# Health literacy and Australian Indigenous peoples: an analysis of the role of language and worldview

*Alyssa Vass, Alice Mitchell, Yurranydjil Dhurrkay*

## Introduction

The burden of disease experienced by Indigenous Australians in the Northern Territory (NT) is more than three times that of their non-Indigenous national counterparts.[1] The litany of statistics will be familiar to those working in the field. The prevalence of chronic diseases such as type 2 diabetes, renal disease, cardiovascular disease and chronic obstructive airway disease is substantial.[1] Mental health conditions and infectious diseases such as scabies, skin infections and rheumatic fever also contribute significantly to disease burden.[1]

Improving Indigenous health has become the focus of a public 'Close the Gap' campaign,[2] as well as a stated priority of both State and Federal Governments.[3] A broad range of strategies and policies has been developed to enhance public health and health promotion measures.

Various studies in the literature have concluded that low health literacy negatively affects health outcomes and patient safety.[4] In recognition of its potential role in achieving the desired outcomes, health literacy is beginning to be integrated into policy.[5]

The most basic definitions of health literacy describe it as the ability to understand health information such as scripts, pamphlets and doctors' instructions.[6,7] However, as Nutbeam summarises, "This fundamental but somewhat narrow definition of health literacy misses much of the deeper meaning and purpose of literacy for people".[7] There is considerable debate within the literature as authors search for a more complex definition or model for health literacy. Greer, Pleasant and Zarcadoolas developed a comprehensive, detailed model for health literacy using the following definition:

> *"The evolving skills and competencies needed to find, comprehend, evaluate and use health information and concepts to make educated choices, reduce health risks, and improve quality of life. A health literate person is able to apply health concepts and information to novel situations. A health literate person is able to participate in ongoing public and private dialogues about health, medicine, scientific knowledge, and cultural beliefs. This dialogue, in turn, advances health literacy, individually and collectively."*[8]

However, there is little research that explicitly seeks to examine the impact of Indigenous-specific factors on health literacy.

Some research has been done exploring Indigenous perspectives on various diseases, for example cancer[9] or diabetes.[10] These reveal, in general, that traditional and contemporary Indigenous beliefs about the causes of illness can vary considerably from biomedical explanations. Anthropological studies have also highlighted these differences in worldview. Worldview can be defined as the way that groups of people categorise and conceptualise their reality. It is the foundational philosophy that informs each group's perception of their respective worlds. Reid[11] explored the worldview of healing of Yolŋu, the Indigenous people of north-east Arnhem Land. She concluded wellbeing and sickness are inextricably linked with human behaviour, social order, ritual practice, sorcery and spiritual wellbeing.

**Abstract**

This article delineates specific issues relating to health literacy for Indigenous Australians. Drawing on the extensive experience of the authors' work with Yolŋu people (of north-east Arnhem Land) and using one model for health literacy described in the international literature, various components of health literacy are explored, including fundamental literacy, scientific literacy, community literacy and cultural literacy. By matching these components to the characteristics of Yolŋu people, the authors argue that language and worldview form an integral part of health education methodology when working with Indigenous people whose first language is not English and who do not have a biomedical worldview in their history. Only through acknowledging and actively engaging with these characteristics of Indigenous people can all aspects of health literacy be addressed and health empowerment be attained.

**Key words**: health literacy, health belief, health education, health promotion, Indigenous

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**So what?**

The health literacy of Indigenous Australians can be improved by promoting the oral use of the people's first language in the health sphere and the use of in-depth language and worldview-based educational methodologies. It is also necessary to support Indigenous patients in decoding public health information and to place greater value on the Indigenous health worldview.

There has also been some research exploring the impact of language differences to effective communication and understanding within the health sphere. English is frequently a second language for Indigenous people in the NT. Following in-depth evaluation of clinical interactions with Indigenous patients, the authors of *Sharing the True Stories* found that "the vast cultural and linguistic distance between staff and patients … impeded communication".[12]

In this paper, the authors will argue that it is these two factors – language and worldview – that are the linchpins that determine the advancing of health literacy in the Indigenous context where English is a second language.

