

Diet, diabetes and relatedness in a central Australian Aboriginal settlement: some qualitative recommendations to facilitate the creation of culturally sensitive health promotion initiatives

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Introduction

WHO predicts that without concerted local and global efforts, diabetes death rates will increase by more than 50% over the next 10 years, bankrupting ill-equipped health care systems worldwide.¹ Since the lethal scope of diabetes mellitus disproportionately targets Indigenous peoples, the United Nations has addressed the issue with a decree that “right to health” requires governmental bodies to ensure “health facilities, goods and services accessible to all”.²⁻⁵ Yet Indigenous peoples continue to be short-changed as too often medical initiatives ignore, minimise or vilify the local and socio-cultural circumstances of Indigenous health.⁶⁻⁸ In the

past decade, important studies conducted in the Northern Territory (Australia) have demonstrated that social, economical and political factors on the health of Aboriginal and Torres Strait Islander peoples need to be taken into account to design culturally-sensitive health promotion programs.^{9,10} However, the practical implications of their research have been met with resistance.¹¹⁻¹⁴ Moving away from a focus on risk factors, the goal of this paper is to provide a better understanding of localised indigenous notions of caring to humanise relationships between patients and medical staff, and assist in the creation of culturally sensitive and pragmatic community-based health promotion initiatives.

Abstract

Issue addressed: At the request of chronically-ill Aboriginal patients in Central Australia with whom I have worked for the past 25 years, ethnographic research was conducted to provide a better understanding of how diabetes sufferers cope with their illness in everyday life for the creation of more culturally sensitive health promotion initiatives.

Methods: Based on analyses of participant-observation data and semi-structured interviews over an eight month period with 84 Aboriginal diabetic sufferers and their kin, as well as conversations with medical staff working at the local clinic, this paper discusses contemporary Aboriginal contemporary dietary practices, post-colonial demand-sharing economy, deployment of various regimes of care and health promotion initiatives.

Results: Diabetic patients lack access to what is determined key by health care providers to offset ill-health such as diabetic-friendly food. In order to cope and make sense of their chronic illness, diabetic patients oscillate between different regimes of care – biomedical, demand-sharing economy, and traditional and Christian religious institutions.

Conclusion: To ensure a certain measure of success, long-term health promotion initiatives need to be grounded in a Warlpiri caring praxis of ‘looking after’, and rely on realistic collaborations among patients and their kin, local health care providers, and other community-based organisations.

Key words: Aboriginal people, Central Australia, diabetes, relatedness, health promotion initiative.

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So What

An analysis of ethnographic qualitative data on diet and sharing practices provides a basis on which to ground much-needed partnerships between medical establishment and patients to assist with the creation of a culturally-sensitive and pragmatic health promotion program in the socio-political complex environment of what is often called ‘remote’ health.

Background

Building on recent paradigmatic works, which examined the historical contexts of health disparities, an ethnographic study was instigated on how Warlpiri men and women living in a Central Desert settlement cope daily with chronic illness such as diabetes mellitus.^{15,16} Warlpiri men and women are 10 times more likely to suffer from diabetes mellitus than non-indigenous peoples, and according to conservative statistics collected in 2004 by the local clinic, 35% of people who live in the settlement, between the ages of 15 and 60, have diabetes.^{17,18} As with most Aboriginal peoples in Central Australia, Warlpiri people were forced to abandon a healthy nomadic lifestyle in 1946. Brought from various areas, the newly settled Indigenous populations had every aspect of their lives controlled by the Director of Social Welfare and his proxies. Food habits changed dramatically under a ration-regime, and tastes were reshaped by daily intake of sweet milky tea, white bread, domesticated animal meat, salt, sugar and tobacco.^{19,20} If food consumption was transformed by colonial and post-colonial eras, so have regimes of care. Today, the experiences of chronic illness and the search for coping, are shaped by the nature of kin relations, engagement with biomedical organisations, traditional health practitioners, as well as Christian congregations. Warlpiri people have now come to rely upon these institutions, often at odds with one another, for care, treatment and solace; thus, it is against this background that health promotion initiatives need to be locally-formulated and negotiated.

