybody else, that's okay; if I tried to go back and there was no house, I wouldn't go because there is not enough housing—even if there is a dialysis machine there I wouldn't go if there isn't a house available.

Again, there are few opportunities in current practice for meaningful dialogue between staff and patients about issues of crucial importance in ensuring optimal services and access to appropriate treatment options.

Medication

Shared understanding about concepts related to medication was extremely limited and even the ways in which staff and patients use and understand the English term 'medicine' is very different. This was explained by one of the patients:

...Yolŋu say 'medicine' if you swallow it through your mouth or put it on a sore; if you give it through an injection it's called 'djektjin'. (researcher's note: not medicine)

The Yolŋu patients also used the term 'medicine' to refer to substances such as phosphate, although when asked about her understanding of this term one patient was unsure if phosphate was a 'medicine' or a 'poison'. Confusion is therefore inevitable when talking about the action of medications on the chemical components of blood if Yolŋu use the same term to refer to both medications and other chemicals.

Examples of miscommunication related to the names and functions of medications used in renal care have been described elsewhere. The extent of this problem is illustrated even more vividly in the following extract from an interview with a long-term renal patient. This patient, who has a high level of fluency in conversational English, talked about her knowledge of the names and actions of her medications:

...I've forgotten all their names. I can remember one or two—Caltrate— we take two with food three times a day, morning, dinner and afternoon; the Caltrate brings down the levels of phosphate if they are too high; (phosphate) makes you better again, no, it makes you bad, if we don't look after ourselves with the Caltrate, if we don't take it, the thing called phosphate will reach high levels and hit our head—give us brain damage'...

...I don't really know what their (the other medications) names are: there's Caltrate, that's the one I know best, and magnum—the medicine called magnum is like this, orange— when we take that, it's a separate thing for our hearts and we eat it so we can walk for long distances but whenever I take it my head goes a bit crazy and spins around. I become dizzy, my head spins around; I'm sorry I don't know the names of the other medicines; you know—you're a Balanda!

²⁷ There are very strong restrictions on what a Yolŋu woman can do and say in front of anyone who is classified as her brother according to the Yolŋu kinship system and these restrictions are still widely respected by Yolŋu.

5. Key features of communication in renal care encounters continued ...

The patient did not mention any of the medications administered by injection, which, as she later explained, was because she was asked about medicines, the term used by Yolŋu only for medications taken by mouth or applied to the skin. When asked specifically about medications given by injection she replied, ‘

...One injection, EPO; and what else?’ Another of her regular medications is Heparin, an anti-coagulant given to prevent blood clotting, which is administered directly through the tube while the patient is on the machine:

- **if the Heparin hadn't been doing its job properly the blood would just keep going through;**
- **that's the story about Heparin. They put it through the tube and they keep it there—to**
- **make the blood flow less strongly so that the blood doesn't go too fast—so the blood**
- **doesn't flow too fast.**

The patient's understanding that this medication has an action that is opposite to what is actually the case had never been identified—and therefore never rectified—during her many years on dialysis. Her suggestion that there needed to be better education about medications, particularly for new patients, could ensure that the poor education she has received is improved:

- **...the doctors need to do more with the new patients to explain things properly—it's**
- **not so much for those of us who have been here a long time; they need to really think**
- **about the new people because they are very worried—they always sit in there with**
- **worried heads so it's up to me to help them. We need more information— they need**
- **to talk more and explain more when I'm lying on the bed—they should talk about all**
- **the different medicines and say, 'look, this one here is Heparin and what's it going to**
- **do? It's going to stop your blood, and this one is EPO and you're going to get this for the**
- **rest of your life.'** (interview with renal patient)

The patients' extremely limited understanding of their medications was not simply due to lack of information about the medications themselves. It is clear that such information has little meaning without first achieving a shared understanding about how the body works, the nature and causes of renal disease, and the connections between food intake, the biochemical components of blood and the ways in which the various medications act on the body.

There is a strong expectation that patients will take their medications as instructed and staff express frustration when this does not occur. As long as patients are unable to make an informed choice about treatment, however, this is simply a matter of trust:

- **...all comes to a bit of trust—take this and you'll get better—yeah, right...**(interview with renal physician)

This is problematic even in a culture that has a tradition of 'compliance' with medical advice, but it is seriously inadequate for patients from a culture that does not. In 1971 Hamilton recorded the following observation about Aboriginal health care, which unfortunately remains just as relevant to current practice:

The communication difficulties between medical staff and Aborigines are not merely a result of language difficulties: in order to give meaning to medical instructions and the reasons for them it is necessary to find concepts which overlap the two cultural systems. If this cannot be done the result is simply a chain of apparently arbitrary orders and a kind of bullying to see they are carried out. (2)

Key concepts in renal care: the Yolŋu priorities

There were very few opportunities for the Yolŋu patients to initiate or influence the topics of discussion in the interactions, and the issues of concern to patients, mostly expressed through the interviews, were very different from those of central interest to the staff. It must be noted, however, that the interactions in this study were all concerned with medical management and it is likely that interactions with the social worker and Aboriginal Liaison Officer are very different.²⁸ Encounters with these staff members are often initiated by patients to deal with issues about which patients are concerned. As a consequence of the compartmentalised approach to management in this setting, non-medical aspects of patient care are segmented from the biomedical aspects and excluded or marginalised in medical interactions.

Most of the concerns that emerged as Yolŋu priorities primarily through the interviews and informal discussions were social, cultural and economic. This project did not attempt an in-depth analysis of Yolŋu perspectives overall, although this is clearly important for improving the quality of renal care. The following discussion is concerned only with the extent to which a shared understanding was evident about non-medical concepts related to renal care, and the relevance of such concepts in the interactions, which were the focus of this study.

Leaving home/ going home

Many of the issues of importance to the Yolŋu participants related to the consequences of forced relocation. These issues were recognised to some extent by staff, but there was no opportunity for the complexity of these consequences and the depth of trauma experienced by patients and their families to be expressed through these interactions. These are some of the perceptions of staff, expressed during the interviews, about what is important to Yolŋu patients:

● ...I think there are profound barriers and fears, the way I perceive it, for Aboriginal people from remote areas in coming to Darwin to have treatment and to be explained, you know, to discuss with health care workers about what's wrong with the kidneys and changes required to their lifestyle because they have kidney disease, in order for them to survive. I think...a huge problem, and I think it's one, it's a big issue. There are key issues relating to, that the way we have offered treatment in the past and still probably now requires that they move (from) their land and their family and their community, and I perceive that as being very distressing to them. So people's families often visit here but that's obviously not an answer. And there's lots of issues where people say to us they need to go home to attend functions of, you know, significant ceremonial functions and things that have been seen as...I'm not saying this service is worse than anyone else, in fact there are many ways it's very aware of this. They have been perceived as people not complying with treatment and etc., in fact I think in many ways the renal service knows that that is important and tries to come up with ways around it, but it is really hard with renal disease because people, many of them on haemodialysis, need to be treated regularly. So it's a very big issue. So I think separation has a profound effect on the people, on the patients and on their emotional health and probably their physical health. So I think that's one big issue. (interview with physician)

● ...relocation to Darwin, the changes in culture, the changes in money—where the money comes from, like the pension if they're not on the pension in the community, having their family with them; housing is a huge problem; there's a huge waiting list, the hostels are always full—and the food—if they've got all their family—they don't have access if they don't have enough money; they don't have access to their community food, like hunting, so they've got just the food here which can be quite expensive, the expense of living in Darwin compared to the community—they find it a huge strain because they've got (a) power bill, phone bills, shopping bills, they're using taxis, their money just goes and they've got no money for the rest of the fortnight for food, so the social worker and (Aboriginal Liaison Officer) are always working out money and social problems—it's just huge. (interview with educator)

²⁸ There was an intention to include an interaction with one of either a social worker or Aboriginal Liaison Officer. However, at the time of data collection both positions went through a change of staff and there was no opportunity for their inclusion in the videotaping of interactions.

5. Key features of communication in renal care encounters continued ...

- ...They want to go home. In the context of end-stage, it's dislocation, no family, no support—fear, terror, get on (the machine) and people die—never go home—they've been given a death sentence...If you are in the community—these people get renal disease, they go to Darwin, you might see them once or twice and then they die and they go home to be buried—you just die on the installment plan which is what renal medicine is all about. (interview with physician)

And another staff member bluntly observed:

- ...while you're on dialysis you're not normal—you're sick but you're just not dead ...

The burdens of chronic illness and relocation are often common to more than one member of the family, stretching resources and support systems even more:

- ...there is always someone that they know, which is sad but good, so there's someone else in their family with renal failure or someone married into their family. (interview with educator)

The same staff member also commented on another consequence of cultural dislocation:

- ...I think when they've been here a long time—especially the younger patients—they really miss out on learning how to cook; that they're here so long and they're away from the training that would go on—especially the women, and they don't always know how to cook the way their mothers or their grandparents do.

Such missed educational opportunities would be expected to go far beyond knowledge of food preparation and deny patients the opportunity to develop knowledge in many other aspects of Yolŋu life.

The issues identified by these staff as important to Yolŋu were certainly consistent with those expressed by Yolŋu. The experience of one patient illustrated the stark reality, shared by other Yolŋu, as she talked about some of the problems she had to deal with as a result of living in Darwin:

- ...I told her (the staff member) the truth—that I wasn't getting enough (food); like this time, this week, when I get my children's allowance, they take all the money for accommodation and leave only \$30 for food—that's not enough; (in the past my husband) used to go out fishing and all my children used to help me with the money and I used to buy food from the shop and there used to be plenty of food all the time; they were drinking only alcohol before but these days they are drinking and smoke marijuana too— that's why they keep money for themselves; (husband) isn't hunting now because no one is helping to pull his boat with the car. Before, he used to have lots of friends living nearby who liked going out fishing with him (they lost their house and moved to a hostel in a different suburb). ...When I put (food) there to feed the children, (my adult children) with alcohol and marijuana, they go and eat it all—I can't even talk to them—I've got no strength to talk to them...all I've got at home at the moment is flour, sugar, teabags—no meat or anything and there is no money until next week, my husband is going fishing tomorrow and I asked him to get more fish...(interview with Galikali)

One patient explained that her adult children were in Darwin only because she was there for dialysis: if she could be in the community they would also stay in the community. In that year she had lost a son and a nephew: both were living in Darwin only as a consequence of Yolŋu needing to relocate to Darwin for dialysis. The focus in medical encounters is consistently on the physical dimensions of the renal experience and management, and even when questions are asked about more general issues, such as eating and sleeping, they were in connection with their physical state rather than in the wider context. For example, when one patient responds to a question by describing an emotional problem, the staff member responds sympathetically but the sleeping problem and its causes are not pursued.

Galikali tells the nurse educator about her eating patterns and what she likes to eat, then they talk about sleeping. Galikali describes her problem with sleeping because of thinking about her son who recently passed away. The nurse educator then asks about going home and Galikali is telling her when she will go, when the nurse educator notices a sore on Galikali's arm and reaches across to touch it. (researcher's videotape description)

Even when staff members acknowledge the influence of the social and cultural dimensions of the patients' experiences on their renal management, there are challenges in knowing how to talk about such issues:

- **...the other communication problems are when patients are not turning up to dialysis you want to know why not, but how do you make that non-judgmental and non-threatening? Because there might be family issues and social issues that interrupt their treatment, which we want to make known to them that if they ring us we can rearrange their dialysis. But I think the non-judgment needs a lot of work as a lot of patients feel judged if they don't come.** (interview with nurse educator)

Stingray and White clay: Yolŋu ways of managing their renal disease

There were no explicit opportunities in any of the interactions videotaped for this project for Yolŋu to discuss their own approaches to managing their health. In two of the interactions the patients attempted to talk about their knowledge and management practices (related to Yolŋu food) but these attempts were either not understood or not acknowledged by the staff members.