The authors will use the model of health literacy described by Greer, Pleasant and Zarcadoolas[8] in their article *Elaborating a definition of health literacy: a commentary* to draw out the interplay of these two factors, particularly in relation to Yolŋu people.

By illuminating existing barriers to health literacy, we aim to show potential areas for improving health education and communication. The paper will draw on the collective professional experience of the authors and their Yolŋu and non-Indigenous colleagues at Aboriginal Resource and Development Services (ARDS), using vignettes from our experience to highlight the key arguments.

## Setting

The authors are all health educators at ARDS and between them have many years of medical, nursing, linguistic, training and health education expertise with Indigenous, and particularly Yolŋu, patients, staff and communities

ARDS is a non-Government, Indigenous community development organisation. Under various names, the organisation has been working with Indigenous people across the NT for many decades. ARDS has developed significant expertise in health literacy over the past 10 years by working primarily with Yolŋu.

There are about 8,000 Yolŋu,[13] the majority of whom live in the communities of far north-east NT. There are also a number of smaller homelands or outstations situated on ancestrally connected lands.

Yolŋu have a complex system of languages; it is generally recognised that there are six different languages, made up of up to 50 different dialects, collectively called Yolŋu Matha. Most Yolŋu are multi-lingual, but do not speak English as a first language. In general, English is only used during their occasional interactions with non-Indigenous people.[14]

Yolŋu also continue to practice many of their traditional cultural ceremonies and maintain a strong connection to their traditional kinship, legal, governance and health systems. Yolŋu do not have a biomedical worldview in their history and yet are increasingly involved in interactions with a biomedical, Western health service due to an ever-increasing rate of disease.

Each major Yolŋu community is serviced by a community health clinic. Health services are provided by a mixture of doctors, nurses, Aboriginal health workers, public health officers, health promotion and education teams, and community workers.

## Key domains of health literacy

Greer, Pleasant and Zarcadoolas[8] describe four key domains of health literacy – fundamental, scientific, community and cultural. We will explore each of these domains in turn, highlighting how understanding the role of language and worldview form the foundations for understanding health literacy with Yolŋu.

## Fundamental literacy and numeracy

The first domain in Greer, Pleasant and Zarcadoolas' model is *fundamental literacy and numeracy,* which is "competence in comprehending and using printed and spoken language, numerals, and basic mathematical symbols and terms".[8]

Fundamental literacy significantly affects health literacy for Yolŋu primarily because the health sphere is English dominated. Health information, diagnoses and instructions are generally discussed using English. Because English is usually a second language for the Yolŋu people, fluency in and understanding of spoken and written English is highly variable in this population. Also, access to appropriately trained interpreters and tools such as Indigenous language dictionaries is limited.

Many health promotion programs tend to address this issue by making pictorialised messages. What this fails to recognise is that pictorial literacy is different across cultures, potentially limiting the efficacy of this type of health promotion. Kress explains, "The placing of the elements of image and writing on the space of the screen (or of the page) matters because that placing expresses principles of visual grammar through which this now visual entity is organised".[15] This visual grammar is different for different cultural groups and thus perceptions are not uniform.

Pictorialised messages also tend to be quite simplistic, and therefore do little to address the other core areas of health literacy, contributing little to health empowerment. Commonly encountered traps with pictures include placing an image of an organ by itself on a page without contextualising it within a human body, drawing microscopic creatures in an out-of-size context and assuming knowledge of the microscopic world, and diagrams of smoke inhaled by a mother reaching a baby in utero. These can all lead to confusion because they depend on assumed non-literal interpretation of the messages in the pictures.

The authors maintain that low levels of fundamental literacy need not be a barrier to improving health literacy. Oral education or information dissemination in the first language of the patient or community can counteract communication failures and information deprivation.

