

URAPUNTJA HEALTH SERVICE AND UTOPIA COMMUNITY

**A REPORT TO THE TEASDALE-CORTI COMPREHENSIVE PRIMARY HEALTH CARE PROJECT
'REVITALISING HEALTH FOR ALL'**

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This project has brought together for us and the rest of the world, through the efforts of the GHRI, an extremely important document that can be held for the community for many years to come. It has shown us that we have many friends and relationships across Australia that contribute in strength, support and knowledge to bring us to the place we are today. We can see that the Utopia community has befriended many, shown much compassion and returned a spiritual blessing to all who come out to Utopia.

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HISTORICAL INFLUENCES ON CONTEMPORARY SOCIAL INDICATORS AT UTOPIA

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INTRODUCTION

Employment, income, housing and education are important social determinants of health (CSDH, 2008). Each has clear and immediate effects on the ability of individuals and families to access basic necessities for living. International studies have demonstrated consistent associations between economic, social, psychological and educational disadvantage and higher rates of cardiovascular diseases, especially ischaemic heart disease (Eriksen, 1994; Tennant, 1999; Rozanski et al., 1999; Kuper et al., 2002). Some investigators argue that the increased risk of ischaemic heart disease contributed by such psychosocial stressors may be of a similar order to the more conventional risk factors (Bunker et al., 2003). While the interpretation of socioeconomic data is clear for European populations, for whom each of these indicators predicts morbidity and mortality, their meaning in other cultures may be different. Likewise, access to health service provision is assumed to correlate with the presence of clinical services but the cultural norms underlying personal interactions associated with service access for the mainstream population do not necessarily apply cross-culturally. For Aboriginal people the definition of health is broad, including the social, spiritual, emotional and physical wellbeing of the whole community (National Aboriginal Health Strategy Working Party, 1989). Cultural norms, expectations and responsibilities differ from those of mainstream Australia. Hence interpreting the social determinants of health may also be more complex and assumptions about the way in which known factors operate (and interact with other influences) may not hold (Walters and Siggers, 2007).

Relationships to land and people and cultural and historical factors feature prominently in literature as contributors to the health of Indigenous peoples and communities (Thompson and Gifford, 2000; Tynan et al., 2007; Giles et al., 2007; Reilly et al., 2008). Such factors do not appear in Western biomedical models of health nor as part of chronic disease management guidelines, although Western cultural norms and expectations presumably underpin the development and implementation of the latter. The benefits of connection to land have been acknowledged in reports of Aboriginal and Torres Strait Islander health (e.g. Trewin 2006; Burgess et al., 2005; Kingsley et al., 2009), and the importance of language and culture is implicitly acknowledged by their inclusion in surveys like the National Aboriginal and Torres Strait Islander Social Survey (Linacre, 2004). Historical factors determine the extent to which cultural practices are maintained, have adapted and can be incorporated by communities in service provision for Aboriginal People. Likewise, socioeconomic characteristics evolve from aspects of earlier economies and ongoing access to resources.

We have sought to interpret contemporary indicators of the 'social determinants of health' at Utopia in the context of certain aspects of the community's history.

DATA SOURCES

Data from the 2006 Census of Population and Housing were accessed on-line to obtain information on education, housing, income, employment and language for Aboriginal people and other persons in the Northern Territory and corresponding data for the Urapuntja Outstations Indigenous location. This location (population 769) includes the 16 outstations serviced by Urapuntja Health Service for which health outcomes were previously reported (Rowley et al., 2008). Data relating to living on traditional country was from 2001 NATSISS for the NT (Linacre, 2004) and for Utopia was estimated by reference to population lists for each outstation. Distance from primary health care service and hospital was from the 2004 NATSIHS for the NT Aboriginal population (Trewin and Madden, 2005) and by reference to maps and empirical observation at Utopia. Archival materials as cited in Anderson (2010), Bartlett (1998) and other sources as cited were reviewed in order to identify potential influences on housing, employment, income, education, health service access and cultural indicators.

INDICATORS OF SOCIAL DETERMINANTS OF HEALTH

Data from the 2006 Census of Population and Housing (Table 1) for the region corresponding to the Utopia Homelands communities indicate high prevalence of overcrowding, low income and unemployment. In the 2006 Census, no adult in the region reported having completed high school. Two thirds of the population lived more than 25 km from a primary health care facility. All of these figures were worse than for the NT Aboriginal population, and much worse than for the NT non-Indigenous population. Despite this, as previously reported (Rowley et al., 2008), all cause mortality was significantly lower than for the NT Aboriginal population (but higher than for the non-Aboriginal population) and cardiovascular mortality and morbidity were also lower than expected (Table 1). In contrast, cultural indicators collected by ABS showed favourable profiles for Utopia with respect to language and living on traditional country (Table 2).

Employment and income

Employment through the 1930s to 1950s was primarily casual employment in the pastoral industry, paid mainly in rations for workers and their extended family groups. The Equal Wage decision in the 1960s, which determined that Aboriginal workers be paid award wages, was followed by mass lay-offs of Aboriginal staff on the stations. Short-term stock work continued to be available for some men, but families were generally not permitted to remain on the stations (see Bartlett, 1998, p.111). However, unlike surrounding stations, A. McLeod at Utopia continued to support extended families with rations (against government policy). Later, when M. Chalmers took over the Utopia lease in 1965, local Aboriginal people remained on the property, although the paid workforce was reduced.

