

Lessons from East Arnhem Land

Improving adherence to chronic disease treatments

BACKGROUND It is generally accepted that adherence or compliance to medical therapy can be poor in indigenous Australian communities.

OBJECTIVE This paper describes approaches and techniques to improve adherence that have been gleaned from four and a half years of clinical experience in the remote district of East Arnhem Land.

DISCUSSION First, the importance of gaining trust and credibility with a community is discussed. Approaches to gain that trust are then described. It is critical to overcome the considerable language and world view barriers that exist to good communication. The use of anatomical models and high quality illustrations combined with the development of 'key language concepts' in the indigenous language have achieved some success in this area.

There has been a major change of focus in the Northern Territory (NT) to the management of chronic disease in the hope that this will reduce the mortality rate from these diseases, particularly in Aboriginal communities. Resources are being directed toward electronic and paper based recall systems, as well as the greater utilisation of preventive health medications such as ACE inhibitors and lipid lowering drugs.

It is acknowledged that the words 'adherence' and 'compliance' are often used interchangeably in the medical literature. For the purposes of this paper, the term 'adherence' will be used. It is understood to describe the degree to which a patient accurately takes a regimen of medication and the degree to which a patient succeeds in lifestyle modifications advised by their health care provider (eg. weight loss or smoking cessation).

Unfortunately, medication adherence appears poor in NT indigenous communities. In 1998, an Arnhem Land study showed adherence to unsupervised oral iron therapy to be less than 5%.¹ Similarly, a 1992 study of antibiotic therapy, also in Arnhem Land showed correct administration in only three of 20 subjects.² A survey of donovanosis

management in the Top End again showed poor compliance to be a major problem.³ Unfortunately (but perhaps understandably) health staff can become demoralised and fall into the trap of 'blaming' indigenous patients for not 'fitting in' with their own medical model.^{4,5}

In contrast, a Tiwi Islands study showed interventions improved both blood pressure control and the prevention of renal failure, suggesting that good adherence was indeed achievable.⁶ It is worth noting that the Tiwi Islanders would have benefited from a significant degree of community control of health programs, a strong focus on health education, and considerable injection of extra health dollars from the MBS/PBS 'cash out'.⁷ By allowing a community to have genuine control of a health service, levels of adherence can indeed benefit from a sense of ownership by the community and more culturally sensitive delivery of health care. However, in practice in the NT, indigenous communities have often struggled to adequately run their own health services due to inadequate funding, inadequate administrative infrastructure or lack of expertise in health service management.

Stephen Bryce



Stephen Bryce, MBBS, DipObs, FRACGP, is Community Medical Officer, Gapuwiyak Health Centre, Northern Territory.

Background

Throughout this paper the term ‘Yolngu’ refers to an East Arnhem indigenous person and the local term ‘Ngapaki’ refers to a nonindigenous person.

The Yolngu occupy much of the district of East Arnhem Land and remain largely ‘unwesternised’ and traditional. Fluency in English is comparatively low. With five years’ experience as a general practitioner in the district, I developed an interest in increasing adherence in an attempt to improve health outcomes in the region. This paper does not attempt to summarise the formidable literature on adherence, rather shares some stories and observations from first hand experience.

The nature of the problem

The Yolngu, along with the general Aboriginal population, have an increased prevalence of chronic diseases such as cardiovascular disease, diabetes, and renal failure. It is accepted as good medical practice that addressing the risk factors for these diseases long before their manifestations present, is the most effective treatment. As with all patients, adherence to lifestyle changes when there are no obvious signs or symptoms of illness is difficult. Added to this innate difficulty is the high rate of modifiable risk factors such as smoking and diets high in saturated fat that exist in the East Arnhem Land population, and the endemic distrust the indigenous population has of Western society, in particular Western medicine.

Establishing credibility with the patient

Literature on compliance shows that the quality of the relationship and level of trust between patient and health practitioner is an important predictor of good adherence^{8,9} and is the first major barrier that needs to be understood and addressed.

Many Yolgnu are suspicious of the basic premises of Western medicine. Some Yolngu have expressed the opinion that the germ theory is a story that Ngapaki propagate to coerce patients into taking Western medications. Other practices such as Pap smears have been viewed as simply a means of gaining superiority over indigenous populations through humiliation.

How trust can be gained

Gaining trust with a traditional Aboriginal community has few short cuts. A powerful aid to

promoting trust and acceptance from Yolngu is to learn their language. This is seen by the indigenous people as an important sign that the practitioner is genuinely trying to see the world from their point of view.

Such trust building is on top of the enormous boost it will provide to one’s effectiveness as an educator and ability to communicate with patients. Aborigines from throughout the NT consistently speak with great respect of any non-Aboriginal who has learned to speak an indigenous language. Employing bodies could consider putting specific incentives in place to encourage health staff to study language.