In the interviews and informal discussions that occurred during the project, Yolŋu participants often discussed at great length and with passion the value of traditional Yolŋu foods in maintaining their health. Creating opportunities for hunting and gathering of their preferred foods is a central concern for Yolŋu living in town, both dialysis patients and their family members. These opportunities are highly variable and limited primarily by access to transport (either having the minibus fare to Buffalo Creek or finding a car to pull the boat owned by one family member from the hostel to the water), and some of the patients were also limited by their physical capacity to participate. When the researchers visited a remote community during the project, there was some contact with pending patients who appeared to be staying relatively healthy despite their chronic renal failure. Other Yolŋu attributed this primarily to the pending patients' high consumption of appropriate Yolŋu foods and the exercise involved in hunting and gathering these foods.

Another strategy—self-medicating with white clay—was also described as highly prevalent amongst the Aboriginal patients of the Renal Unit as well other Yolŋu with health problems:

- **...all the dialysis patients like to eat clay and also pregnant women and some children like it very much—when I feel weak I have clay and then I feel better: strong, healthier—walk around, wash clothes. We used to eat green clay but that was hard for our teeth—it's like rock and we dig it out from the salt water in front of old hospital. Sometimes people sell clay at card games—it comes from Groote and Goulburn—it gets stuck in your throat—and Darwin—it's just right—people from Galiwin'ku like Darwin clay best. They ring up for it and your märi (maternal grandmother relationship) sent two boxes and people paid \$20 for one bag—hard work to collect it—she digs it out then sits in the shade and cleans it up with a knife then it's dried in the sun to make it white, then it's packed and sent away.** (interview with Galikali)

Although the use of white clay is a common topic in the Yolŋu discourse about managing their illness, there is little awareness of this amongst staff. One of the reasons for this is the lack of opportunity for Yolŋu to express their health-related knowledge and practices in renal encounters. It is also likely that past experiences of medical disapproval of the practice inhibits such sharing of information.

5. Key features of communication in renal care encounters continued ...

Supernatural agency

Surprisingly, sorcery was not identified as a cause of renal disease, even though sudden death and many other illnesses are frequently attributed to sorcery. When this was discussed with two long-term renal patients they were adamant that renal disease is never due to sorcery, but this may not reflect the views of other Yolŋu, particularly those without renal disease. Supernatural agency within a (partially) Christian framework is, however, a strong theme in Yolŋu discourse about curing sickness, including renal disease.

Some of the Yolŋu participants expressed strong convictions that there had been, or would be, supernatural intervention in their renal disease. One long-term dialysis patient believed that:

- **...one day I will be off from machine—that's my faith.** (interview with Wurrapa)

A family member of another patient reported that her sister was improving according to the doctor at her sister's last medical review. She said the doctor had told her the test results showed that the kidney was working:

- **because of my prayer, I put my trust in God and that's why...**(interview with Njarritjan's sister)

Although such beliefs were not expressed in the medical encounters, the nurses on the floor were aware of their importance to Yolŋu:

- **...(Yolŋu) are very religious. ...even (a young male patient)—said to me once that so and so went home and he's okay—and he's dialysing okay because God's looking after him—he brought it into the conversation—the East Arnhem people are really religious compared to (other Aboriginal people).** (interview with renal nurse)

The complex interplay and potential conflict between belief systems was powerfully illustrated during one of the encounters in which a Yolŋu woman, although not a trained interpreter, assisted the physician in communicating with the patient and his family. This section of the video was analysed with the assistance of an experienced interpreter who summarised what the Yolŋu assisting the physician said to the family about the patient's current status and prognosis:

- **...she's saying 'yes, you've heard the story from the doctor, your body is good, the blood test is showing that both kidneys are falling, dropping (presumably in function) but don't necessarily believe that there is no hope—have faith in above, believe in him'.** (interpretation of video data)

A Yolŋu woman who was also assisting with the video analysis explained what she thought was going on:

- **she is rejecting doctor's story, maybe because a lot of Yolŋu believe in God...when we get sick then we can pray to the Lord, God will give us comfort, a lot of Yolŋu are using these words in the hospital with sick people—we have to trust the doctor and God, both ways because the doctors are working to make Yolŋu healthy, that's how Yolŋu feel, prayer—tell Him what sickness the person's got...sometimes Yolŋu reject the doctor's story and let God's power become greater, sometimes Yolŋu get the information from the doctors and get it into their heart but there is someone above that can make their fear invisible.** (interpretation of video data)

There was considerable discussion between the researcher and the interpreters who were assisting with the analysis about what was actually being communicated to the family and why. The Balanda interpreter suggested that his understanding of her (possible) intended meaning was that:

- **...she's saying this is a story that the doctor is telling you—it's true but it's not the final thing, the most important thing is that you have your faith, that you believe in God, that you find comfort in God, yes, accept that story but don't believe it is the only answer. God is the answer, God will comfort you.**

He suggested that the meaning may be ambiguous to the family members, who might have interpreted her meaning differently, but this could not be determined from the video data.

Fear

Fear is a common theme in the Yolŋu experience of renal disease and treatment. For one patient, fear prevented her going to the doctor to find out why she was sick until she reached end-stage:

- **I was feeling really bad as I have described but I didn't want to talk to the doctor about it. I felt general malaise right through my body and I didn't want to go to school to work and I didn't want to walk very far, certainly not long distances...I was worried but I wasn't thinking that I had this kidney problem; I thought I had something wrong in my back or up in my chest but I didn't know it was kidney...I didn't know what was wrong and I was frightened of the doctor.** (interview with Galikali)

She explains how this problem of avoiding or rejecting treatment could be addressed:

- **Yes, it's good if I can tell them about my own story and what happened to me and how I went on to start getting dialysis—and so those Yolŋu sitting there all look at me and some are actually frightened—they think dialysis might be anything at all, they might get it and die; and so when I tell them, their heart and their emotions settle down and they're not frightened.**

During one of the interviews a group of women, including Galikali, recounted a story about another patient's experience:

- **Njarritjan was very frightened so (a group of women) came in to talk to her at the hospital, telling Njarritjan that they were there to help and that her kidneys were dead—both of them—and she said she didn't want the fistula so they asked her if she wanted to die and she said, 'yes, it doesn't matter' and (her sister) was upset; Njarritjan's sister told Njarritjan that if she refused to do it she wouldn't look after her but would go back to her community. We (the four women) kept trying to help and other also came to help. Her sister asked Njarritjan if she wanted to get better and she sat quietly— then she said 'we'll all go and you can all have the operation first' (lot of laughing and joking); next day (some people) came to talk to her and prayed and then she said she would have the operation—then she changed her mind...**

The patient's sister explained that Njarritjan finally agreed to the fistula only because she ran out of cigarettes and no one would give her any until she had the operation.

During this study the Yolŋu researcher was often involved in supporting other patients, often her own close family members. Some came to Darwin for a fistula, others arrived already very sick and needing immediate dialysis, and some continued to struggle even after long-term treatment. It is a distressing and demanding role and the need for her support is increasing with the rapidly rising number of Yolŋu with ESRD. The experience of such patients and their families was vividly described by one of the physicians:

- **They want to go home. In the context of end-stage, it's dislocation, no family, no support—fear, terror, get on (the machine) and people die—never go home,—they've been given a death sentence. If you are in the community—these people get renal disease, they go to Darwin, you might see them once or twice and then they die and they go home to be buried—you just die on the installment plan, which is what renal medicine is all about.**

5. Key features of communication in renal care encounters continued ...

Quantification and other metaphors

In the previous section the very serious limitations in shared understanding about key concepts—for both staff and patients—were clearly illustrated. Not only specific topics and terms were a source of difficulty: the use of metaphor, which is common but very different in both biomedical and Yolŋu discourse, was also important in contributing to miscommunication.

Quantification, for example, was a constant source of difficulty. Many of the key biomedical topics are expressed through quantitative metaphors, for example percentage of function; relationships between different quantities, like the patient's weight in fluid as opposed to muscle; the amount of certain foods consumed and the amount and frequency of medications and blood test results; length of visits home/time without dialysis; fluid consumption and body fluid retention; high and low blood pressure; and high and low blood test results. Litres and millilitres, hours and dates, grams, kilograms and percentages have little if any relevance in the experience of most Yolŋu and the Yolŋu ways of expressing quantity and spatial and temporal concepts and relationships are completely unknown to staff.

A clear and shared understanding of the terms and metaphors used in talking about these concepts is crucial to ensure informed choices, effective management and optimum health outcomes and yet this was rarely, if ever, achieved. The many examples of miscommunication related to quantification described above repeatedly demonstrate this. These difficulties are further expressed in the following extracts from the interview and video analysis conducted with one of the staff members as she struggles to understand the difficulties associated with talking about quantification and how to deal with these challenges. Her experiences vividly illustrate the problems that are common in any encounters between staff and patients that require quantification.

The participating staff members were all aware to some extent that quantification can be a source of difficulty in communication, but their understanding of the complex linguistic and cultural reasons for this was generally very limited. The educator describes her confusion about what she perceives as inconsistencies in understanding of quantitative concepts:

- **it makes me feel a bit futile when I talk about numbers because if there is more than one there is no difference between two or three or more. There is one or big mobs...**
- **what doesn't make sense to me is that I know that they are quite good with money and I know that they can count money...**(interview with educator)

Earlier sections of this report describe numerous examples of patients attempting to respond as best they could to the many questions posed by staff that relate to quantification. In another example, the educator asked the new patient about his weight and he responded by listing some numbers in a genuine attempt to accommodate the educator's request. It was clear, however, that he had no idea what his weight was. The staff member persevered regardless, even though a shared understanding of the central concept in this discussion—body weight expressed in kilos—did not exist. The staff member described some of the difficulties she encountered in this and other situations where she attempted to talk about body weight:

- **I think (the patient) is just repeating numbers and this is what happens sometimes when I say to them what is their weight on the scales—they know that I want a number and sometimes they just give me numbers and he's just rattling off numbers—that is not always typical—he is only a new patient; once they've been on for a while they do actually know their number but they know the number that they should be but not the number that they come in at because it's drummed into them 'your ideal body weight is x'. (interview with educator)**

In other interactions some of the more experienced patients had indeed learned which number was an appropriate response to a particular question. Further discussions revealed, however, that there was little understanding of what the number represented and, therefore, of the health implications of changes in the numbers or relationships between interventions and these numerical levels.