Methods

Between October 2006 and June 2007, I conducted in-depth qualitative interviews with 84 diabetic patients (60 women, 24 men, 10 employed by CDEP, two employed by the school and the rest were unemployed) between the ages of 16 and 81, as well as with 14 family members of diabetic sufferers. In accordance to the National Health and Medical Research Council's (NHMRC) guidelines, one of the aims of this research was to engage patients, kin, and medical staff

in reflecting on ways to better the everyday life of diabetic sufferers.²¹ The age distribution of sufferers of diabetes is illustrated in Figure 1.

Prior to conducting an interview, each person was provided an informed consent form outlining the purpose of the interview. All the interviews were conducted in Warlpiri – the main Aboriginal language of the people who reside in the settlement – by the author (FD) and were written down. Interviewees did not feel comfortable with the use of a tape recorder. One of the diabetes sufferers with whom the interviewer has worked for more than two decades provided assistance with translation into English. The research was also discussed with several members of the local clinic. Combining methodologies from interpretative phenomenology and thematic analyses, interviews were coded to identify how diabetic patients construct their experiences of living with diabetes and its related illnesses in everyday life. During eight months in the field, the daily routines of 12 diabetes sufferers (eight women and four men) were followed for three months to collect data on their dietary habits, daily activities, interactions with health care providers at the local clinic, traditional and Christian healers. More than half the interviewees and five of the eight medical staff also discussed possible initiatives that could better the everyday life of diabetic sufferers in the settlement.²²

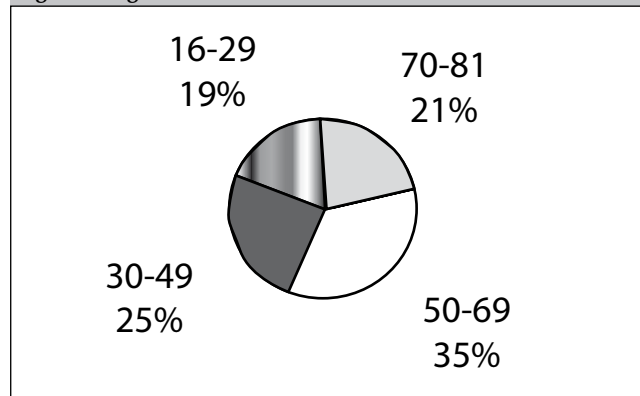
Discussion of ethnographic data

Food habits tell cultural tales, not biological ones²³

Currently, the diet of the 800 Warlpiri people who live in this Central Desert settlement is inordinately low in fibre and high in total fat, saturated fat, sugar, and refined foods. Six decades of settled-life have redefined bush-food access and consumption.²⁴ Interviews revealed that both men and women, regardless of age, divide food into two categories, bush and store-bought. They distinguish three kinds of bush- and store-bought food: essential or good/proper (*ngurrju*) for which people are 'ravenous' or 'hungry for', delicacy (*pama*) and supplemental or food needed to accompany essential food and 'snack' food (*miyipardu*). Ideally, game meat should always be supplemented with yams and other vegetable gathered in the bush. Seasonal delicacies accompanying game meat and yams, according to interviewees, such as honey, witchetty-grub, bush raisins, or bush tomatoes would make any senior Aboriginal person perfectly content. But such feasts have become rare in the intricacies of post-colonial settled life.

If bush-foods from bio-medical and Warlpiri perspectives are unequivocally considered healthier, Warlpiri valuation of store-bought food rests on unsteady ground due to a history of conflicting and confusing mainstream, 'bio-medical' advice.

Figure 1: Age distribution of interviewees.