Table 1. Socioeconomic indicators, all-cause and CVD mortality, and CVD hospitalisation rate for Utopia, with comparisons to NT Indigenous and non-Indigenous populations.

	Utopia	Northern Territory	
		Aboriginal	non-Aboriginal
Employed (including CDEP)*	6%	35%	77%
Income less than \$400/week	86%	72%	27%
Households with >3 residents per bedroom	25%	8%	0%
Completed high school*	0%	9%	46%
Resides > 25km from PHC service*	67%	13%	N/A
Mortality, per 1000 person-yrs, 1995-2004			
All-causes*	9.6	15.6	4.6
CVD (25y+)	3.6	6.9	2.8
Hospitalisation for CVD*, per 1000 person-yrs	13.4	33.4	14.8

*Persons aged 15y and older; Income, employment, housing and education data from 2006 Census of Population and Housing (ABS, 2006); distance from clinical services data from NATSIHS 2004 (Trewin and Madden, 2005); mortality and hospitalisation data from Rowley et al. 2008, Li and Guthridge 2004, ABS 2004.

Table 2. Indicators related to Indigenous culture and language.

	Utopia	NT Aboriginal
Language spoken at home		
English only	12%	36%
Indigenous language and English well or very well	55%	40%
Indigenous language and English not well or not at all	18%	12%
Lives on Homelands/traditional Country	approx. 100%	37%

Language data for NT from 2006 Census of Population and Housing (ABS 2006); NT data on living on traditional country from 2001 NATSISS (Linacre, 2004).

The pastoral industry, although locally important, employed about 1500 Aboriginal people Territory-wide in 1964 before the equal wages decision (representing less than 10% of the NT Aboriginal population at that time, this population figure itself only including persons of wholly Aboriginal descent; Bartlett, 1998, p.152). In 1973 Aboriginal people on reserves and remote communities became eligible for unemployment benefits, with the aim of ‘encouraging employment’ (Bartlett, 1998, p.159). The Community Development Employment Program (CDEP) was introduced in the NT in 1977 in response to Aboriginal requests for an alternative to unemployment benefits (Bartlett, 1998, p.172). Income from art became significant at Utopia in the 1980s, with a number of artists becoming prominent internationally. The 2006 Census data indicated a low rate of participation in the ‘workforce’ in the Urapuntja region, with 71% of adults 15-64 years of age stating they were neither in paid employment nor were they ‘unemployed’ (compared to 48% ‘not in the workforce’ for Aboriginal people in the NT generally, and 20% for other Territorians). CDEP was abolished in 2007 as part of the Northern Territory Emergency Response to Aboriginal child welfare issues, but reinstated in a different form 12 months later with an emphasis on transition to paid employment (Yu et al., 2008). Statistics on the impact of this

on employment in the Urapuntja region will emerge from the 2011 Census. Urapuntja Health Service currently employs over 40 persons, the majority of them local Aboriginal people.

Housing

From the 1930s until the 1950s, when the pastoral industry was established and Aboriginal people were employed as stock workers and house staff, basic provisions were provided for employees and their extended families by Lease holders. However, housing was not provided. During the 1950s, as part of a national assimilation policy designed to incorporate Aboriginal people into mainstream society and thereby remove them as a distinct cultural group in Australia, Government pressure was placed on station owners to provide housing for employees and their nuclear families. This policy was resisted by the Utopia Pastoral Lease holder at that time, Mr McLeod. Some huts were built in 1957 but little used as “employees preferred to live in the main camp” (NAA E740, P116, cited in Anderson, 2009), that is, traditional living arrangements were continued to the extent possible. Aware of the social problems associated with large settlements elsewhere in the Northern Territory, in 1969-70 there was successful local opposition to Government plans to establish a settlement in the area to be administered by the Welfare Branch. Prominent in this opposition movement was local man Mr J. Skinner, and Aboriginal opposition was supported by station management (Anderson, 2009, p.41)¹. In the 1970s, ahead of the successful land rights claims to the Utopia Pastoral Lease and adjacent Crown land, people began to move back to traditional country from their camp near the Utopia homestead where they had been congregated (see below). From the 1980s onwards, infrastructure was developed at these Homeland communities but housing development lagged behind need as indicated by the 2006 Census data. With the advent of the NT Emergency Response in 2007, as Utopia community has no centralised township over which a lease was compulsorily acquired by Government, no additional housing has been built through this program despite the area having far worse overcrowding than the general NT Aboriginal population (Table 1; see Yu et al., p.40).

Education

The first government primary school was established near Utopia Homestead in 1969. There was little involvement of the Utopia lease holders with the school, and there is evidence of concern about the motives and methods applied at government schools at the time (Chalmers 1972; Denham, 1973 – both from the AIATSIS website). Aboriginal residents of the adjacent McDonald Downs pastoral leases sent their children to the Utopia school. Currently there are primary schools at six Homeland communities, and a high school was established in 2010. Thus respondents in the 2006 Census who were over the age of about 40 years had no primary school to attend as children, and until last year attendance at high school required leaving the community, often to attend boarding school in Alice Springs, over 200km away.