The same staff member expressed similar difficulty with discussions about quantities of food that patients consume and why it was so important for effective management:

- **They've got no idea—or what I perceive as no idea—of telling me how much they eat—the quantity. If I was to ask an Anglo-Saxon, 'how much meat do you eat at a meal time?', they would be able to tell me, 'as big as my palm and fingers' or 'two small lamb chops'. Never once do they say, 'I eat half a kangaroo'—they just say 'roo or wallaby or turtle—I don't know if it's a (freshwater) turtle or a sea turtle—and I go further into it but I don't get any further—because I'm concerned about how much protein they're getting because they need extra on dialysis and it's worked out on body weight and I want to be quite proscriptive in the treatment that I give so that they are meeting their requirements but it's very hard to work out how much they're eating because they eat together.** (interview with educator)

Meaningful communication about quantity is crucial also in management of fluid (see above). This staff member describes the extent of inadequate fluid management in this patient group and the struggle she has had in trying to develop strategies to improve her communication about this concept in which quantification is central:

- **one of the biggest problems is fluid overload—basically if they have more than five per cent of their ideal body weight taken off (in a dialysis session) that's deemed fluid overload and about fifty-four of our patients in January when I did the statistics were fluid-overloaded and that maybe about three or four litres taken off in dialysis and that's quite a lot of fluid; so I developed a tool called the water story' ...I'd like people to have an idea of how many drinks they have a day but there (are) all different kinds of cups and pannikins that they use and I talk about four drinks, trying to get a very basic message across...**
- **...something I discovered when I asked a group of Tiwi to teach me how to count to ten and they had to look at each other to confirm whether they were saying the right words and when they got to nine they couldn't actually think of a number and they said they'd get back to me, so all that did was highlight to me that numbers aren't very important to them—you ask any five-year-old and they can count one to ten in our culture, whereas to them, they said seven was the same word as axe because of the shape of it ... and I've heard somebody else—because you listen to other people—say that they only count up to four—like four is useful, after four it's not so useful but I don't really believe that because they all know money and they're very quick to tell if they're ripped off, so they must know how to count money; but when I say four drinks to them and hold up four fingers, you don't get that registration in the eyes whereas with other things you do—I don't know what to do about that but there may be clearer ways than numbers...**
- **...and then I went to practical things—I use a jug and I use a soft drink bottle size because I was reading that you work on things that they are already associated with—even if they don't drink soft drink they know what a soft drink bottle is—I use that and I use the cups that they would use and I pour water in and it gets fuller and fuller and fuller...**

The challenges of applying Western concepts of time and routine are another barrier:

- **and the other problem is that the literature says you should drink 1.5 litres from the end of one dialysis session to the start of the next, which is a day, but to them that is not a day—a day is when the sun comes up ... their day is interrupted by them coming here and they often don't eat anything before they come, then they're on the machine and then they go home so it's very hard to say, 'you can have four drinks' or this much in the jug in one day, because their day is so broken.** (interview with educator)

5. Key features of communication in renal care encounters continued ...

An understanding of the complex relationships between different quantities and the implications of this information for health outcomes is extremely important if patients are to make informed choices about management of their renal disease. Achieving this, however, seriously challenges the communicative capacity of staff:

- **Sometimes by this stage they can tell you their own body weight because they are weighed every day they come in. He was rattling off numbers so I think he was thinking I was asking him could he count...He wasn't able to tell me his weight but when I said forty-one kilograms it did ring a bell and I was saying weight goes up quickly over ninety days, but it's fluid gain. And that's not what we want, we want gradual increase in weight and, you know, muscle.** (interview with educator)

The effort to achieve more effective communication, and the frustration in trying to do this without appropriate training for this communicative context, is clear from these interview extracts. Similar feelings and experiences were expressed by other staff members. Current attempts to use meaningful metaphors have so far met with limited success, for example:

- **that's why you come back to say it's like an oil filter in a car—they may have pulled a car apart and they may not have...**(interview with physician)

Other attempts have assumed a shared cultural knowledge that does not exist, such as using the analogy of a tea strainer, which is a rare sight in remote communities, to talk about kidney function; or describing the early placement of a fistula as 'insurance' against a sudden deterioration in kidney function that would require dialysis.

There is an urgent need to find more effective ways to communicate such information, which patients can access as they need it to make informed choices about their renal care. One of the physicians gave an example of one strategy he believed would be useful in communicating about blood pressure: using more concrete visual representation and demonstrating the cause–effect relationship between the numerical measure and medication:

- **...(use a dynamak) machine so it shows it and when (blood pressure) is high (you say) 'take your tablets for a day or two and come back and we'll actually show you what it is when you're taking the tablets'.—You've got to have the community do it and they can't afford to have a dynamak—it would be a very good small project to do to look and see if someone measures your blood pressure and tells you what it is and then gave them the visual readout, go away, take your tablets, come back in a couple of days and do it yourself and see what (happens) —not too hard.** (interview with physician)

However, this still assumes a shared understanding of the circulatory system and the consequences of abnormally high blood pressure. Development and evaluation of strategies that comprehensively address these communicative challenges is a central aim of Stage 2 (see Attachment 1).

The use of metaphor is a powerful and widely utilised communicative tool. There are problems, however, when people using metaphor in biomedical discourse fail to recognise the extent to which metaphors are culturally specific and not necessarily meaningful to patients from a different cultural background, even if they may use and understand the individual words.

In Australia, health staff make extensive use of a machine metaphor when talking about the body and its functions, comparing the body to 'some sort of machine prone to breakdown but capable of repair by injections, manipulations, incisions, and replacing and mending parts' (Pauwels 1995:172). Pauwels suggests that the solution to these potential areas of miscommunication is not to list all possible health beliefs and associated metaphors for different cultures. Due to the many variations within any culture, such an attempt risks over-generalisation and cultural stereotyping. Health staff members do need to be aware of, and sensitive to, potential differences and to reflect on how their own use of language may be open to different cultural interpretations.

As part of a careful educational process, however, an understanding of the cultural dimensions of metaphor can also enable much more effective communication between cultural groups if metaphors from the target culture are used to help explain concepts from the other culture.²⁹ Just as this strategy can be effectively used in education approaches about biomedical concepts with Yolŋu, there is also potential in using a similar approach to assist health staff to better understand Yolŋu concepts. Such a process can only be effectively realised through a close collaboration between members of both groups, with a constant awareness of the ontological and epistemological diversity (e.g. differences in ideas about the nature of reality and of knowledge) among both health staff and Yolŋu.

Another crucial aspect of this is the general reluctance (or perhaps a lack of awareness) of health staff to admit that the Western biomedical theory, and especially quantification itself, is saturated in metaphor. In the example of the dynamak machine, the readings of the machine actually provide an analogue for the blood levels (not necessarily mediated through quantification at all). Staff may think that the numerical value is the objective truth, and the machine indicator is the analogue. But this is in fact not the case. The numbers are the metaphor and the machine readings may in fact provide a better metaphor.

It may be that the objectivist assumptions of the health practitioners actually prevent them from further and more actively exploring the possibilities of developing shared metaphors with each other and with their patients. One of the strategies in Stage 2 is to assist health practitioners to critically analyse the nature of the biomedical model, and to identify ways of working that model together with other models.

²⁹ For further discussion of this approach see Trudgen 2000.

5. Key features of communication in renal care encounters continued ...

Different ways of talking

The earlier sections have focused on the semantic dimensions of language as a major source of communication difficulty in these interactions. However, the sources of miscommunication went well beyond the semantic domain. Scollon and Scollon (1995:xiii) suggest that, from their research experience, 'the major sources of miscommunication in intercultural contexts lie in differences in patterns of discourse'. Similarly, Pauwels (1995) suggests that it is crucial that all participants in health care encounters become aware of differences in communication routines. Some of the communication routines, which are common in health care encounters that are based on a biomedical approach, are particularly problematic when Yolŋu patients are involved. A few examples are described below to illustrate some of the communication difficulties that relate to cultural differences in communication routines.

Giving and receiving information

In different cultures there are often important differences in the ways that information is shared. These differences relate to cultural beliefs about the nature and production of knowledge as well as preferred discourse styles, which structure interactions concerned with sharing information.

Question and answer routines

Question and answer routines are a central feature in biomedical discourse. Such routines are not, however, a common feature of Yolŋu discourse, particularly in relation to sharing information about highly personal topics. In contrast, Yolŋu favour highly detailed, even-focused narrative when sharing information about their renal experiences, although this only occurred in the interviews, as opportunities for Yolŋu to influence the structure of interactions were almost non-existent.

The question and answer approach to information sharing is complicated by a number of factors affecting Yolŋu, including conventions about who has the right to ask for or give specific information, which may be quite inconsistent with Western cultural expectations. This is also important—and often problematic—when considering who has the right to give consent for medical intervention, as it may not be the right of the individual alone even where adults are concerned.

Many of the difficulties related to the question–answer routine found in this study were also described by Cooke (1998) in his study of Anglo/Yolŋu communication in the criminal justice system. Cooke explained that a 'vener of adequacy in communication is often achievable through...collaborative discourse, verbal scaffolding, prompting replies, and exploiting gratuitous concurrence' and served to mask English insufficiency (Cooke 1998:340). All of these features were also common in the interactions between Yolŋu and health staff in this study and contributed to the masking of miscommunication described earlier in this section.

When 'yes' means something else: gratuitous concurrence ...

In Yolŋu discourse it is generally considered impolite to directly contradict or respond negatively to the questions or propositions of others, particularly in encounters of unequal power or when the participants do not have a close relationship. This communicative feature is also related to the Yolŋu orientation to knowledge production, which is fundamentally one of negotiation. No matter what the other person says, it is best to agree with them if possible, just to keep open the possibility of a negotiated agreement further down the track. It is a principle of Yolŋu negotiation that has its underpinnings in a particular epistemology (see Christie 1994). Yolŋu therefore expect that the other party to the negotiation (i.e. the health professional in this case) is also struggling to build agreement from diverse perspectives, an expectation that is not necessarily warranted when the health professional has a very different epistemological orientation...

The Yolŋu patients without exception all worked hard within the interactions to accommodate what they perceived to be the staff members' requirements. As a result patients gave the responses that they believed the staff members wanted to hear. Only through the process of triangulation of data did it become evident that these responses were not necessarily representative of the patients' true feelings or experiences. In many instances the patient had either no understanding, or only a partial understanding, of the question.

A very common communicative routine, particularly in the medical encounters, is one in which the physician asks questions requiring a yes/no response. Such routines are highly susceptible to miscommunication due to gratuitous concurrence.³⁰ Some staff members were aware of this potential for miscommunication at least to some extent:

- **probably getting the proper feedback, knowing that what you've just said, what has actually been interpreted; so if I'm explaining to someone what a fistula is about, a new patient, what they're true understanding is because I still get a lot of nodding and I still get a lot of 'yes' and I'm not sure if that's a politeness or, yes, they truly understand what is happening with their body.** (interview with nurse educator)

Other staff members, even those with considerable experience, were very surprised when they became aware of this feature of Yolŋu discourse through their participation in the video analysis. In the medical review with the new patient, for example, there were many instances in which the patient responded to the staff member's questions quite convincingly (from a Western interpretation), but which later discussion revealed to be instances of gratuitous concurrence. The physician explained:

- **we are interpreting her confident responses with 'and that's the answer'—when she responds positively we feel we've got the answer.**

This patient works hard to participate effectively in the interaction despite her very limited fluency in English and the absence of an interpreter. She is particularly concerned to give what she considers the 'right' responses to questions about fluid³¹ although later discussions reveal that her actual consumption is very different:

- **... the physician asks Njarritjan how much she is drinking, then immediately asks more specifically, 'how much water?', and Njarritjan says, 'little bit water ga (and) tea, little bit ga bilin (and that's it)', then (the physician) asks, 'how much each day? Water, tea?' and Njarritjan says, 'Three cup, two cup, little bit', very confidently.** (researcher's description of videotape)

The physician had initially been impressed with this patient's response:

- **the way she talks about fluid is quite detailed compared to other people—that's amazing—when she's talking about the size of the cups and she's talking about tea and water and the numbers.**

It was only through later analysis of the video and discussion with the researchers that this was clarified for the nurse involved in this interaction:

- **just from looking at that video—I just learnt so much from that; I never even considered that they might be saying 'yow (yes)' when they are really saying 'no', I never even thought of it; it was really, really interesting that they say they are understanding and they haven't got a clue.** (interview with nurse)

This increased understanding then influenced her communication in a subsequent interaction with the same patient:

- **I did find today that I wasn't paying much attention to the 'yows'—I was actually working out that the 'yows' were really just something that you wanted to hear so you really had to ask her, so that's why I did a bit more later privately with her to find out whether this was true or that was true because today she was really giving 'yows'.**

³⁰ Eades (1991:91) describes 'gratuitous concurrence' as an agreement or confirmation which 'does not necessarily signify the speaker's actual agreement with a proposition'.