Between 2006 and 2007, most of the food items available and affordable at the two settlement-run stores were purchased with the main sources of cash available at the settlement – governmental welfare income, salary, revenues from art sales and gambling. These food items were described in conflicting terms as tasty and as diabetic-unfriendly in all interviews as illustrated in the following excerpt:

“What we buy here [we are told by nurses and doctors] is too fat and too sweet, but [it] tastes good. We are told that it is full of sugar and that it is bad for us. But I like sweet things.”
(56-year-old diabetic man)

With little access to bush-food, the daily regimen of an adult – when money is available – usually consists of the essential store-bought red meat combined with white bread, and/or potatoes, pasta or rice, soft drinks (diet and non-diet), sweet milky teas or other sweet drinks such as cordial or fruit juices. Chicken remains a sub-standard meat item to beef, lamb or sausages. Potatoes, pasta and white rice and even frozen pizza, are prized over other store-bought fresh vegetables such as pumpkin, cabbage or carrots, but all are considered supplemental. While older generations rank tomatoes, grapes, bananas, apples, mangoes and oranges as delicacies, younger generations tend to see them more as supplemental food. Men and women between the ages of 18 and 45 ranked the following delicacies higher than fruits: ice cream, potato chips, meat pies, biscuits, chocolate and candies. It is important to note here that all these delicacies are quite expensive compared to other locally conceived essential items. If fresh or frozen foods (including frozen cooked meals) cannot be purchased, canned meat and preserves are consumed for the midday meal. **Embedded in a demand-sharing economy constitutive of Aboriginal social relations guided by a strong egalitarian ethos, every Warlpiri person is pressured daily to share and reciprocate food items.**^{25,26} Lack of access to food will make any person feel neglected by his or her kin, especially if they feel ill. In an environment rife with stress and constant pressures for generosity, store-bought prepared foods are a welcome relief in the daily negotiation of post-colonial kin relatedness. Prepared foods were rated by all interviewees as the most convenient (producing least stressful condition) as they necessitated little deployment of social engagement apart from a financial input. They require little to no heating up; they can be consumed instantly, thus not necessarily at home, and shared.

Autonomy and caring

To be successful, any initiative to better the health of diabetic patients must be cognisant of the delicate balance between personal autonomy and social obligations embedded in a demand-sharing economy.^{27,28,29} The traditional nexus between Aboriginal notion of personal autonomy and caring

or “looking after” - *jinamardani* or *warrawarrakanyi* in Warlpiri – still prevalent among Warlpiri people runs often counter to Western assumptions about autonomy and care. The paradigmatic declaration of personal autonomy distilled in the following statement by an adult Warlpiri: **“I am boss for myself. I can decide for myself, no one can decide for me,”** hints at the fact that the imperative form and associated threats, so pervasive in bio-medical diagnosis and recommendations, is an anathema to the Warlpiri people. For example, **daughters or sons cannot ask a diabetic parent to refrain from eating shared food that is ‘too fatty’ or ‘too sweet’.** Why? The demand would infringe on the patient’s personal autonomy, **who alone may decide what to eat and when.** Here we can start to understand why Warlpiri patients tend to recoil when subjugated to biomedical imperatives clashing with indigenous forms of sociality.³⁰ The breadth of this conundrum finds its clearest expression in the following excerpts from respectively a diabetic patient and a relative struggling to regain a sense of personal autonomy, to perform kinship obligations meaningfully, in short to maintain their humanity:

*“They [biomedical staff] say that my diabetes will kill me if I do not take pills everyday and if I do not eat right. Sometimes I forget. **I eat with my kin. I cannot be selfish and eat my food alone. I cannot do what they tell me to do.** I have to decide for myself. They scared me! They told me that I will die if I do not listen. Well, I will die soon anyway.”* (28-year-old diabetic woman, 2007)

Later one of her close relatives confided her sense of despair:

“We are worried [for her], and we have so many responsibilities towards our relatives today. So many [of our relatives] are ill. When a person is really sick, like being on the [dialysis] ‘machine’ we do not know what to do for them, they have to go away [nearest town, 300 km away]. We are not sisters [medical nurses], they know what to do better than us. Nurses and doctors have to take care of our sick relatives here so they do not leave the settlement, because they cannot stay apart from us [their kin] for too long...” (54 year old woman, 2007)

If patients can withstand physical discomfort associated with chronic illness, they find their separation from the settlement and their kin insurmountable. While their kidneys may get cleansed some hundreds of kilometres away, their sense of identity decays, their sense of usefulness turns toxic, and their relatives are deprived of their caring roles as well.