Health service access

The first regular form of Western medical service provision was provided from the 1970s when Health Department Sisters visited on a 3-weekly basis. There was one doctor appointed to service the area from Docker River near the Western Australian border to Lake Nash near the Queensland border. Pastoral stations had a radio for emergency contact with medical services in Alice Springs and aerial medical services but access to this for Aboriginal

¹ In fact, Mr Skinner had originally contacted the Welfare Department in 1969 to request improved housing, a store and greater employment opportunities. Opposition was to the Welfare Department’s apparent response which was to propose a settlement, to be administered by them, for Anmatyerr people from all around the region (Anderson, 2009, p.41).

people was variable. In the 1970s an excision from the Utopia pastoral lease for a clinic site was negotiated with the lease holders.

In 1977 to 1978 the Angarapa Health Program was commenced by Central Australian Aboriginal Congress following Dr T. Cutter's recommendations and successful funding proposal (Cutter, 1976). The program serviced seven outstation communities. Staffing included a doctor resident at the Three Bores clinic site, a Nangkari (traditional Aboriginal healer), nine Aboriginal Health Workers (local male and female health workers at most outstations), a Health Educator, and a Counsellor (who was a local Aboriginal man; Tom and Sawenko, 1978). The service was refused access to communities at McDonald Downs and Derry Downs by the lease holders of those stations. In 1979 Urapuntja Health Service was incorporated as an independent entity, moving to its current site at Amengenternenh in 1986. After successfully resisting pressure from ATSIC to relocate to Arlparra New Store to form a service hub, upgrades to the clinic were successfully funded in the 1990s. Outreach services continue to the present time, with a regular fortnightly Homelands visiting roster in place. Thus although the conventional indicator of service accessibility based on a geographic criterion indicates a lack of access, the outreach style of PHC implemented by UHS coupled with a culturally safe model of care overcomes issues of distance from the health service building. With enforced regionalisation of health services from 2008, UHS is again resisting external pressure to regionalise on purely geographic criteria and is developing an expanded model with other organisations delivering services to people of the Alyawarr Nation. This community-initiated strategy is consistent with the philosophy underlying the regionalisation process which is one of community control, the rationale being that "greater levels of community and family functioning that is cognisant of cultural values and process may contribute to better health and wellbeing" (Northern Territory Aboriginal Health Forum, 2009).

Language

The first known use of the English language in the region was probably Stuart's north-south crossing of the Australian continent in 1860, which bisected Anmatjerr Country. There was a Government survey of the eastern border of the Northern Territory including Alyawarr Country in 1878, then in the 1920s the Sandover region was subdivided for pastoral leases. Brothers Trot and Sonny Kunoth took up the Utopia pastoral lease in the 1930s. Trot married an Aboriginal woman from nearby Alice Springs. Their son later married a local Aboriginal woman and supported the use of the local language, going so far as to encourage that his children were brought up with their mother's language and culture (Anderson 2009, p. 23). The Kunoths continue to have strong ties to the community to this day. By 1976 the population around the Utopia Homestead was still more than 95% local Aboriginal people (Cutter, p. 67) and the regional demographics remain so. As noted, Western education was not present until the 1970s, and there has never been a mission or government settlement in the region with a policy of preventing the use of Indigenous languages. Thus interruptions to learning of local language have not been a major part of the history of this region, and this is reflected in its maintenance to the present time (Table 1).

Living on country

From the 1920s to the 1960s, Anmatjerr and Alyawarr people lived and worked on Utopia and surrounding pastoral stations. Employment conditions in the stock industry allowed access to Country, maintenance of sacred sites, and ceremony. Some station managers respected sacred sites, keeping stock away from such areas. The marriage of A. Kunoth to a local community member was important for cultural relations (Anderson and Kowal, in press). The equal wage decision of the 1960s led to mass lay-offs of workers but the lease

holder at Utopia continued to support the local population with rations and people stayed on or near their traditional Country on rations rather than leave. The Department of Aboriginal Affairs purchased the Utopia Pastoral Lease from the Chalmers family in the 1970s on behalf of Alyawarr and Anmatjerr peoples, establishing the Angarrapa Aboriginal Land Trust under the Land Rights (NT) Act, and the Alyawarr and Kaytetj claim over vacant Crown Land was also successful. The NT Government vigorously opposed these claims (Anderson, 2009, p.46; Pitjarra et al., 1988). It was around this time that clan groups began to move back to their traditional country to establish the Homeland settlements that make up the Utopia community today. The outcome of these historical events – pastoral work, the lack of settlement, and the subsequent land claim – is reflected in the remarkable statistic that close to 100% of Utopia’s residents live on their homelands/traditional country in comparison to 37% of Aboriginal Territorians (Table 2).