³¹ It is very unlikely that this is a deliberate attempt to mislead, as the patient openly discusses her actual fluid consumption in another context, but rather it is an attempt to communicate in a way that she believes is appropriate for this particular context.

5. Key features of communication in renal care encounters continued ...

One of the reasons gratuitous concurrence goes unnoticed is the very limited use by staff of strategies to verify the patient's understanding of the message. As a result responses are taken at face value. Some staff members make considerable attempts to check their own understanding of the patient's message, but again gratuitous concurrence limits the extent to which this is effective. In the medical review, for example, the physician frequently restated what the patient had said, apparently to verify his interpretation of what she was telling him but, as this extract from the video analysis illustrates, it does not necessarily provide a valid answer:

- ...the physician tells Njarritjan that he'll write a script and then explains at some length about what Njarritjan should do if it doesn't stop and why—Njarritjan is convincingly responding with 'yow, yow' at appropriate points as the physician is talking—he moves back towards the desk while saying 'very good, Njarritjan', then summarises the medication: 'diarrhoea medicine tomorrow, we'll give you some cream to try and make the skin less itchy; I think that's all we need to do now', looking at Njarritjan for confirmation and she responds to each statement with 'yow'. (description of video data)

Such instances of gratuitous concurrence occurred again and again in all the encounters and thwarted the attempts of even the most experienced staff to verify their own and the patients' understanding. As Galikali explained when talking about feedback of blood test results:

- when Balanda tell us straight from the book Yolŋu say, 'yow, yow, yow, yes, yow', and that's it but they don't really understand what you are telling them— when we really want to know we have to ask you what it all means...

Verbal scaffolding

Miscommunication in response to open-ended questions or questions expressed with multiple response options was also frequent due to the patients' use of verbal scaffolding, that is, the repetition of some or all of the staff members' utterances. Again, this example illustrates how the strategies the patient uses to facilitate the communication in fact mask the absence of shared understanding:

- the physician asked the question about the cramps and she says 'yow' but because he didn't go back into it—he went straight to his book ... and then I said about the cramps everywhere and she says,—'cramps everywhere'—she was letting me know that she understood what he said. (video analysis with nurse)

The physician was also convinced that the communication about cramps was successful:

- she understood about the cramps by the end of that and was telling us about her cramps. (video analysis with physician)

However, later discussions between the patient and the Yolŋu researcher during the analysis of the videotape revealed that the patient did not understand the English term 'cramp' or the term 'dizzy' or the term 'phlegm', all of which the staff members assumed she understood even after the encounter.

Another example of scaffolding occurred when one of the physicians was given assistance with interpreting. When the physician talked to the pending patient and his family about percentage of function, the Yolŋu researcher, assisting with interpreting, repeated what he had said using the English numerical terms and the term 'percentage'. The physician assumed that this indicated the Yolŋu researcher understood the concept, but acknowledged it may still have been unclear to the patient. This is another important example of how such scaffolding can keep the interaction flowing but in no way improve the patient's understanding. For inadequately trained interpreters working with inadequately trained staff, strategies such as verbal scaffolding will inevitably be used to comply with Yolŋu politeness conventions and approaches to knowledge production. This is exacerbated when staff members are not trained to reflect on the extent to which the concepts they are using are culturally specific and therefore unlikely to be easily translated.

Wait time

Another feature of discourse, which was a source of considerable difficulty and which limited opportunities for more effective communication was 'wait time', or the length of pause taken between turns in an interaction. According to Scollon and Scollon (1995:60), 'very small differences in the timing of interturn pauses can lead conversationalists to develop negative attitudes toward each other'. They explain that:

- **if two speakers (or more) differ in the length of the pauses they take between turns, the speaker with the shorter pauses will come to dominate the conversation. This is because at each point where turns might be exchanged, the faster speaker recaptures the conversational floor. (78)**

The lengthy pauses that are common in Yolŋu discourse are recognised as a source of confusion for Balanda in their encounters with Yolŋu. Some of the more experienced staff waited for relatively lengthy periods before either repeating or rephrasing a question. For example, one of the physicians waited for twelve seconds before rephrasing his question. Less-experienced staff assumed that a lengthy pause indicated some kind of problem with the communication or an indication that the patient did not intend to respond. In one of the education sessions the staff member assumed her utterance was too long or complicated for the interpreter and that was the reason that she did not translate immediately. The educator was apparently unaware that lengthy pauses are a common feature of Yolŋu discourse.

In one of the encounters, both the staff participants recognised that they had not allowed sufficient wait time, but only after having the opportunity to review the video recording of the interaction:

- **yes, especially looking back now—about coughing up the blood—she was going to tell me, she got it out but if I had waited she would have told me...**(video analysis with nurse)

And:

- **probably— when you look at it now I hadn't waited all that long but I probably felt that I needed to rephrase it to help her understand.—From looking at it I probably thought she wasn't responding and thought how can I rephrase it—I didn't wait long.** (video analysis with physician)

Pauses have been classified according to their different types in other studies, for example, a 'cognitive' pause is one which allows time to think and an 'interactive' pause allows time for the other participant to take the floor (Scollon and Scollon 1995:63). In this study, some of the participants did interpret pauses differently depending on the context. In the same interaction as the example given above the nurse explained how, in another instance, she did wait longer and why:

- **I gave a little bit of time because I feel they think about the answer—I thought she was thinking of an answer so I waited for an answer but then I saw that it wasn't going to come—we'd already made our decision that she didn't understand earlier; here we don't think the same—we think she has understood and I believe we're giving her time to think about it...I think we made the judgment at the beginning that she didn't understand and here we're making the judgment that she does understand but we're waiting and I think that's the difference between the two.** (video analysis with nurse)

As with many other features of discourse, a greater shared understanding of cultural differences in pause time and an accommodation of these differences could directly and substantially improve communication. This is particularly important in encounters in which question and answer routines dominate and when one or more participant is unfamiliar with, or uncomfortable with, such routines.

5. Key features of communication in renal care encounters continued ...

Non-verbal communication

In North-East Arnhem Land Yolŋu sign language is widely used to communicate without speech, for example when communicating over distance, in situations where silence is required or with Yolŋu who are deaf (e.g. Cooke and Adone 1994). All Yolŋu use a range of signs as part of their everyday communicative repertoire, but those who have a close family member who is hearing-impaired often have a much higher level of competence in using this communication system. Yolŋu sign language does not only involve signs, but also other parts of the body. Some commonly used signs, for example, are made with only the lips or the eyebrows. These signs are often the only response made to a question and these responses are often invisible to Balanda, for whom they do not have communicative significance.

The nurses participating in this study described patients' use of signs as a source of miscommunication for nurses who are unfamiliar with this form of communication. These very experienced nurses were familiar with some of the commonly used signs and found they even started to use them in their own interactions. For staff members who are unable to 'see' the responses which are being given to their questions, the patient's apparent lack of response results in immediate communication breakdown. This could easily be prevented by improved understanding about the range of communication forms commonly used by these patients.

In addition to this formal system of signs, there are also other important differences between Yolŋu and Balanda non-verbal communication, many of which have been written about extensively, but not always accurately. Most staff had some awareness of different cultural conventions regarding eye contact, for example, but these understandings were generally superficial. Even those Yolŋu patients who had very little experience communicating with Balanda before becoming sick made extensive attempts to accommodate the Balanda non-verbal communication practices. For example, in the medical review the patient repeatedly repaired or prevented misunderstanding by supplementing her Yolŋu spoken and non-verbal responses with the Western conventional indicator of a negative response by shaking her head from side to side. Non-verbal communication, even more than oral communication, is often subconscious and awareness of the extent to which our practices are culturally specific is often limited. Again this is a feature of communication, and a source of miscommunication, about which far greater shared understanding could easily be achieved through effective education.

contrasting theories of knowledge

Any analysis of communication depends upon a theory of knowledge, and of how it is structured, produced and shared. All such theories depend upon metaphor because the process of defining knowledge—knowledge about knowledge—is always reflexive.

Aboriginal patients arrive at their first encounters with the Western theory of renal function, renal failure and treatment options with their own theories of life, of the body, of health, and the relation of health to their history, their spirituality, and the politics of their family and community lives. The health practitioners also arrive with their biomedical model of renal function, disease and treatment.

The two models have a number of features in common:

- both are inherently structured, that is, they both consist of a vast variety of elements which relate among themselves in a consistent, structured way. Any claim made makes sense only in terms of the entirety of the system from which it derives;
- both are inherently dependent upon metaphor. The Western biomedical model, for example, depends upon a carefully woven articulation of both the organic metaphor—body as organism—and the machine metaphor—body as machine;
- both depend upon narrative, that is, they both depend upon people telling stories to others in a particular context, and they both depend upon processes as well as structures. The stories have a beginning and an end, they link chains of function and causality, and they generally imply something about what is to be done. Sometimes health professionals working from the biomedical model believe that they are working with simple biomedical facts, but these facts are merely special examples of, or moments in, narrative;
- both depend on a theory of cause and effect, on before and after, and on some ontological commitment (belief about the nature of reality) to the world as it is, including its moral imperatives; and
- both are represented by their individual perpetrators in idiosyncratic ways. Each person tells his or her own story in his or her own ways, and works hard in each context to produce a story that is meaningful, true, and convincing to the other. Neither the Western biomedically-based constructions nor the Aboriginal patients' constructions are always consistent or flawless. There is never universal agreement on either side about what the story is or how it should be told. Communication is always a struggle. It is not communication breakdown that is remarkable; it is the moments of successful communication.

The health professionals have a perspective, commonly regarded as the biomedical model, which they derive from their own world view and the training they have received. They work hard to renew that knowledge in an ongoing way professionally through reading, talking with their colleagues and privately as they think about their lives and their work.

The Aboriginal patients arrive from a family and a community context: their joys and sorrows, their histories, languages, stories and theories. They, like the health professionals, work hard to develop a theory of their own disease and treatment options from what they bring to the context of their treatment and continue to develop it either with or without the ongoing support of their community members. Like most white Australian renal patients, they have seldom if ever thought about their own kidneys before they are told they have renal problems. Many health professionals have little awareness of the important work which Indigenous patients do to develop a narrative covering their bodies and their world. As a result, some health staff seem to assume Indigenous people are in a conceptual void which must be filled with biomedical facts.

5. Key features of communication in renal care encounters continued ...

These two systems of knowledge and knowledge production underpin the expression and interpretation of messages from both sides. The communicative work between carer and patient is successful to the extent that there is some congruence between their linguistic and knowledge systems and constructions. The work that is done when one particular health professional interacts with one particular patient is only a moment of cross-fertilisation in those two ongoing separate processes. This encounter is not the only determinant of successful communication, but in fact the important work in terms of construction of knowledge occurs outside, or alongside, the medical encounters.