Traditional healing practices

Most diabetic patients interviewed refer to diabetes as ‘the blood sugar’ disease perceived as a direct consequence of **settled life** – defined in opposition to their hunting-gathering pre-colonial life – **environmental pollution** and **lack of an**

adequate health care system. While diabetes itself as a diagnosis is rarely discussed or attributed to sorcery, the related symptoms that accompany diabetes – sleepiness, headaches, backaches, gangrene – **are articulated and often explained in light of older physical injuries originally caused by sorcery.** To cope with such symptoms, people with diabetes will **often combine different healing practices such as their biomedical regimen of pills, visits to the local clinic, as well as ethnomedical and Christianised health-curing rituals.** Both the Aboriginal doctor (Ngangayi in Warlpiri) and Christian congregations are seen as more caring agents who are too often negatively contrasted with the **perceived less empathic environment of the local clinic.** More than half the interviewees – among the older groups – saw an Aboriginal doctor at least once after receiving their biomedical diagnosis of diabetes, to seek treatment for symptoms interpreted by the clinic staff as associated with the onset of diabetes and attributed to sorcery actions by both patients and Aboriginal healers. During the fieldwork period, there were only two male healers, living respectively 50 km and 200 km away from the settlement. Thus, close relatives assumed the responsibility to organise a vehicle for the trip, money for petrol and payment for the consultation. The visits often took place late afternoon or in the early evening, hours propitious to the intertwined expressions of pain, worry and care. And if traditional healers were found at such hours, the local clinic was shut and staff only accessible for biomedically defined emergencies. In most cases, patients believed that the counter-spells uttered **by the healer would alleviate their sufferings, but could not remove their diabetes.** When, after several days, aches and pains returned, patients openly voiced their discontent with both biomedical and traditional treatments of pain. Slightly disenchanted, most sufferers reclaimed attention and care from their senior relatives who sing songs from the Dreaming to ease pain and restore health. If most diabetes sufferers saw their visits to both the clinic and the Aboriginal doctor as actions embedded in the deployment of a larger caring system, **the youngest diabetic patients (18 and 27 years old) did not want to engage with medical staff or traditional healers.** In fact, most rejected the dividends of all healing practices, and young men even more acutely.

Christian healing practices

Faced with chronic illness and limited options to avert it, to say little of their political and socio-economic status, Aboriginal peoples, living in remote communities have increasingly turned to Christianity to cope with their ill-health. For converts aged between 30 and 49, Christian congregations often provide empathic answers to chronic illness. While access to both traditional healing rituals and biomedical services relies on complex kin negotiations as well as cross-cultural

interactions, Christian healing rituals are free and accessible by all at any time of day or night. However, **Charismatic-healing performances come at a price as it discourages access to any other healing protocols** as illustrated in the excerpt below:

“Only the Almighty saves, not your pills. Quit your drinking, clean the rubbish around your homes, do not eat apples as they are the fruit of evil [unfortunately the most affordable fruit for sale at the local stores], abandon the rituals of the past, because God is the only way. If you listen, then Jesus will be in your heart, then you can be saved. So I have to believe.”
(41-year-old Warlpiri male with chronic kidney disease)

These new imperatives collide harshly with a demand-sharing economy, the support relatives offer to the sick and biomedical treatments. This may explain why 14 of the 84 interviewees and aged between 30 and 49 who had embraced Charismatic Christian faith, engaged sporadically with all healing practices or one or two. The nature of their ambivalence towards choosing a path to better health is crystallised in the following quote:

“Some people think God will save them. Maybe God cares. I do not know. The traditional healers, most of them are fraud, and nurses do not care about us. They tell us that we are sick, we only get pills and then nothing happens. Pills are the only thing [treatment] we get so we get sick again. Nurses never listen to our stories [about why we are sick], and when we need them, the clinic is closed and they hide in their houses. They [nurses] come, then they leave. We never know them, and they do not know us.” (68-years-old-male with chronic illness)

Embedded in this last quote is a recurrent theme: a call for creation of ‘looking after’ relationships between health care staff and patients – the driving force behind Warlpiri caring praxis.

Conclusion: preliminary recommendations

There have been some noteworthy efforts to improve the health of Aboriginal peoples in the Northern Territory, and most notably the five-year long project (2001-2005) *Sharing the True Stories: Improving Communication In Indigenous Health care* conducted among the Yolngu people of North-East Arnhem Land.⁹ However, such long-term interventions all too often fall short because of high turn around in medical staffing, inadequate funding, and a focus on acute health care delivery that takes the local medical staff away from prevention and health management.³¹⁻³³ For a health promotion program to succeed it must take into account how patients live and access different regimes of care. **Programs need to be fiscally lean, designed to function within the structures of Aboriginal social organisations, sustain high turn-around in medical staff, partner with other local agencies and programs and grow.**³⁴ In order to create bonds of relatedness, interviewees suggested

that the program could adopt a two-pronged approach. Such focused community-based interventions could combine workshop-sessions run by health-care staff and held where patients live with caring relatives, as well sessions organised to elicit conversations between diabetic patients of the same age group and medical personnel. These combined events would create social spaces where the following initiatives, suggested by patients, to promote better health could take shape. Creating partnership among patients, relatives and health care providers to devise daily and weekly menus, using available resources at the local grocery stores and cognisant of Warlpiri notions of a 'proper' diet. Enabling the creation of a diabetic-friendly take-away establishment. This initiative was mentioned as one of the most efficient solutions to better nutrition by all interviewees. Diabetic-friendly take-away foods would be a welcome relief from the daily struggles to find proper ingredients, a place and pots to cook with, and engage in sharing the wrong foods. Developing culturally sensitive and sustainable physical activity programs catering for different age groups and genders. Medical staff in collaboration with other local organisations – art centre, women's centre, senior centre, youth centre, police station, school, local shops – could promote and participate in hunting and gathering activities, gendered sports activities, dance competitions and other physical activities non-Indigenous people enjoy. These interactions would enable the participants to develop with the medical staff better trusting relationships key to better health results as articulated by the NHMRC guidelines. Institutionalising two or three outings per year in the bush with several patients, their kin and medical personnel. These trips would enable patients and their kin to give back and care by sharing their spiritual and environmental knowledge of their land with medical staff who cares for them. Younger interviewees, aware of a similar project undertaken in Yolngu territory, discussed the possibility of creating radio segments in collaboration with their on-site community-run media organisations. These programs would be created in partnership with diabetes sufferers and medical personnel to sensitise listeners to chronic health issues from a wide range of perspectives beyond the biomedical realm.³⁵ Young interviewees also mentioned the importance of having a mediated space on the Internet such as health chats with other sufferers and medical specialists. Several proposed to create diabetes-awareness activities such as song-writing and painting. Clearly these initiatives require planning, a willing medical staff, co-ordination among the different settlement's organisations, and a sound reward system and oversight. The health situation is dire in Central Australia, and interactions based on relatedness between health care providers and Aboriginal peoples can only be a step towards a better health.³⁶⁻³⁹ If the different initiatives sketched out above may

seem fraught, they are the first practical steps in providing both the settlement inhabitants and health care providers the means to re-articulate their own ideologies and practices about health, illness and regimes of care. As one frustrated interviewee succinctly summarised the issue about diabetes among her people: "We need help now, not tomorrow because we will be dead."

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