DISCUSSION

The conventional socioeconomic indicators cited here for Utopia community demonstrate a low level of economic development in the Western sense. Clearly, poverty and its associated lack of physical infrastructure are problems for the population of Utopia, even more so than for Aboriginal people generally in the NT. The indicators of employment, income, housing and education are predictable in the context of the history of contact and Western economic and social development at Utopia, but their relationship to the health outcomes observed over several decades for the Utopia population is less so. In contrast, Utopia scores well on certain social indicators that are consistently identified by Aboriginal people as important components of wellbeing: language and connection to Country. The historical circumstances at Utopia have simultaneously led to disruption of traditional economies and the development of dependence on Western welfare economies and food supplies, but also allowed the maintenance of certain cultural imperatives for health and wellbeing, the latter achieved by Aboriginal people exerting a degree of agency through ‘cultural autonomy’. The history of Utopia community has been one of determination to remain on Country, and to have models of service provision for health and education, among other things, that support a decentralised mode of living.

‘Employment’, in addition to being a source of greater income, represents engagement in meaningful activity. Apart from work associated with the pastoral industry, infrastructure maintenance and, more recently, health services and the like, cultural activity, hunting and other traditional activities have continued uninterrupted to a degree. Elsewhere we discuss the ongoing role of traditional medicine and healing practices as important parts of primary health care service delivery (see Rickards et al., this report). Such practices have been enabled by ongoing access to Country through the pastoral industry times and subsequent gaining of freehold title to land under Western law. The type of employment is also important – the Whitehall study identified employment grade and the balance of responsibility and decision-making power as independent predictors of health outcomes (Marmot, 2006). Hence a commonly reported indicator of employment, which in this case includes paid employment for as little as one hour per week and the CDEP work-for-the-dole (i.e. work for welfare payments) scheme is a poor indicator of ‘engagement in meaningful activity’, and a broader understanding of meaningful work is required, as are indicators that reflect it. Additional evidence that employment may not have the same meanings in Aboriginal contexts is the finding that Indigenous Australians do not generally experience unemployment as a stressful life event (Kowal et al., 2007). Nevertheless, poverty reflected

in income figures is presumably a major barrier to improvement of health status, and economic development remains important. Data from North America indicate that sustainable economic development for Indigenous communities is underpinned by self-determination and good governance (Jorgensen and Taylor, 2000; Cornell and Kalt, 1992). Utopia may therefore have a good basis for such development.

Education figures for Utopia also indicated a gap with respect to both Indigenous and mainstream NT populations. While the value of Western education is clearly recognised, as evidenced by community advocacy for the establishment of a high school, the indicator (high school completion rates) ignores important traditional knowledge and pedagogy that operates at Utopia and provides grounding in social and cultural norms and identity. This is reflected in very high rates of language retention at Utopia. While it is not yet established in the literature that traditional knowledge is associated with good health in a setting where Western knowledge is poor, Utopia would be an ideal setting for such a study.

Housing is an ongoing problem and is illustrative of the dilemma surrounding the social determinants of health at Utopia. The resistance that the community has shown towards attempts at centralisation are indicative of the strength of traditional culture and social organisation. However, the successful community action against centralisation means that the community misses out on conventional government investment in community development such as housing. This raises the issue of how the community can benefit from improved government services while maintaining the benefits they appear to have derived from the maintenance of traditional culture and strong ties to land. Elsewhere in this report we note that a lack of understanding on the part of Government of community priorities and worldview is a barrier to improved health outcomes for residents of Utopia (see Rickards et al.).

Measuring health service accessibility using an indicator based solely on geographic proximity to a health service also has limitations. UHS provides regular outreach services at the direction of the community-controlled Health Board, and has done so since its inception. Having health workers located at outstations also facilitates this model. In addition, other aspects of 'access' are important for facilitating delivery of appropriate services. UHS has always employed local people in traditional and western health care roles. The health service was established in the 1970s with a vision consistent with comprehensive primary health care as it was originally defined (Cutter, 1976; WHO, 1978). We argue that, despite geography, PHC access is very good for residents of Utopia (see also elsewhere in this report). Health services thus provide the exception to the 'conventional' social determinants of health at Utopia (Berkman and Kawachi, 2000): while education, employment, income and housing are all low in both absolute and relative terms, and thus cannot explain the relatively good health of Utopia's residents, the provision of health care, including primary health care, is one area where conventional determinants of health may be operating.

With regard to the historical record, it appears that the collective agency exercised at Utopia has been central to the community's health outcomes. This finding supports literature that links the exertion of personal or collective agency (in response to demands) to the risk of chronic disease (e.g. Roepke and Grant, 2011). However, as Anderson and Kowal argue, policies of "self-determination' *per se* cannot be expected to improve Indigenous health outcomes" (Anderson and Kowal, in press). Rather, the case of Utopia points to the additional importance of the maintenance of social and cultural structures, avoidance of the worst effects of the forced 'Aboriginal Diaspora' described in the preface to the National Aboriginal Health Strategy (NAHS Working Group, 1989), and the opportunity to assert a degree of sovereignty, over nearly a century of colonial incursion.

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LOCAL ABORIGINAL KNOWLEDGE OF THE DETERMINANTS OF HEALTH AT UTOPIA

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INTRODUCTION

Utopia ‘community’ consists of 16 separate Homeland settlements located across the Alyawarr and Kayitij and the Angarrapa Aboriginal Land Trusts. The former had previously been unalienated Crown Land, the latter the Utopia Pastoral Lease. The region includes traditional Country of Alyawarr and Anmatyerr peoples. There is no centralised ‘town’ as such. This decentralisation was a deliberate strategy implemented by community leaders during the 1970s, to enable family groups to live on their traditional Country and to avoid the social health problems associated with living in large towns with other tribal, clan and family groups from numerous areas. We have previously reported relatively good health outcomes for the Aboriginal population at Utopia community, occurring despite a poor profile in relation to the conventional social determinants of health (Rowley et al., 2008).