In the Yolŋu theory of *galtha*³², knowledge production and communication is understood using the production and celebration of a ceremony as a metaphor. Participants arrive at the context of negotiation with their own history, their own language, their own land from which the language derives, and their own theories of life, health, action and agency, and what is to be done. Communication here is seen as the production and performance of narratives, which are woven together in community, through negotiation, to produce a truth from ongoing interaction. There is no simple communication of an objective truth, but rather an ongoing struggle to weave together a useful understanding out of divergent perspectives. This requires hard work, respect, patience, time, and a lot of talking, listening, thinking and performing.

People come together in the *galtha* (the agreed and negotiated site for the production of a new negotiated narrative) from their own family and community traditions. They are deeply invested in their version of history and truth. They must work together carefully and respectfully if there is to be a successful interaction. This model of *galtha* has been used by Yolŋu to represent their picture of true intercultural education, in which traditional Aboriginal perspectives can be woven together with Western scientific knowledge to produce strong and confident Yolŋu who can work productively within two systems without repudiating either of them. The approach used in Stage 2 to increase the extent of shared understandings between health staff and Indigenous patients will be closely aligned with this theory of knowledge construction.

³² For more detailed discussion of this theory see Christie 1994.

6. The missing link: Effective education

Neither staff nor patients came to the interactions with the shared understandings necessary to successfully work together to achieve optimal health outcomes. The importance of effective health-specific education for renal patients is widely recognised by staff members, who also acknowledge the consequences of the current inadequacies in education. The importance of appropriate education and training for staff to accommodate the communicative needs of Aboriginal patients was also recognised to a limited extent, but the comments of staff indicate that this aspect of education receives far less attention. Both areas of education are currently highly unsuccessful.

The shared understandings between staff and patients, which are essential to improving communication, can be achieved through effective education for both staff and patients. There are, however, many barriers to achieving this.

The organisational structure in renal care in the Northern Territory does not provide adequate educational support for patients at any stage from the time of diagnosis of predisposing conditions (such as diabetes or hypertension) through to ESRD. This ignores the crucial importance of patients understanding their diagnosis and their treatment options if they are to make informed choices about managing their renal disease. It also ignores their need to understand the *consequences* of these choices. If people reject treatment for ESRD, the consequence is inevitable death, yet the findings of this research suggest that a Yolŋu patient who makes such a choice cannot be assumed to be making a genuinely informed decision.

The complete absence of any specialised training for staff in how to work effectively with Aboriginal patients is another important organisational barrier. Even more importantly, staff members who do have relevant expertise for working with Indigenous patients—that is, staff from the same language and cultural groups as the patients—are rarely employed. During the period of the study there were no Yolŋu staff or staff fluent in a Yolŋu language (or any other Aboriginal language, for that matter) employed in the renal unit.

Although education is part of the role of most of the renal staff, none are trained in intercultural health education practice, and the organisational structure and its culture limits the extent to which such education actually occurs. There are *no* departmentally funded patient educator positions within Renal Services in the Northern Territory. There is one temporary educator position for pre-dialysis patients located within Top-End Renal Services, which is currently funded by a private company.

Opportunities for patients and their families to access biomedical information independently as part of the process of developing their understandings of, and control over, their renal disease management are crucially important but extremely limited. The renal education resources that are currently available—books and videos produced in English primarily for non-Indigenous users—are recognised by staff members to be of very limited use in their work with Yolŋu patients and families. Although some staff members are attempting to develop more appropriate educational materials, this complex and time-consuming task is almost impossible to achieve without additional support.

Apart from a video about the treatment options for ESRD (available in a few Indigenous languages), there are no other resources in Aboriginal languages and few of the resources in English are considered appropriate. As the nurse educator explained:

- **we've got the video on treatment options in seven languages including English; there's**
- **a basic flip chart done by the Australian Kidney Foundation; one that was done by**
- **Menzies (School of Health Research) a few years ago and that was done on (their)**
- **study; and now the Chronic Disease Network for their screening program about why**
- **you should check your kidneys and keep your kidneys healthy. Basically that's it for**
- **what each community has; (it's) not adequate. The video is very good on treatment**
- **options but prior to that you need from the beginning the whole story: what kidney**
- **function is, what happens when that function starts reducing, what happens to the body,**
- **what treatment you need and then what happens when they stop working completely;**
- **there are some materials down south—but they are not probably appropriate for all**
- **the Aboriginal communities so that is what I'm trying to develop—that story from the**
- **beginning up to that treatment option video; and from there, once they're on dialysis**
- **there's that information they need to know that continually about their medication,**
- **about pathology results. (interview with nurse educator)**

b. The missing link: Effective education continued ...

There are many illustrations of these consequences of inadequate education in this report, one of the most important being the absence of opportunities for patients to make informed choices about treatment:

...generally we perceive that it's mostly the understanding that's not there—that they think they're cured and they go back (home), get sick again then come back in until they then understand—(they come back) by Airmed and are hospitalised as well for a couple of days at least; and that's what I'm trying to capture now in my statistical work to push this job to say that pre-dialysis education is a requirement because it's more financially viable: (if) the person's understanding before they come onto dialysis is greater—the uptake of treatment is greater—or not if they chose with a solid (basis) of knowledge that they don't want dialysis. We'll still probably get that not attending but it won't be as extreme as with no education or understanding.

We documented it in the self-care program—we had the patients we did self-care with and the number of times that they used to not attend dialysis compared with when they started training and their knowledge grew—and the stats went down on the number of times they didn't come so I was able to prove then to the financial people that it's more viable (with better education). We needed more staff to educate, more money, but in the long run it saved these people—they got better education, understanding of their treatment—that's a huge (issue) that uptake of dialysis at the beginning of treatment, their understanding of what it actually is—not a cure but a treatment and there is no easy answer and the hardest thing is establishing the education program—how do you establish an education program with one (educator) in an urban centre and (patients) live 800 kilometres away and have once come in for fistula education, go back out in the community and there is no reinforcement? So again (we need) that community and me setting up a system for the patients to have access to information and their families as well. (interview with nurse educator)

Existing programs, such as the self-care training for patients described above, provide some direction for future action, if adequate staff training and time for education are available. The nurse involved described why she thought this was a successful educational process:

just by sitting down, having more time, speaking to people and asking what does this actually mean to you, actually taking the time: what does a fistula mean, what does dialysis mean, what are your numbers, what is your weight? Because I was designing a book at the same time (self-care manual); a lot of that all came out then, whereas previously we thought they had that knowledge base.

Another apparent consequence of inadequate education about biomedical concepts for patients was the limited extent to which patients and their families communicated about these aspects of their renal experience. Researchers in Central Australia identified serious gaps in communication between patients and their family networks, although they felt that the underlying reasons for this remained unclear (Devitt and McMasters 1998).

It is recognised that constraints based on kinship, age and gender that govern the right to know and to discuss health information with or about another person have complex impacts on communication between patients and their family members (e.g. Trudgen 2000). Inadequate education may also be an important factor, although there was little opportunity to explore this in detail in this study. The findings indicate, however, that the patients do not have sufficient understanding of *any* aspect of the biomedical story about their renal disease to be able to effectively communicate it to family members, who may have even less experience of the biomedical domain. To attempt to recount in Yolŋu Matha complex biomedical concepts, which have been poorly explained in English and which have no direct Yolŋu equivalents, is clearly an impossible task. Even those who have experience with interpreting in medical contexts find it extremely challenging.

A number of possible strategies have been identified through the study, which may help to improve communication, not only between staff and patients, but also between patients and their families. These include:

- providing opportunities for increasing shared understanding before and beyond the clinical encounters;
- changing the structure of interactions to include appropriate family members in encounters; and
- collaborating with appropriately trained interpreters.

The need for staff members to increase their own understanding beyond the medical dimensions of renal disease was also evident. As discussed earlier, it is not practical or achievable for staff to learn about the different ways of communicating in different cultural groups, just as it is not possible for staff to become sufficiently competent communicators in the languages of their patients without many years of cultural and language immersion. It is possible, however, for staff to become more aware of the extent to which their own communicative practices, such as their use of metaphors, are culturally specific.

There is also an urgent need for staff to learn how to work more effectively with Indigenous patients and interpreters, and for Yolŋu to work together, to find ways to achieve greater shared understanding. This must go beyond the current practice of producing a few materials in 'simple English', which sit on a shelf, ineffective and unused. For example, one of the interpreters who assisted with data analysis made this suggestion:

- **We need to bring Yolŋu experts, interpreters, together so they have the opportunity to talk in their own language; the metaphors (the educator) is using are Balanda metaphors. I think it is appropriate to change the metaphor completely to match the situation—it's very important—and the role of the interpreter then changes—they are actually trying to give the same meaning...Balanda need to use some metaphors and Yolŋu can pick them up and maybe use them or maybe adapt them.**

Indigenous renal patients and their families have the right to make *informed* decisions about their renal care. This requires a serious commitment to meeting the educational needs of both staff and patients to enable more effective collaboration to occur as they work together in managing this complex health problem. It is also essential that this process reflects the communication and educational practices and theories of knowledge relevant to the patients themselves.

The ideas for action, which emerged from this study, as well as other strategies suggested during the dissemination process with stakeholders, will inform the second stage of this project. Ideas for improving communication between health staff and Aboriginal patients, which have been suggested in many other reports (e.g. Eckermann *et al.* 1992; Hill 1994; Campbell 1995; Weeramanthri 1996; Devitt and McMasters 1998; Humphery, Japanangka and Marrawal 1998; Trudgen 2000) will also inform the development of Stage 2 (see Attachment 1).

7. Conclusion

This research has demonstrated that miscommunication between health staff and Yolŋu patients is pervasive in the context of renal care in the Top End of the Northern Territory.

Prior to the study it was recognised that there were systematic difficulties in communication between renal staff and Aboriginal patients. There was sufficient concern for staff both to propose that the research be conducted in the renal context and then to actively participate in the project. However, this study found that the extent and severity of miscommunication was *far greater* in all the encounters than either group of participants anticipated or recognised. A shared understanding about key concepts was rarely achieved even in interactions between the most experienced staff and Yolŋu with a relatively high level of fluency in English. It is likely that the extent of miscommunication is at least as severe in other Indigenous health care contexts, as many of the factors influencing communication in renal care are common to all forms of chronic disease management, as well as other areas of health care.

Lack of awareness and an acceptance of 'a grossly deficient cross-cultural communication standard as the norm' have been described in Central Australia (Devitt and McMasters 1998:147). In this project, a similarly 'grossly deficient' communication standard has been clearly demonstrated in the context of renal care in the Top End. The extent of *unrecognised* miscommunication is of particular concern and has serious implications for the quality of care currently provided to Indigenous patients.

The severity of the communication problem in these encounters was only revealed through extensive use of triangulation, a key technique in strengthening the quality of this research that was both trustworthy and authentic.³³ Triangulation occurred at various levels. First, there were multiple sources of data—videotapes of interactions, interviews and the various interpretations of the video data. In addition, there were multiple 'observers' of the interactions: staff and patient participants, as well as relevant experts, linguists and interpreters, were involved in analysing the videotapes.

At another level, triangulation occurred through the multiple theoretical perspectives brought to the study by the diversity of the research team. Another strength of this research approach was the extent of participation achieved through the involvement of staff, patients and other stakeholders as members of the research team. This greatly enhanced the relevance and authenticity of both the research process and findings, and facilitated changes in staff practice as a consequence of participation in the research process.

Many *challenges to achieving effective communication* between health staff and Yolŋu patients in renal care encounters were identified. These stemmed from a range of sources including cultural, linguistic, social and political dimensions of communication. Often instances of miscommunication were due to an interaction between various factors. A single cause—and therefore a simple solution—can rarely be isolated. Communication in the renal care context, and indeed in the management of any chronic disease, is complex. This complexity is compounded when diverse cultural groups, which do not share a common first language or culture, are forced together to confront a profoundly life-altering and life-threatening problem.