However, this is not as simple as translating the words. With most, if not all Australian Indigenous languages, extensive exploration of the 'areas of meaning' of words that exist in specific domains, such as health, has not happened. English terms that non-Indigenous people might consider simple, carry significant conceptual information for which there may not be an easy match in Yolŋu Matha and vice versa. This is because the worldviews are so different. Yolŋu need to understand the concept before they can understand the word, or apply a term from their first language. For many of these words, little work has been done to find accurate translations, which severely hampers the use of English health terms.

A few examples that we have encountered that are not easily translated from English into Yolŋu Matha are the terms pain, muscle

(as contractile tissue), cell and infection. Likewise, with Yolŋu Matha words; the Yolŋu Matha term *ŋir'yun,* which is often translated as breathing, has a greater area of meaning than the biomedical function of the lungs. The term also incorporates elements of the following English words and concepts: life, spirit, the movement of the heart (but not its function in a circulatory sense) and pulse (as felt at various parts in the body).

## Scientific literacy

The second domain of health literacy described by Greer, Pleasant and Zarcadoolas is *Science and technology literacy*. This is "knowledge of fundamental health and scientific concepts, ability to comprehend technical complexity, understanding of common technology, and an understanding that scientific uncertainty is to be expected."[8]

This domain is one of ARDS primary focuses. Extensive education experience with Yolŋu has revealed that a number of key foundational biomedical health concepts are not present in the Yolŋu worldview, and thus have no words that correspond, hampering communication and understanding. This is because language intimately informs worldview.[16]

One of these foundational scientific concepts is the microscopic world. This has significant implications for understanding the germ theory of disease, post-infectious complications such as rheumatic fever, and diseases such as cancer.

Circulation and digestion are two other biomedical processes that are not within the traditional worldview. Dialogue conducted during education sessions has shown that traditionally, Yolŋu do not perceive the blood as circulating around the body, nor that food is broken up into small (microscopic) pieces and absorbed into the circulation to be utilised as nutrients, energy, etc. Yolŋu understandings about the role of blood in the body are highly sacred knowledge and appear quite different from the physiological process.

The following vignette reveals how understanding these foundational concepts is essential for effective decision making in the contemporary health setting.

> *ARDS health educators and an interpreter were assisting a doctor to obtain informed consent from a patient who needed surgical treatment of an abscess in her leg but who was quite reluctant to have the procedure. The abscess was causing compression of her femoral artery. At one point, describing the need for adequate circulation and perfusion, the doctor said, "If we don't remove the abscess, the oxygen and nutrients won't be able to get to your leg." The interpreter had received some training in biomedical concepts and thus translated "oxygen and nutrients" as "air and food", the only easily accessible translations from a non-science perspective. The patient replied, somewhat incredulously, "What food and air? What are you talking about?" At this point, the consultation broke down because of worldview knowledge gaps related to circulation and digestion.*

Another aspect of science or biomedical literacy is to understand the biomedical concept of being 'sick'. When non-Indigenous staff use the word 'sick', the meaning is context dependent. It may be acute or chronic, infectious or non-infectious, curable or manageable only etc. When Yolŋu people use the dominant Yolŋu Matha word for sick, *rerri*, they have very different connotations. It appears to be essential that one feels and/or looks sick. Diagnoses are often translated by naming the body part affected and then adding *rerri*. For example, **ḏoṯurrkpuy rerri** for heart disease. However, the same phrase can be used to mean heart attack, chronic heart failure, valvular disease, acute rheumatic fever or any other disease affecting the heart. ARDS educators have seen that this can then create extreme confusion or misunderstanding when trying to discuss, for example, the differences between infectious illness and chronic disease, particularly in relation to treatment.

Further to this, if one does not actually feel sick, it is difficult to use such phrases.