DOCUMENTATION OF LOCAL ABORIGINAL KNOWLEDGE OF DETERMINANTS OF HEALTH

Documenting local knowledge of the determinants of health was a community-directed condition of conducting a related epidemiological study of long-term biomedical health outcomes at Utopia, written into a project agreement prior to commencing clinical data collection. To this end, the academic investigators planned a series of focus groups.

Focus group discussions

Khan and Manderson (1992) describe a focus group as a ‘formally constituted, structured group which is brought together to address a specific issue within a fixed time frame’ (p. 59). Participants are selected purposively and there is emphasis on their homogeneity with respect to characteristics of particular relevance to the discussion. Since there is emphasis on interaction and conversation within the focus group method, it was anticipated that the groups would provide access to data not available from participant observation or individual interviews. Thus it was intended that focus group participants would be recruited from among outstation residents and conducted on-site at the outstations. To guide the focus groups a set of *a priori* themes was constructed, consisting of a list of the domains of knowledge of which the researchers hoped they may gain a shared understanding. This list was derived in part from a review of the literature on Indigenous understandings of health

and chronic disease². PR spent some time in the community prior to conducting these focus groups, and several of the other academic investigators on the project (KR, AB) had a history of collaboration with Urapuntja Health Service on various health projects that included substantial time in the community collecting data (Rowley et al., 2008; Peiris et al., 2009) and their familiarity with the community likely influenced the choice of *a priori* themes. We have previously hypothesised a link between access to Traditional Country and the social and physical factors associated with this phenomenon as potential protective factors for this population (Rowley et al., 2008; McDermott et al., 1998).

A priori themes for discussion were:

- Alyawarr and Anmatyerr notions of health and wellbeing;
- Health and wellbeing pressures and enablers;
- Causes of ill health;
- Heart stories;
- Ethno-anatomy and –taxonomy. Ethno-anatomy refers to cultural conceptions of the body, and ethno-taxonomy to the way in which these conceptions are classified, organised and described;
- Ethno-botany, particularly the use of traditional bush medicines and flora in the management of health problems;
- Role of kinship, obligation and avoidance in health maintenance;
- The use of Ngangkari and traditional healing;
- Contemporary manifestations of historical events (including colonisation, dispossession, violence and trauma) and of re-traumatisation (especially due to high rates of premature death, community violence and extreme social disadvantage), and the consequences of poor diet and nutrition and alcohol abuse;
- Articulating the link between colonial and pastoral history and the current land tenure security as it is reflected in issues of sovereignty and governance, opportunities for self determination and empowerment.

The focus groups discussions were not to be restricted to these domains but were semi-structured so as to allow inclusion of other information known by residents to be relevant to health. It was anticipated that up to 30 participants would be included, depending on the number of focus groups required in order to achieve data saturation. However we did note prior to commencement that only specific individuals may have the authority to discuss particular issues and this may largely determine the sample size. In practice this was indeed what happened – focus groups were conducted at two outstations, at which up to eight

² including the work of: Bartlett and Scrimgeour (1989) who have previously proposed a model of three broad “causative factors” as a more meaningful way of considering ‘causation’ in health outcomes: physical environment, nutrition/exercise. and social/mental environment. These concepts have also been presented as “Land”, “Body” and “Spirit” (Reid, 1982); Weeramanthri and Plummer (1994), who used this framework in the context of discussing mortality in Top End Aboriginal communities and found it useful in promoting dialogue of disease causation, sharing of stories and subsequent community development activities. CVD in this scheme fell into the “Body” (nutrition/exercise) category; London and Guthridge’s analysis of Aboriginal perspectives of diabetes, which reported that “Aboriginal participants viewed diabetes and its treatment within a broad holistic context, as an outcome of both their social and physical environment. Health was maintained by activities which include hunting and gathering ‘bush tucker’ and by having stable relationships with family and other community members. Illness was viewed as a disruption of that harmony. Elements of Western health explanations such as ‘diet’ and ‘infection’ have been incorporated into the contemporary model of health...” (London and Guthridge, 1998); likewise, urban Aboriginal People in Melbourne described diabetes as arising from ‘loss of balance’ in connections to family, land, history and community (Thompson and Gifford, 2000).

residents attended but at which one Elder made the majority of verbal contributions, the other participants ‘witnessing’ this process. The focus groups were conducted at a time and place of the Elders choosing negotiated by RT. When we arrived and introductions were completed, we sat down on the ground in a roughly constituted circle. The ‘witnessing’ was done by other family members (to whom PR had been introduced and their family connections explained e.g. Aunty, cousin, nephew, wife) who sat a short distance away facing the group but not contributing to the discussion unless explicitly addressed by the Elder. These conversations were conducted in language and the essence distilled by the Elder and RT. After the second focus group, the academic investigators were queried by community-based investigators about their intention to continue conducting focus groups at other outstations, as the same information was likely to be imparted and continuing in this manner would be construed as ‘checking up’ on, and disrespectful to, the Elders who had chosen to participate. Thus there was some discordance between Western academic method and its definition of ‘validity’, and Indigenous knowledge and social protocols for imparting it. We gave priority to the latter. Conducting further focus groups risked damaging the working relationship between academic and community partners. Focus groups were audio recorded, transcribed and analysis of the transcripts conducted.