One of the most important understandings to be drawn from this research relates to the wider political and social context within which communication occurs. Crawford (1999:29), in a study of communication issues in South African health services, succinctly states:

- **It is not possible to isolate the patient disempowered in terms of the language barrier from the whole biomedical discourse in which patients occupy a disempowered position.**

A range of **systemic and political barriers** to achieving effective communication was identified within this renal care context. One of the participating physicians concluded that, from his experience with Aboriginal patients:

- **providing treatment to people without being able to communicate with them must be**
- **providing fundamentally poor health care.**

And yet the organisational and educational practices in health care, which perpetuate this situation, are rarely contested.

³³ See Section 3 for an explanation of these terms as alternatives to the concepts of validity and reliability.

- **The need for structural changes to the current health care system to enable a genuine shift in control and to better accommodate Aboriginal people's needs has been extensively documented (e.g. Reid 1982; Humphery, Japanangka and Marrawal 1998; Humphery, Weeramanthri and Fitz 2001). In the National Report of the Royal Commission into Aboriginal Deaths in Custody, Johnston questioned the continuing emphasis placed 'on Aboriginal failure to assimilate to our norms (which) should rather be placed on our failure to devise strategies that accommodate to their world view' (Johnston 1991:47). This emphasis on Aboriginal, rather than institutional, failure was also illustrated in the context of renal care in Central Australia by an attitude found among service providers that 'Aboriginal patients were somehow culpable in their linguistic difference'. (Devitt and McMasters 1998:148)**

Equity of access implies accommodation of the needs of specific cultural and linguistic groups (Pauwels 1991). The National Health Strategy Issues Paper (1993) recognised the importance of the mismatch between the culture of the health system, which essentially operates within a Western medical model, and the needs and expectations of people from non-English-speaking backgrounds and suggested that the *onus for change lies with the mainstream health bureaucracy and institutions*. The writers of *Binang Goonj* (Eckermann et al. 1992) also argue that it is easier for health care providers, from their position of relative power, to adapt to the differing needs of their patients and that failure to do so will endanger the social, cultural, physical and mental health of Aboriginal people.

In renal care in the Top End, the Aboriginal patients and their families are still required to accommodate the structures and practices of the renal service, which are strongly grounded within the Western medical model. Among those structures and practices, the language of the service providers—English—is the only option in any engagement with these services. All encounters consistently feature the location of control over all aspects of the communication, which is predominantly with the renal staff. There were very few opportunities for the Yolŋu patients to initiate or influence the topics of discussion in these encounters. As a result, the patients' knowledge, experiences and priorities are excluded or marginalised. Most of the concerns that emerged as Yolŋu priorities, primarily through the interviews and informal discussions, were social, cultural and economic. They related mainly to their (currently) unavoidable relocation to Darwin if they wished to access the treatment essential for their survival.

Other systemic barriers were also identified, such as:

- time constraints, which inhibit changes in practice;
- the segmentation and reductionism that characterise the biomedical approach to management;
- the (often unrecognised) cultural specificity of health services;
- structural inertia; and
- the absence of processes and resources for identifying problems or for planning and implementing change.

As well, the individual and institutional capacity required to meet the needs of Yolŋu patients is not critically assessed or addressed. This *inadequate capacity* is particularly evident in the lack of effective training and education for both staff and patients to enable optimal renal care to occur in this intercultural context (see below).

Differences in language and cultural knowledge are inevitably a major source of miscommunication when the cultural distance between staff and patients is great, and the extent of shared language ranges from limited to almost non-existent. In a recent book, which also considered communication between Yolŋu and health professionals, Trudgen (2000:77) described a two-way crisis in communication:

- **While dominant culture professionals are unable to communicate meaningfully to Yolŋu even the most basic concepts affecting their life and well-being, Yolŋu in turn can neither explain what is happening in their lives nor share with the dominant culture the wisdom which has been part of their culture for thousands of years.**

7. Conclusion continued ...

This study demonstrates that shared understandings between renal staff and Yolŋu patients are rarely achieved in relation to any of the key concepts in renal care—from either the Yolŋu or the biomedical perspective. As a consequence the effectiveness of communication is seriously limited and the quality of care inevitably compromised.

The communication practices employed by renal staff in their interactions with Yolŋu patients were highly ineffective. There was little evidence that staff members considered—or had the expertise to assess—the level of risk for miscommunication in specific encounters. As a result, they attempted no preventative measures such as the employment of interpreters, even though interpreters in Yolŋu languages were readily available. Few strategies were employed to monitor the patients' understanding—or that of the staff members—and as a result most instances of miscommunication went unrecognised and therefore unrepaired, often with potentially serious consequences. No staff members had received training in intercultural communication although such expertise is clearly crucial to their work.

Shared understandings of key aspects of discourse, from specific concepts to metaphors and communicative routines, are essential for achieving effective communication and therefore patient access to optimum care and the opportunity for informed choice. It is clear from the findings of this study that a sufficient level of shared understanding to achieve such outcomes does not exist, even between the most experienced and well-intentioned staff members and long-term patients with a high level of conversational fluency in English. Although this research focused on communication within the interactions between staff and patients in renal care, serious communication difficulties outside these encounters were also repeatedly identified. These include communication difficulties between staff within the same workplace and between the staff of different health care settings, as well as inadequate communication between patients and their family members.

Most of the interaction between staff and patients in renal care focused on renal disease, renal failure and renal treatment, that is, the biomedical communication priorities and constructions. There is, however, extensive prerequisite knowledge from the biomedical domain that is essential for making sense of any information relating to renal issues. A shared understanding of the function of the heart and the nature of the circulatory system including the components and function of blood, for example, is necessary for many of the discussions about renal issues to make sense. As there is no prior shared understanding for many of these underlying concepts, effective communication cannot be achieved in much of the interaction between staff and patients in renal care. The opportunities for staff and patients to work together to develop these shared understandings are seriously limited. Resources for effective patient education are either non-existent or inadequate: staff members have little time and there are few of the required educational materials and little expertise.

In current practice, the clinical encounter is the only opportunity for patients to access biomedical information about renal disease and its management in general, and about their own renal care specifically. Again, control lies with the health staff and, in this case, it is control over information. Giving patients more effective means of finding out this information involves:

- using *interpreters* and ensuring pre-existing shared understanding of crucial underlying concepts and processes from both the Yolŋu and biomedical domains; and
- developing improved staff expertise in intercultural communication.

There is also an urgent need, however, for patients to be able to access and share significant biomedical information *outside* the clinical encounters. This requires the development of appropriate educational resources and the meaningful presentation of test results and treatment regimes. The long hours which patients spend alone or in small groups, without the attention of a health professional, could produce shared understandings if they could readily find interesting, text-independent and meaningful information.

Better shared understanding is essential for both staff and patients, both as an end in itself to improve access and effectiveness of renal care and as a prerequisite to effective communication within the clinical encounter. This can best be achieved through a collaborative process in which Yolŋu and Balanda work together to develop more informed and sophisticated constructions about renal disease, care and management and associated issues.

Achieving shared understanding requires a process in which the Indigenous patients, their families and supporters have the opportunity to collaboratively construct their own discourses of life, the body, health and sickness that are related to the particular renal issues they confront. Such discourses would inevitably and appropriately integrate the biomedical concepts with Yolŋu concepts, which should mean people gain better understanding about, control over, and responsibility for management of their renal disease.

Similarly, communication would improve if health professionals learned to listen to the Yolŋu story and let it shape the structure of their own biomedical perceptions. Both staff and patients need to recognise that their understandings come from their own backgrounds, and are therefore saturated in their own histories, languages and cultures.

The findings of this study demonstrate that any substantial and sustained improvement in communication, and therefore in health outcomes, requires an approach that simultaneously addresses the range of barriers to change. The **strategies for improving communication** identified through this project go beyond the solutions often proposed in the past, which target only one component of the problem, such as communication practice within the medical encounter.

'Solutions' within this narrow frame, for example, the learning of Aboriginal languages by health staff, are often unachievable, unsustainable or ineffective. Differences in cultural knowledge and world view cannot be addressed simply by achieving a greater level of shared linguistic knowledge (e.g. Clyne 1994). Similarly, institutional, political and socio-economic barriers to effective communication cannot be overcome through focusing on the actions of individuals (e.g. Humphery, Weeramanthri and Fitz 2001).

The broad range of communication issues and potential solutions, which emerged through this research, was in part a function of the collaborative and multidisciplinary approach as well as of the constructivist theoretical model within which the research was framed. This process identified a need for integrated action in three interdependent areas:

- shifting control;
- increasing shared understanding; and
- improving communication practices.

Some of the strategies that will form the basis of the next stage³⁴ in which they will be further developed, implemented and evaluated are summarised below.

a) *Shifting control* means addressing the barriers to effective communication at both system and service levels, by, for example:

- increasing participation of patients and families in service planning and management (patient-centred/integrated);
- facilitating involvement of staff from relevant cultural/language groups;
- accommodating Indigenous organisational and communication processes through changing institutional practices;
- increasing opportunities for patients to initiate and structure interactions; and
- creating conditions for patients to make genuinely informed decisions (through increasing shared understanding and improving communication practices).

³⁴ See Attachment 1 for an outline of the Sharing the True Stories Stage 2 plan.

7. Conclusion continued ...

b) *Increasing shared understanding of key processes and concepts in health care involves:*

- staff and patients, interpreters and health workers working together to construct a shared understanding of key processes and concepts in renal care, and developing resources to help share these understandings with others;
- ongoing educational programs between and within groups; and
- improved patient–staff collaboration in case management, including better patient access to their medical records.

c) *Improving communication practices in Aboriginal health care through institutional support and strengthening individual expertise, includes, for example, developing intercultural communication training for staff and patients (informed by Stage 1). This should be integrated with:*

- support for ongoing training for interpreters in health with opportunities to specialise in renal care;
- evaluating and improving current practice in terms of the extent to which it enables genuinely informed choice and informed consent; and
- developing, implementing and evaluating specific communication strategies to increase the capacity of staff to prevent, monitor and repair communication difficulties in interactions with Aboriginal patients.

Implementation of strategies within any one area alone will, at best, meet with only limited success. Action across all three areas needs to be coordinated and sustained. Simply increasing staff awareness of miscommunication will not address the absence of shared understanding, which is crucial to achieving effective communication. Similarly, increasing shared knowledge will have less effect if patients do not gain greater control over their renal management including timing, focus and structure of renal care encounters. For example, working with an interpreter will be far more effective if the encounter is part of a patient-centred approach to management where health staff, interpreters and patients have developed a shared understanding about renal care which is informed by both biomedical and Yolŋu perspectives.

The severity of miscommunication identified in this study suggests that Yolŋu renal patients and their families have seriously **limited opportunities to make genuinely informed choices** about management of their renal disease. For example, any assumption that consent for medical interventions is genuinely 'informed' must be questioned. The evidence indicating inadequate application of ethical principles, which are of central importance in health care, requires urgent attention. Humphery, Weeramanthri and Fitz (2001:106) have suggested that many health professionals see the institutional practices contributing to the poor standards of Aboriginal health as '*given rather than contestable*'. This project has shown that such practices can be transformed if and when health staff and Aboriginal patients collaborate in bringing about change. The small steps made in this project are just the beginning of a process that will continue to strengthen through the participatory action approach of the second stage of this research.