> *A mother was adamant that her daughter was not sick because she was able to regularly participate in local basketball games, when in fact she was on dialysis due to end-stage renal failure. ARDS educators attempted to explain in her own language that her daughter's kidneys were not working properly, but the dialysis was treating her such that she had no symptoms. However, the mother consistently wanted to know whether the doctors were telling the truth when they said her daughter had* **ḏiny'ṯinypuy rerri** *– kidney sickness. The use of the word rerri was stretched in this context.*

This has significant implications for early intervention, ongoing management and prognosis, as well as simply gaining the attention of patients and communities to create dialogues around health.

However, Indigenous language can be used creatively and intelligently to improve scientific literacy effectively. The following vignette illustrates this point.

> *ARDS recently completed a DVD about antibiotics in Yolŋu Matha (with English subtitles). Antibiotic resistance was a significant and challenging concept on which to reach a shared understanding. Through dialogue conducted in Yolŋu Matha with ARDS health educators, Yolŋu were able to consider new, biomedical information about antibiotic resistance and find an equivalent term. This term generated the same concept, but was not a direct translation. The Yolŋu Matha term selected was drawn from traditional warfare. It refers to knowing how your enemy fights and what his strategies are so that you can predict his actions; you can counter his attack because of your knowledge about him and successfully resist him. These terms (in context) can be applied to bacteria that become familiar with antibiotics and become resistant to them. More importantly, it creates an immediate intellectually meaningful picture for Yolŋu that the English term 'resistance' does not.*

Contributing further to the challenges of the scientific domain of health literacy is the presence of the scientific uncertainty that pervades medical treatment and advice. This relates to both the changing nature of scientific knowledge, but also the implicit understanding of risk at individual and community levels. The concept of risk (as an abstract notion) does not appear to exist in Yolŋu worldview.

What does appear to be known regarding risk is a much more concrete appreciation for specific and immediate situations that

are (potentially) dangerous to one's life. No words seem to exist for 'danger' or 'safety', rather each situation is seen to have its own warning signs, actions to take and outcomes.

> *When walking through the bush it is known that fresh buffalo excrement is a sign that such an animal may be nearby. If a buffalo is then seen or heard, certain specific actions should be taken, such as standing very still or running to and climbing a particular type of tree. Not taking these actions can be called being* **dhuḏi-dhäwumiriw** *(not knowing, or not acting upon, specific knowledge for this situation) and the implication is you will be killed.*

There appears to be no conceptual frameworks for understanding degree of risk, nor how multiple risk factors may interact with each other or vary in impact relative to time and exposure.

The Western worldview of risk is a foundation of health promotion and preventative measures such as screening, certain chronic disease medications and behavioural strategies. The difference in worldview of risk creates great difficulties for Yolŋu as they attempt to interpret mainstream health promotion messages or understand the relevance of healthcare to their immediate lives. By dialoguing in Yolŋu Matha, it is possible to find points of worldview crossover, and use them as starting points for health education.

## Community literacy

The third described domain of health literacy is *Community or civic literacy*. This is "knowledge about sources of information, and about agendas and how to interpret them, that enables citizens to engage in dialogue and decision making".[8]

For Yolŋu, community health literacy is especially important in relation to understanding Western health systems. Many Yolŋu people often have a limited understanding of what a hospital or clinic is, what the inter-connecting roles of different staff and departments are, and what are expected patient behaviours, responsibilities and rights. For example, Yolŋu inpatients often do not realise that it is expected behaviour to remain in their allocated beds, particularly at key times such as ward rounds.

The following vignette further reveals the potential impact of language, understanding hospital structures and patient rights on patient outcomes.

> *An elderly woman was in the emergency department following an acute myocardial infarction. Once she had been stabilised, the nurse informed her she was being moved to RAPU. Following this, the patient became quite agitated and anxious, refused the medication she had been prescribed and eventually tried to leave the hospital. At this point an ARDS educator was contacted who talked with the patient in her own language and discovered that she had no understanding of what RAPU was. The patient had become frightened because she believed she was being transferred interstate, not down the corridor to the 'Rapid Assessment and Planning Unit'. She also did not have an understanding that such a transfer would not happen without her consent.*

The worldview that creates and sustains these Western health systems does not exist traditionally in the Yolŋu world. Traditional healers and medicines function in a different, yet equally rich, complex and sustaining way in Yolŋu societies.[11]

Community literacy also relates to a person's ability to understand how health messages interact with broader Western systems. ARDS educators have commonly found a lack of understanding within Yolŋu communities, as the following vignette shows.