Yolngu society has traditionally paid greatest deference to old people — that is those over the age of 40. For Yolngu, the elderly were their maps, their libraries, their instruction manuals, their physicians, their priests and their evening entertainment. Such people are still treated with great respect and still wield considerable authority — despite a growing generation gap. Making a good impression with a key older person in a clan can strongly influence the acceptance of a health care worker.

Death is the cultural and ceremonial centre of a Yolngu community. This is reflected in the enormous amounts of time, resources and energy that are commonly invested in people as they die and in their funerals.

When a Yolngu person is dying it is critically important to the community that their medical care is handled diligently and sensitively and that the family is regularly provided with accurate information. Palliative care provides an important opportunity to become a trusted and credible health care provider.

Other important areas to handle sensitively include emergency care and antenatal/obstetric care. It is worth noting the achievements of the Congress Alukura in Central Australia where women’s health services have been specifically set up to be sensitive to the local indigenous culture. Increased participation rates of female Aboriginal patients as well as improved relationships between indigenous groups and the health department were achieved.¹⁰⁻¹²

Communication issues relating to health

There is often a lack of understanding of fundamental health issues in the Yolngu community —

commonly resulting from communication difficulties. There is also considerable ignorance about treatments and how they work.⁴

For Yolngu, having an understanding about their health and treatment options enables them some ownership of their own health. The literature suggests that by giving a patient a ‘sense of control’ of their management can improve adherence.⁹

Some health staff take a ‘keep it simple’ approach when doing any health education with indigenous people. However, local experience has shown that Yolngu usually expect and respect being told their diagnosis and management in significant detail. More traditional Yolngu have extremely detailed anatomical knowledge — with their own names for all important body structures. The ability to build on this knowledge base is a powerful educational tool.

Educational techniques used in Gapuwiyak

As fluency in Yolngu language is likely to remain limited among health professions, other aids to communication are essential. A good way to ‘bridge the gap’ is to use high quality teaching illustrations and anatomical models, combined with use of a collection of ‘key language concepts’ about common diseases.

‘Key language concepts’ are Yolngu phrases that have been agreed with the health workers in discussions around anatomical models or medical illustrations. These phrases are used in the consultation when showing the patient a relevant model or set of illustrations. The resources have proven popular with both patients and health workers and have helped overcome many communication shortfalls.

The Gapuwiyak clinic now has a collection of high quality, relevant illustrations, models and other aids. The most useful is a set of 200 indexed photographs. The sources have been varied, from medical journals and educational catalogues to school texts and drug company materials. Health workers have frequently commented on the improved understanding of many health issues achieved by using this process.

‘Making contact’ with the patient

If the patient looks straight ahead and says ‘yes’ or ‘no’ to everything said and then says ‘thank you’ for the explanation, this does not necessarily mean

understanding has been achieved. Patients in circumstances in which they feel uncomfortable or threatened will say whatever is necessary to bring the consultation to the most swift and painless conclusion possible.

In contrast, explaining a diagnosis using the illustrations, models and ‘key language concepts’ has often been followed by a very animated conversation between the patient and health worker, which is a greater indicator that understanding has been achieved.

Cases in point

After having her chronic obstructive airway disease (COAD) explained to her, an elderly woman asked the health worker and doctor to wait until she returned. When she came back, 15 minutes later, she had 11 of her adult children, nieces and nephews with her. She said (in language): ‘Now, I want you to show the pictures and tell that whole story again.’ She then gave the 11 relatives a stern lecture about their cigarette smoking.

A Yolngu man in his 40s was found dead in his bed one morning. The autopsy showed myocardial infarction. Due to the unexpected nature of his death, sorcery was assumed to be the cause. Interclan tensions flared and there was talk of payback against the alleged secret assassin (a common scenario in Arnhem Land). Our senior male health worker met with the aggrieved family armed only with the models and teaching cards. By the end of the meeting, all tensions and threats of payback had disappeared. Over the next week, several of the dead man’s relatives presented to the clinic requesting a ‘full heart checkup’.

It is important to recognise that Yolngu (particularly older people) believe if a doctor explains a health issue in a way that is confusing or does not make sense, then it is usually because the health professional does not really understand the issue. That is to say, the confusing story is assumed to be an attempt by the health professional to hide his or her own ignorance. Even worse, it may be assumed that the doctor has more sinister intentions. Conversely, if a Yolngu patient hears their health story in a way that makes sense to them then this is considered proof that the health professional is competent. Good communication is an important way to establish credibility.

Developing specific local health education techniques

Aboriginal communities are not homogeneous. Each one has unique local issues and ways of talking about and thinking about health. A health education story developed in one community may not be useful in another. In an ideal world, health staff would stay long enough to get a basic grasp of the language, get a 'feeling' for how their patients think. Then they could develop, test and refine resources tailored to the particular community health needs.