Until Yolŋu with renal disease, and Aboriginal patients with any form of chronic disease, have the opportunity to make genuinely informed decisions about their health care, and to access treatment that accommodates their cultural and linguistic needs, any attempts to improve communication can meet with only partial success. However, every attempt must be made to improve communication within these limitations while also working towards achieving the more fundamental changes that are essential to achieve equity of access to effective health care. Planning and implementing strategies for change requires collaborative action for optimum outcomes: collaboration between staff and patients; collaboration between staff from different disciplines and with different expertise; and collaboration between Yolŋu patients and their families, health workers and interpreters. Such a process is a powerful means to increase shared understanding. As well, this process optimises the relevance and sustainability of any action that is undertaken.

As a Yolŋu family member and interpreter suggested:

- **It's important that Yolŋu and Balanda work together and listen to one another...if you want to help Yolŋu you have to help us the right way—with your own thinking you can't help us but if you stick with Yolŋu...the relationship will go right**

8. List of shortened forms

CRCAH	Cooperative Research Centre for Aboriginal Health
CRCATH	Cooperative Research Centre for Aboriginal and Tropical Health
ESRD	end-stage renal disease
NAATI	National Accreditation Authority for Translators and Interpreters
PAR	participatory action research
PD	peritoneal dialysis
SAE	Standard Australian English



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Attachment 1

Sharing the true stories: improving communication between health staff and Aboriginal patients—pathways to change.

Stage 2 Project Plan

(This is a provisional plan only, which has been informed by the findings of Stage 1 of the research as well as extensive consultation with stakeholders—to be further developed during Stage 2 through the responsive and flexible processes that characterise participatory action research (PAR).)

Outline

- The research team from Stage 1 will continue as the research management team (funded predominantly through core partner in-kind contributions) for Stage 2 (with additional Indigenous members) and will include a project manager/evaluator (one full-time or two part-time positions—funding requested from the CRCATH).
- The project manager/evaluator will work collaboratively with the action teams in conducting the evaluation, which is the research component of the project (see CRCATH full submission for further details).
- Two advisory groups will support and monitor the project—one general advisory group including representatives of all institutional stakeholders and an Indigenous advisory group, which includes patients, family members and interpreters, to facilitate greater Indigenous involvement in, and control over, the project.
- Three action teams will each work on a range of strategies within one of the key focus areas (see detail below)—these activities will be funded by in-kind contributions from core partners and/or financial support from other organisations—CRCATH project funding is NOT requested for action team personnel and activities (with the possible exception of strategies that are directly concerned with transfer of Stage 1 findings). Each sub-project will operate independently (with independent funding if required) but will be linked to the other projects through the research management team, which will be responsible for coordination and evaluation both across and within the action teams.
- Teams will include Aboriginal clients, family members, health workers and interpreters as well as health staff, with additional evaluation and coordination support across the project—confirmed participants (predominantly in-kind) include a wide range of staff members from Territory Health Services and Charles Darwin University, interpreters, patients and family members and other stakeholders in each area.
- A PAR approach will provide the project framework, with multiple methods utilised in evaluation (both process and outcome evaluation) as appropriate for the various strategies and intended outcomes:
 - quantitative (e.g. evaluating effectiveness of interventions in terms of biomedical measures and service uptake measures utilising available clinical and service provision data);
 - qualitative (e.g. evaluating effectiveness from multiple perspectives obtained through semi-structured and in-depth interviews, participant observation and PAR team documentation).
- The realistic evaluation approach (see CRCATH submission) requires a strong emphasis on process evaluation. The CRCATH-funded evaluator will be responsible for ensuring that the action team participants are fully aware of the importance of documenting their activities, and will support the team participants to record the assumptions underlying their decisions and the contexts in which they are applied. This information will provide material for ongoing reflection within the action teams (PAR) and also will provide data for the overall evaluation that will inform learnings about the transferability of these methods in other contexts.
- A developmental web site will provide:
 - a tool for managing the project and facilitating communication between participants and others during the project;
 - access to resources and processes emerging from the project, which can be continually expanded and improved as part of evaluation and transfer.
- Stage 2 will continue to focus on the same context as Stage 1 (Yolŋu clients of Top-End Renal Services) but as soon as practical *will expand to other language groups within renal services, then to other health care contexts*. The strategies outlined below are specific to renal services but, as part of Stage 2, the transferability of these strategies to other health contexts will be explored.

Aims of the project

1. To develop, implement and evaluate strategies for improving communication in renal care through three interdependent processes:
 - a) shifting control through addressing the barriers to improving communication at both system and service levels and strengthening Indigenous participation in health care;
 - b) increasing the extent of shared understanding between health staff and Indigenous clients; and
 - c) improving communication practice in Indigenous health care through strengthening both institutional support and individual expertise.
2. To assess the relevance, and facilitate transfer as appropriate, of the research findings into policy and practice across a range of Indigenous client groups and health care contexts.

PART A: Shifting control —addressing the barriers to improving communication at both system and service levels		
Aim: to develop, implement and evaluate strategies to shift control through increased Indigenous participation in overall management processes and in structuring specific encounters.		
Objective:	Action strategies*:	Evaluation strategies*:
1. To increase participation of clients and families in service planning and management through genuine and consistent collaboration (system level).	<ul style="list-style-type: none"> ● Facilitate ongoing dialogue between renal staff and community members—meetings in communities and Darwin to discuss future service possibilities. ● Develop a formal structure to ensure client and family participation on a regular basis in service planning/ evaluation. ● Negotiate changes to current practice with clients and trial alternative approaches, e.g. modifying the review process to include discussions between staff and clients and families at their preferred location; developing protocols for the use of interpreters (see Part C). 	<p>Evaluation strategies*: (to be implemented by action team and/or members of CRCATH management team as negotiated during the establishment phase)</p> <p><u>Process evaluation:</u> Maintain ongoing record of discussions, proposed, attempted and actual changes.</p> <p><u>Impact evaluation:</u> Monitor changes in practice as perceived by service providers, clients, families (interviews).</p> <p><u>Outcome evaluation:</u> Monitor involvement of clients and families in planning and management (staff records).</p> <p>Monitor changes in effectiveness of management (quantitative, e.g. biomedical measures, service uptake statistics; qualitative, e.g. client and staff reflections on changes in practice and outcomes).</p>
2. To increase opportunities for clients to initiate and structure interactions (service level).	<ul style="list-style-type: none"> ● Improve client awareness of staff roles, service structure and management processes and routines—produce educational pamphlets/posters/videos in conjunction with Part B. ● Create opportunity for clients to make an <i>informed choice</i> about use of interpreter through education (e.g. adapting tapes used to inform legal clients about interpreters) and improving access (e.g. regular booking of interpreters for medical reviews). ● Develop and implement procedures for identifying and responding to client preferences in terms of participants in interactions, time and place, language, focus etc. 	<p><u>Process evaluation:</u> Record processes and resources used and/or developed for clients.</p> <p><u>Impact evaluation:</u> Monitor use made of resources, and the context in which they are used.</p> <p><u>Outcome evaluation:</u> Monitor level of interpreter usage (Northern Territory Government Interpreter Service data); conduct regular interviews with staff and clients to assess views of extent of client input.</p>
3. To develop a more client-centred/integrated approach to renal care (integrating systems and service level change).	<ul style="list-style-type: none"> ● Implement a patient identification system using regionally relevant naming practices. ● Develop and implement formal procedures to ensure discussion and negotiation between renal staff and individual clients and their families about all issues related to individual patient care, including going home, delivery of dialysis, diet, use of medications, transplantation etc., occurs in their preferred language. 	<p><u>Process evaluation:</u> Document the development of new systems and procedures, and the settings for which they have been developed.</p> <p><u>Impact evaluation:</u> Monitor use of new procedures (regular meetings with staff to discuss use).</p>

PART A: Shifting control continued ...

	<ul style="list-style-type: none"> ● Develop a more sophisticated case management approach (from chronic to ESRD) involving client, family, interpreter, relevant community health and renal staff. ● Conduct team development workshops to facilitate a more transdisciplinary team approach through improved communication and reciprocal education between staff (relates to case management approach above). ● Structure dialysis organisation around language groups: <ul style="list-style-type: none"> ● same language group at same time on dialysis and therefore also same review day; ● primary nurse to have patients from same language group, develop the role to achieve greater interaction/ collaboration in management and education for both staff and clients. 	<p><u>Outcome evaluation:</u> Interviews with clients, staff and families about effectiveness of new systems and procedures.</p> <p>Monitor changes in uptake of treatment options (clinical records).</p>
<p>4. To increase involvement of staff from relevant cultural/ language groups.</p>	<ul style="list-style-type: none"> ● Negotiate with the Department of Health and Community Services to identify realistic strategies to achieve this objective, e.g. create opportunities for work experience in 7A/Nightcliff for health workers from remote communities and work experience for renal nurses from 7A/Nightcliff in remote communities. ● Maximise health worker and interpreter participation in other Stage 2 activities, e.g. as core members of action teams. 	<p><u>Process evaluation:</u> Document process, identifying barriers and solutions. Document extent and nature of participation in all aspects of project.</p> <p><u>Impact and outcome evaluation:</u> Document changes in work practice and staff and client perceptions of benefit (interviews).</p>

Part B: Increasing shared understandings between health staff and Indigenous clients

Aim: To enable Indigenous clients to make more informed choices about their health care through development of an educational framework which integrates Indigenous and biomedical knowledges and includes both sustainable educational strategies and multimedia, multilingual resources for use by clients, their families, other community members, interpreters and health staff.

Objective:	Action strategies*: *action and evaluation strategies are tentative and will be confirmed, modified and expanded as appropriate within the PAR process	Evaluation strategies*: (to be implemented by action team and / or members of CRCATH-funded management team as negotiated during the establishment phase)
<p>I. To identify existing educational resources and develop additional interactive multimedia resources which can be utilised across client groups and health service contexts (beginning with the languages of North East Arnhem Land and the renal care context but extending to other medical areas and language groups as funding allows.</p>	<ul style="list-style-type: none"> ● A collaborative team (or teams) of interested Yolŋu³⁵ (patients, their families and/or interpreters), health staff, language and resource development specialists will collect (e.g. existing dictionaries and renal education materials) and develop as required health-specific educational resources for clients/ families, staff and interpreters. ● Resource development will focus initially on underlying biomedical concepts about which there is little shared understanding between health staff and Indigenous clients³⁶ (e.g. circulatory system, respiratory system and metabolism, followed by other key areas such as renal function and renal failure, diagnostic and monitoring procedures and interventions as funding allows). 	<p><u>Process evaluation:</u> Document approach used, level of participation, and materials gathered and/or developed, and the settings for which they are intended.</p> <p><u>Impact evaluation:</u> Monitor use made of materials in specific contexts (regular meetings with staff to discuss use) and of web site.</p> <p><u>Outcome evaluation:</u> Assess changes in participants' understanding of key concepts (interviews) and changes in biomedical measures related to these concepts (e.g. improved fluid control, calcium, phosphate, anaemia management).</p>

³⁵ This project will initially be conducted with Yolŋu, but as soon as practical other language groups will be invited to participate.

³⁶ As identified through recent research, e.g. Stage 1: interim project report of the Sharing the True Stories project.