> *Following an education session about the negative impacts of smoking, an ARDS educator began to explain that the government made laws that prohibited people from smoking in certain places because it recognised that smoking was harmful to health. At this point one participant said "They should just not make cigarettes in the first place!" Underpinning this conversation is a lack of understanding of who makes cigarettes and for what purpose, and the role and power of governments to regulate for public health purposes.*

## Cultural literacy

Finally, there is *Cultural literacy,* which is "recognizing and using collective beliefs, customs, world-views and social identity relationships to interpret and act on (as well as produce) health information".[8]

It should be evident from the above discussion that the interplay between the two different worldviews of Yolŋu and Western health systems is a significant factor in health literacy. Understanding the Western collective beliefs about health is difficult for Yolŋu. There is not a word in Yolŋu Matha that easily denotes the English meaning of health. The Yolŋu concept of 'health', as with many other Indigenous groups, is a comprehensive entity of *wellbeing* that is linked with land, law and relationships.[17] Deep and complex elements bound together enable the society, the country and the people to be in a state of wellbeing.[18]

For non-Indigenous health staff, cultural literacy is an area in which there is a need for continual improvement, particularly in relation to understanding Indigenous frameworks of health – both traditional and contemporary. Some attempts have been made within mainstream health services to incorporate the cultural differences of Yolŋu – many health clinics have separate men and women's areas; local people are employed as community liaisons, cultural brokers and clinical assistants; and Indigenous artworks are commonly used in health promotional material. However, it is the authors' contention that until the depth of worldview and language issues are recognised, non-Indigenous cultural literacy of the Indigenous worldview will remain limited.

The authors also propose that cultural literacy is the domain of health literacy that contains the potential for true inter-cultural dialogue about heath in a broader sense than biomedical models, and allows for a respectful equalising of the two worldviews. Here we find the capacity for the Yolŋu worldview to inform the processes of health promotion, for Yolŋu languages to carry culturally applicable health information, indeed for Yolŋu to produce their own health information and interventions.

## Conclusion

This paper has explored health literacy within the Australian Indigenous context, where English is a second language, by drawing on the collective professional experience of ARDS.

While language and worldview differences could be considered barriers to improving health literacy, it is our contention that effective methodologies for improving health literacy are those that are based on these two key elements.

In-depth dialogue in Yolŋu Matha allows for access to the existing Yolŋu knowledge base and worldview. From there, Yolŋu Matha equivalents can be found for new English health and biomedical terms. The alternative is to continue to use English terms, no matter how seemingly simple, that people do not fully understand.

Furthermore, this process allows Yolŋu to own new knowledge in a way not possible when it remains situated within the Western health and English domains. New understandings from the non-Indigenous health sphere can be situated within Yolŋu culture and meaningfully integrated. Health empowerment through these processes also creates opportunities for Yolŋu understandings of health to inform and contribute to Western understandings.

While words and worldview concepts vary between Indigenous nations, the principles of working in-depth in language and through the Indigenous worldview are likely to have relevance to any Indigenous groups who do not speak English as a first language and do not have a biomedical or Western worldview.

We would recommend that further research be undertaken into models exploring health education that use the language and worldview of Australian Indigenous people in order to advance health literacy and therefore health outcomes.

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### Authors

*Alyssa Vass, Alice Mitchell, Yurranydjil Dhurrkay, Aboriginal Resource and Development Services, Winnellie, Northern Territory*

### Correspondence

*Alyssa Vass, Aboriginal Resource and Development Services, Box 36921, Winnellie, Northern Territory 0821; e-mail alyssa.vass@ards.com.au*