Data analysis

The principles of grounded theory were applied to analysis of focus group data (Rice and Ezzy, 2000). This inductively derived position states that meaning can be built up through careful observation of the social world. Thus, it is not assumed that all relevant questions are known prior to the research. A grounded theory approach demands a reflexive positionality of the research team where they must continually (and recurrently) return to the initial aims of the study to decide ongoing methodological and analytical issues, to respect the essential idea of research as a *relationship* with a community which must be continually negotiated (and re-negotiated), and to remain ‘in design’ throughout. The iterative nature of grounded theory compels the researchers to keep an open mind and to go on in partnership with the community and is thus congruent with principles identified for the ethical conduct of Indigenous health research (NH&MRC, 2003).

Themes identified in transcripts of the focus groups were grouped into categories as summarised in Table 3. Themes identified independently by the four investigators performing the analyses did not differ substantially.

Positions and roles of authors

It is important to pay some attention to the issue of bias as introduced by the influence of the researcher on the production of the focus group narrative and the fact that the researcher is a participant in the discourse. Firstly, all quantitative methods introduce bias as well, or at least are unable to eliminate it, only to change its form. Secondly, researchers are not unaware of bias, but the method of the focus group discussion grows from a constructive response to the influence of subjectivity. Thirdly, this interpretative approach recognises that there is frequently more than one version of events and meaning is frequently constructed and reconstructed in interaction (Holstein and Gubrium, 1995).

Focus groups were conducted by an academic researcher (PR) with assistance from an interpreter and the Cultural Officer of UHS (RT). PR is a medical practitioner with training in anthropology and public health. He spent a period of six weeks resident in the community conducting participant observation with the UHS and, after the a priori themes were

satisfactorily delineated, subsequently returned for the focus groups. He accompanied the UHS Medical Officer (KS) on home and station visits, and assisted in other ways as the opportunity arose. The opportunity for the researcher to be involved in health service delivery intersects with a broader ethical principle which derives from the participatory action research paradigm and requires the research team to provide appropriate service such as clinical treatment at the point of data collection. It is acknowledged that this affords the researcher privileged access to the community, particularly in light of the fact that ‘Aboriginal people have become increasingly cautious about giving knowledge to visiting scholars and extending hospitality and time, where it is clear that the results are not taken up by the government or fed back to the community’ (Willis et al., 2005). Notwithstanding the benefits afforded the researcher by participation in health service delivery, there exist related effects in respect of reflexivity and positionality which may become important at the time of data interpretation.

Transcripts of the focus groups were reviewed and themes extracted independently by three researchers with professional links to Utopia community (KR, AB and JF), and by a fourth University-based researcher (MG) with no prior connection to the community. KR is an Australian of Celtic background with formal academic training in biochemistry and epidemiology. AB is an Aboriginal doctor from the South Coast of New South Wales, and has lived and worked in Central Australia for 12 years. JF is a Warumungu man from Tennant Creek. MG is a health sociologist with expertise in qualitative health research. Mr Jones (LJ) and Mr Bailey (AB) are senior community members with authority to communicate this knowledge to the researcher visiting the community (PR). RT is a younger community member with authority to communicate with the approval of the senior community members. He was formerly the Cultural Officer at UHS. KS is a General Practitioner who has worked for UHS since 1992.

RESULTS

The themes and categories emerging from analysis of focus group transcripts are shown in Table 1.

Law and culture Underpinning all the themes discussed below are Law and Culture. They inform primary health care delivery by UHS, underpin the exercise of authority and control by the community, and inform practice of traditional medicine and healing. The time of year when ceremonial business is conducted brings families together, promoting cohesion, and the decentralised nature of the community allows families to then return to their traditional country. Maintaining Culture promotes health.

Access to Traditional Country Several themes were apparent that could be grouped in this category: Decentralisation, that is the deliberate establishment of Homeland communities remote from each other and with no centralised service hub or township as such; and Authority to make and enforce decisions for the community.

Decentralisation – Prior to contact with Europeans, clan groups lived on their traditional Homelands in the region. After the Utopia pastoral lease was established in the 1930s, many different clan groups from around the region were congregated at Three Bores³ (see Figure

³ Where they provided a workforce for pastoralists and received rations by way of payment.

1). This “*mix-up*”⁴ of many family and clan groups in a confined area resulted in conflict and a lack of control over damaging social issues like excess alcohol use, and was associated with risk of diabetes and other chronic conditions, “*Just like a welfare town*”. When the opportunity presented itself, after freehold title was obtained, family groups made the decision to disperse to their traditional Homeland areas and establish outstations (Figure 1).

“Yeah from there we went ‘go’. Like in the early days, we were like that one. The old day’s pathway...that’s the same thing we’re doing now”

This move included transferring the clinic from Three Bore to the current location at Amengenternenh⁵, a move supported by the Medical Officer of the time Toby McLeay.

Table 1. Themes derived from focus group discussions.