Part B: Increasing shared understandings between health staff and Indigenous clients continued ...		
	<ul style="list-style-type: none"> ● Appropriate web site/database interfaces will be developed and trialled in negotiation with all team members. Health staff, patients, interpreters and other stakeholders will have the opportunity to access the developing web site and resources and will be encouraged to provide feedback to ensure sustainable and efficient access for all potential users is achieved. 	<p>Assess changes in team members' understanding of key concepts, i.e. effectiveness of participation in the process of resource development, as distinct from use of the resources.</p>
<p>2. To improve accessibility of information related to the care of individual clients: client access to their own medical information in a form that is meaningful and staff access to relevant social, cultural and language information for individual clients.</p>	<ul style="list-style-type: none"> ● More effective ways to present the individual client's medical data which can be understood, easily accessed and used by the clients in discussions with health staff and each other (linked to the multimedia educational resources so clients can clarify meanings and implications/ review related information) will be identified and trialled. ● Ways of documenting non-medical information about individual clients which might assist staff in improving communication, e.g. section in file identifying client's language group, preferred calling name/names, any other family or cultural information client feels it is relevant for staff to be aware of will be identified. 	<p><u>Process evaluation:</u> Record participation in and development of new approaches to presentation of data.</p> <p><u>Impact evaluation:</u> Monitor ongoing use of new approaches (records) and satisfaction of clients and staff with new system (interviews).</p> <p><u>Outcome evaluation:</u> Monitor changes in clients' access to, and understanding of, their own medical records (client and family interviews).</p> <p>Monitor staff application of non-medical information relating to individual clients (staff interviews).</p>
<p>3. To achieve sustainable and collaborative education processes (which optimise use of the resources developed in 1) for staff, clients, their families, and interpreters involved in Indigenous renal care.</p>	<ul style="list-style-type: none"> ● Health-specific education programs/activities for clients, families, interpreters and staff will be developed (initially specific to renal care): in the community (preventative/ pending patient focus) and in Darwin (end-stage management focus). ● Organisational support (e.g. time release, structuring services around language groups) will be established for collaborative educational processes in which staff and clients/staff and interpreters work together to increase shared understandings. ● Consultation will occur with relevant government and non-government organisations regarding adaptation of existing programs and resources to more effectively meet the needs of Indigenous clients. ● An implementation framework will be produced and integrated into policy and practice to ensure consistency and sustainability of programs overall—and within programs, e.g. consistency in how key renal concepts are communicated. ● Adaptation and transfer of the educational framework and resources across a range of health care contexts as appropriate will be facilitated. 	<p><u>Process evaluation:</u> Record participation in and development of systems, including the settings for which they are designed.</p> <p><u>Impact evaluation:</u> Monitor implementation of new systems and use made of them.</p> <p><u>Outcome evaluation:</u> Monitor client's biochemistry targets and uptake of recommended medical treatment during chronic renal stages to ESRD (within and across interventions).</p>

PART C: Improving communication practice in Indigenous health care

Aim: to improve communication practice in intercultural clinical encounters through strengthening both institutional support and individual expertise.

Objective:	Action strategies*: *action and evaluation strategies are tentative and will be confirmed, modified and expanded as appropriate within the PAR process	Evaluation strategies*: (to be implemented by action team and/or members of CRCATH-funded management team as negotiated during the establishment phase)
<p>1. To identify the institutional and individual capacities required to improve communication practice in Indigenous health care (relates also to Parts A and B).</p>	<ul style="list-style-type: none"> ● Integrate findings from relevant research (including Stage 1 and other recent studies) a) in terms of institutional and staff capacities needed to accommodate the communication needs of Indigenous clients and identify the specific implications for employment and training policy and practice and b) to identify systemic and organisational barriers to improving communication practice and strategies to address these (this will inform actions related to objectives 2, 3 and 4 in Part C as well as Part A actions). 	<p><u>Process evaluation:</u> Record participation and resources involved, and record assumptions underlying development of recommendations. Monitor the extent to which the actions below and in other teams are relevant to these identified needs and address the identified barriers.</p>
<p>2. To complete intercultural communication guidelines for health staff including guidelines for use of interpreters (linked with training program below).</p>	<p>Develop (informed by information obtained through meeting objective 1 above and findings of Stage 1) and trial the draft guidelines with renal staff.</p> <ul style="list-style-type: none"> ● Integrate the emerging findings from Stage 2 into the guidelines. ● Trial the completed guidelines in other health service contexts. ● Identify and implement strategies to maximise effective and sustained use of the guidelines. 	<p><u>Process evaluation:</u> Record participation and resources involved in development of guidelines, underlying assumptions and contexts for which they are developed. Record process by which guidelines are introduced to staff in different settings.</p> <p><u>Impact evaluation:</u> Monitor ongoing awareness of guidelines in different settings where they have been introduced.</p> <p><u>Outcome evaluation:</u> Monitor changes in uptake of interpreter service (Interpreter Service data) and perceptions of effectiveness (interviews with staff and interpreters).</p>
<p>3. To improve communication strategies used within clinical encounters.</p>	<ul style="list-style-type: none"> ● Develop and trial tools for assessing communication risk and whether an interpreter is needed to achieve effective communication in a specific interaction. ● Develop and trial techniques to identify miscommunication when it occurs (comprehension checks). ● Develop and trial techniques to repair miscommunication when it does occur (e.g. recognition of source of miscommunication and selection of appropriate responses: e.g. repetition, explanation of unfamiliar concepts, expansion of simplistic information, provision of resources or interpreting support etc.). 	<p><u>Process evaluation:</u> Record participation and resources involved in development of tools and techniques, underlying assumptions and contexts for which they are developed. Record process by which tools and techniques are introduced to staff in different settings.</p> <p><u>Impact evaluation:</u> Monitor ongoing awareness of tools in different settings.</p> <p><u>Outcome evaluation:</u> Assess value/effectiveness of tools and techniques (focus groups with staff). Compare accuracy of staff/client judgments with and without the use of these tools (videotapes of interactions and/or exit interviews with participants).</p> <p>Compare communication effectiveness in interactions (in terms of prevention, monitoring and repair of miscommunication) before and after intercultural communication training and/or introduction of strategies above.</p>

PART C: Improving communication practice in Indigenous health care continued ...

<p>4. To address the intercultural communication training needs of health staff working in Indigenous renal care</p>	<ul style="list-style-type: none"> ● Develop and trial an intercultural communication training program for staff and interpreters working in renal care³⁷ utilising findings from Stage 1 and Stage 2 (e.g. training in communication risk assessment and communication effectiveness evaluation strategies; developing reflexivity) in collaboration with interested training bodies. ● Identify/develop resources to support the training program³⁸, e.g. a team of interpreters and other communication specialists to develop multimedia intercultural communication training materials for staff, clients and interpreters. 	<p><u>Process evaluation:</u> Record participation and resources involved in development of training program and resources, underlying assumptions and contexts for which they are developed. Record process by which training program and resources are introduced to staff in different settings.</p> <p><u>Impact evaluation:</u> Monitor ongoing participation in training and use of resources in different settings.</p> <p><u>Outcome evaluation:</u> Assess value/effectiveness of training program and resources (focus groups with staff).</p> <p>Assess changes in understandings of key communication issues (interviews with staff and clients and families).</p> <p>Monitor changes in uptake of interpreter services and perceptions of effectiveness.</p> <p>Evaluate effectiveness of above strategies through comparison of accuracy of participants' judgments with and without these tools (see below).</p>
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NB: Interventions in each of the three areas (shifting control, increasing shared understanding and improving communication practice) are closely interrelated and interdependent, e.g. improvement in the effectiveness of communication in clinical encounters through implementation of the communication strategies is contingent upon implementation of strategies in Parts A and B including:

- increased reflexivity, i.e. ability of staff to reflect on their own practices and the ways in which both their communication processes and content are culturally constructed and situationally specific;
- increasing shared understandings for both staff and clients about concepts and communication processes in clinical encounters; and
- reduction of systemic barriers, e.g. shifting control over time, place, participants, focus of encounters through negotiation with client; changing organisational values about valid/necessary workplace activities.

Possible nested projects (to be further negotiated with stakeholders—will require additional funding which will be sought as required):

Informed consent study: Royal Darwin Hospital-based study of Indigenous patients undergoing elective surgery or procedures. Assessment of:

- how consent was obtained;
- use of interpreter service/relatives;
- patient understanding of procedure and risks;
- patient understanding of consent procedure;
- the ability of the strategies to predict understanding of key medical concepts relating to consent (e.g. English competence test or others above);
- the effectiveness of strategies in improving the consent process—and ensuring it is genuinely informed; and/or
- 'Operation Story' video evaluation (see CRCATH Concept proposal).



³⁷ It is expected that these programs will have relevance to other health care contexts and transfer will be a focus in the later stages of the project.
³⁸ A previous CRC submission was concerned with this issue and will be revisited.

Appendix 1.

Summary of health care interactions videotaped in this project.

Interaction 1.

A medical consultation with a 'pending patient' i.e. a patient with chronic renal disease who does not yet need dialysis.

Date of videorecording: 9/5/01

Location: a remote community health clinic

Participants: renal physician; Balan, a patient not yet on dialysis
Balan, his mother and grandmother.

Interviews:

Exit interview with Balan, his mother and grandmother conducted by Yolju researcher on 9/5/01
Exit interview and ethnographic interview with physician conducted by Balanda researcher (AL) on 9/5/01
(Ethnographic interviews were not able to be conducted with patient and his family)

Interaction 2.

An education session providing feedback on blood test results.

Date of videorecording: 21/2/01

Location: Nightcliff Renal Unit patient waiting area

Participants: renal nurse educator; patient, Galikali, who is a long-term dialysis patient.

Interviews:

Exit interview with the patient conducted by the Balanda researcher (AL) on 1/3/01
Exit interview with the renal nurse educator conducted by the Balanda researcher (AL) on 1/3/01
Ethnographic interview with the patient conducted by the Balanda research (AL) on 27/3/01
Ethnographic interview with the renal nurse educator conducted by the Balanda research (AL) on 9/4/01

Interaction 3.

A medical consultation to review the progress of a patient currently receiving dialysis.

Date of videorecording: 14/3/01

Location: a doctor's office at Nightcliff Renal Unit

Participants: Renal physician, renal nurse, patient (Narritjan) who recently commenced dialysis

Interviews:

Exit interview with patient conducted by Yolju researcher on 14/3/01
Exit interview with physician and renal nurse conducted by Balanda researcher (AL) on 14/3/01
Ethnographic interview with patient conducted by Yolju researcher on 27/4/01.
Ethnographic interview conducted with physician and renal nurse on 27/4/01 by Balanda researcher (AL)

Appendix 1. continued ...

Interaction 4.

An education session addressing dietary issues with a new patient.

Date of videorecording: 27/4/01

Location: Nightcliff Renal Unit patient education office

Participants: the educator (an allied health professional); a patient, Baḡaḡi, who recently commenced dialysis, the patient'

Interviews:

Exit interview with patient and his sister conducted by the Balanda (AL) and Yolḡu researchers on 27/4/01

Exit interview with educator conducted by the Balanda researcher (AL) on 27/4/01

Ethnographic interview with educator conducted by the Balanda researcher (AL) on 27/4/01

Interaction 5.

A dialysis treatment session.

Date of videorecording: 13/6/01

Location: the dialysis treatment area at Nightcliff Renal Unit

Participants: renal nurse; Wurrapa, a long-term dialysis patient

Interviews:

Exit interview with the patient conducted by the Yolḡu researcher on 13/6/01

Exit interview with the renal nurse conducted by the Balanda researcher (AL) on 13/6/01

Ethnographic interview with the patient conducted by the Yolḡu research (AL) on 13/6/01

Ethnographic interview with the renal nurse conducted by the Balanda research (AL) on 13/6/01