The process of developing a list of 'key language concepts' is central — it is an important relationship building process between health workers and Ngapaki health staff as well as providing the conceptual basis for communication. Enabling people to access health information in a way that makes sense to them is strongly supported by the WHO Ottawa Charter for Public Health.¹³ Yolngu often complain that Ngapaki need to listen more and lecture less — this process is a good first step.

For example, when talking about the concept of a blocked artery, it was learned that the local concept for a blood vessel was a rope or cord ('raki'). Obviously the idea of a blocked rope is meaningless. The explanation was therefore changed to include the word for hollow tube ('gurkurr'). This *gurkurr* becomes clogged ('gungam') with tobacco ash ('ngarali') and fat ('djukurr'). Once we have identified these language concepts, the whole issue of ischaemic heart disease began to make sense to the Yolngu.

In discussing COAD, we describe how the smoke ('ngawulwul') and fire ('gurrtha') enter the lungs ('burruwitj') from cigarettes and then burn or cook ('bathan') the lung tissue. This replaces healthy lung with scar tissue ('barr'). Illustrations of emphysematous lungs are used to support these concepts.

Objective measures of results

In June 2001, a retrospective audit was performed of Gapuwiyak medical records to estimate how much medication patients were collecting from the clinic. In this community, medication is dispensed either in monthly or fortnightly quantities. The onus is on the patient to return for more supplies when they have run out. The audit included notes of adult patients who were on one or more long

term oral medications and living in Gapuwiyak for the 12 months before the audit. Patients with the following conditions were chosen: hypertension, hyperlipidaemia, ischaemic heart disease, proteinuric renal disease, diabetes and hypothyroidism (38 males, 49 females, total 87). The audit found 19% of patients returned for over 75% of their medication, 50% returned for 25–75% of their medication and 31% returned for less than 25%. This compared favourably with the previously mentioned figures.

As another indicator of successful preventive health education, average cigarette sales at the local store have fallen from 7500 boxes of cigarettes and 800 tins of tobacco per fortnight in 1995 to 3600 packets of cigarettes and 32 tins of tobacco per fortnight in July 2001. Also the proportion of maximum strength cigarettes (Winfield Red) has fallen over that period from 95% to 9%. While there are a number of reasons for the drop, including increased pricing and a small but significant black market, anecdotal observations support that health promotion is one factor playing a significant role here.

Recommendations

There are several issues that need to be addressed when attempting to improve adherence in indigenous communities. These include staff building trust and credibility with a community and overcoming the considerable language and 'world view' barriers to good communication. While these issues have been discussed in this paper, there are many others that are beyond its scope. One also needs to address other barriers to adherence such as alcoholism, domestic violence and the 'welfare mentality'. As well, treatments need to be streamlined and simplified as much as possible and systems need to be developed to ensure regular follow up in the face of very limited resources.

The following are recommended.

- Employing bodies should actively encourage health staff to study the indigenous language of the area. Appropriate language learning resources should be made readily available. Also, incentives could be put in place (either financial or professional) to reward staff who have demonstrated a level of language proficiency. Gapuwiyak Health Centre has developed a CD-ROM entitled *Medical Yolngu in 3 Lessons* in an attempt to address this.

- Through cultural awareness courses, health staff should be made aware of how to conduct themselves in critical areas like care of the elderly and palliative care.
- Good quality teaching resources (illustrations, models, CD-ROMs) should be made readily available to remote health staff.
- Staff working in a particular geographical area, in cooperation with indigenous health workers, should be encouraged to develop a list of 'key language concepts' that are relevant to the local language and disease spectrum. Such material should be recorded and compiled for future staff.
- Issues of poor staffing and health care worker 'burnout' should be addressed at a management level so that people are on the ground long enough to achieve the above objectives.

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SUMMARY OF IMPORTANT POINTS

- Two key barriers to good adherence in remote Aboriginal communities are:
 - significant distrust by indigenous patients toward mainstream health staff
 - considerable communication barriers resulting in a poor understanding of disease processes and their treatments.
- There are few shortcuts to gaining trust and credibility with remote Aboriginal patients. However, study of the local indigenous language and the sensitive handling of areas such as the care of the elderly and the dying patient are important ways to help gain this trust.
- The enormous communication barriers that exist can be partially overcome by use of high quality education materials such as illustrations and models. Also, the development of a list of 'key language concepts' in the local dialect (for use with the above materials) has proven highly useful.
- Estimates of medication usage and cigarette sales at Gapuwiyak, NT have suggested encouraging trends as a result of these interventions.

REPRINT REQUESTS

Stephen Bryce
 Gapuwiyak Health Centre
 Community Mail Bag 18
 Lake Evella Via Nhulunbuy, NT 0881
 Email: STEPHENBRYCE@bigpond.com.au