Categories	Themes	
Law and Culture	Access to Country	Decentralisation to Homeland communities Exercise of Authority on Homeland communities
	Health	Being healthy Ceremony Causes of ill-health
	Nutrition	Store foods Bush foods Hunting
	Primary Health Care services	Outreach service to Homelands Cultural protocols Staff orientation Communication Preventive health checks Traditional medicine
	Local priorities & worldview	UHS practices Lack of understanding by Government

Exercise of Authority – Associated with being located on traditional Homelands, as opposed to being congregated together on someone else’s land, is the authority derived from generation after generation of families’ occupation of and connection to their specific Country. This enables decisions to be made and enforced for the benefit of the community. For example, exclusion of alcohol, and prevention of petrol sniffing. However, the absence of police was identified as a problem in terms of enforcing law⁶.

“Got their own Law at their own outstation”

⁴ Mix-up: ‘To mix with another group’. ‘It almost always has a negative association, in that mixing up with another group is seen to be an undesirable thing’ (Arthur, 1996).

⁵ Despite pressure from ATSIC (Aboriginal and Torres Strait Islander Commission, the Commonwealth body responsible for Indigenous health funding at that time) to locate the health service near the store at Arlparra in order to establish a centralized service hub.

⁶ This has since been addressed with the establishment of a police station at Arlparra

“We control all that because we keep an eye on all the youngfellas”

“Whereas here there is no argument ...you’ve got the boss of this place...carry the law for this place...got their grandmother and great grandmother like we were talking about earlier...just that generation after generation after generation keeps it strong...keeps them strong and healthy.”

This authority extends to control of the way in which health services are delivered by the community-controlled Urapuntja Health Service (see below).

“And we listen to the old people...what they want, what’s good and what’s bad”

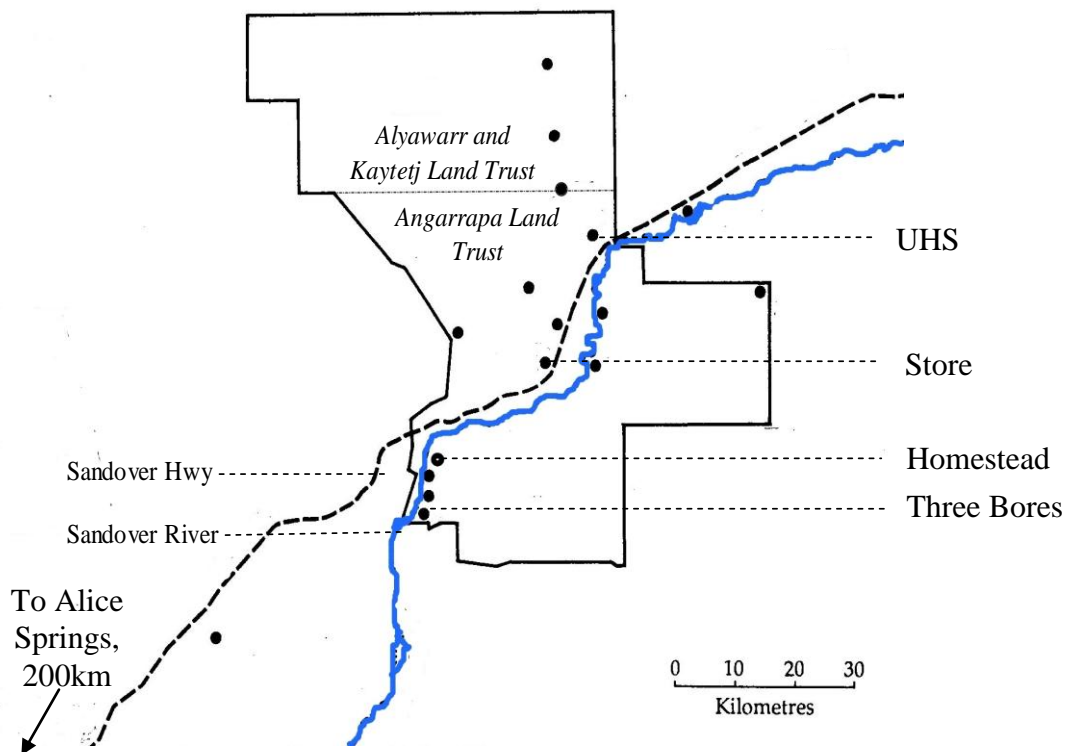


Figure 1. Map of Utopia region. Dots indicate approximate Homeland community locations. Adapted from Gault, c1990.

Health Discussions addressing specific understandings of what constitutes good and bad health encompassed several domains in addition to those related to the Western biomedical model.

Being healthy – ‘Health’ and ‘being healthy’ are seen as the combination of many aspects of living, including family relationships, hunting, managing problems in the community, healthy lifestyle, minimising conflict and Law and Culture. Having control over local community issues was explicitly identified as part of ‘being healthy’.

“That [being healthy] means that as problems coming to you, you have to look after it. Might be some drunken people who come around messing up around here and you gotta

have a meeting all the time to manage it...especially drunken people make a mess not in their own community. That's what we do...it's better that way".

Decentralisation to Homelands is a protective factor, by limiting exposure to foods bought from the store. Maintaining culture is a major protective factor and, conversely, loss of culture is identified as a likely cause of sickness in other communities. A lack of understanding by government of these issues and the manner in which they are managed at Utopia is a negative factor in health (see also below).

"that's why we have our spirit clear on our own land...more better that way...so we can look after themselves"

Ceremony, such as that for young men, is a time when the community comes together from all the Homelands. This is a positive time when Law and cultural "business" is conducted and families connect with each other, then disperse back to Homelands. It is a time when people feel 'happy and healthy'.

"Get together ... good yarn ... business ... sing songs ... do their business and bring everyone together and everyone's happy"

"And when business finished ... go back ... homeland"

Causes of ill-health - There is a specific Alyawarr word for 'sick', corresponding to the clinical idea of disease. There is an understanding of the physical function of the heart, and the results of damage to it, through familiarity with kangaroo anatomy. Alcohol and cigarettes are problems causing sickness for community members, as are sugar and fat associated with store-bought foods. Concern was expressed about the younger generation going to town [Alice Springs] much more frequently than did the older generation, where they are exposed to the ill-effects of alcohol. Violence and conflict arising from alcohol use is strongly identified as a form of ill-health.

"And smoke worse one. And grog worse one. And sugar...especially from the store"

Nutrition was raised as an influence on health in several contexts – the relative merits of store-bought versus bush foods and the physical benefits of hunting. Again, decentralisation was an important factor in allowing hunting to occur regularly.

Store foods with a high sugar or fat content are contributors to kidney disease, heart disease and other chronic conditions. The expense of healthier alternatives at the store is a barrier to their greater consumption in the community. The benefits of bush food, including kangaroo, are clear. The physical activity involved in hunting / gathering bush food and preparing it for eating is considerable and has benefits in itself, and the nutritional value of the food is high. Kangaroo blood is considered a good source of strength.

Primary Health Care Services This category included themes related to the provision of clinical services by UHS and also that organisation's support for traditional practices. Local Law and Culture are incorporated into health services and strategic planning.

Outreach services to Homelands as mandated by the community-controlled Health Board is an essential activity of UHS⁷. A service located at a central point with the expectation that

⁷ All Homelands communities are visited fortnightly as part of the routine outreach roster.

community members will travel to it and attend when they are ill is not the model desired by the community and is considered to be an ineffective way to deliver primary health care services at Utopia. Aboriginal Health Workers live and work at Homeland communities and can telephone the clinic if help is required, either for bringing medications or other medical supplies on the next scheduled visit to the outstation, or for immediate transfer to the clinic or hospital. Cultural protocols are incorporated into health service delivery. Employment of local community members at the clinic facilitates this. It is evident in support for ceremonial business, acceptance of the presence of family members to support and care for the patient, and orientation of new staff. Staff orientation includes an emphasis on appropriate ways of working that respect local Culture. Community members mistrust ‘cheeky’⁸ staff, and avoid consulting them. Community members will not tolerate poor attitude displayed towards them and they work with new staff to train them in appropriate practice.

“...with the staffing that we’ve got [at the clinic], when we get doctors and nurses and that we sit down, we orientate ‘em and we tell them that law and culture is a big part of this clinic”

Communication between UHS staff and community members is important to the strong relationship between the two and for determining PHC policy and practice at UHS. Communication extends to dealing with community issues and emerging health problems. Honesty by UHS staff in communication with patients is important, as is trust in clinic staff. Local people fluent in local language are employed at UHS to allow accurate communication. This includes health and medical advice on clinical conditions like heart disease, kidney disease and diabetes. Clinic staff pays attention to explaining the risk of heart attack and stroke associated with high blood pressure, blood sugar and cholesterol. There is also awareness of the relationship between skin sores and rheumatic heart disease. This awareness of medical models of health contributes to the active participation in preventive health checks – these ‘check ups’ are regularly sought out by community members and are a core component of chronic disease management for UHS.

“Every time in every little clinic out here... They come here or otherwise, when they go into the store, they get a check-up there. They pull into the clinic, get a quick check-up if they’ve been missed you know.”

Traditional medicine – Consulting traditional healers (Ngangkari) is a common practice and one that is supported by UHS by providing transport for community members to visit Ngangkari. Ngangkari are sought specifically when a person is sick, not for routine preventive check ups which is seen as a valuable Western medical practice. Bush medicine is also an important part of staying healthy. Knowledge and use of bush medicine is routinely practiced by many community members, from “*little kid to old men*”. This practice is also supported by UHS, for example through provision of drums of fat which provides a matrix for preparation of active bush medicines such as ilpunga.

“And we keep an eye on the old people and people talk...we all have meetings and discuss any problems. And even though (the community) is all decentralised, we still have that communication going around...and it comes back to the health service, which is good because we know what’s going on...where the problems are, whatever you know”

⁸ Cheeky: There are a number of senses of this word including ‘causing pain’, ‘dangerous, violent’, ‘poisonous’ and (the most likely here) ‘mischievous, but possibly also dangerous’. (Arthur, 1996).

Local priorities and worldview The themes noted above identify some of the ways in which local priorities, informed by Law, Culture and experiences of living in a centralised community model, are put into practice and/or supported by UHS in response to direction from the community-controlled Health Board. A barrier to obtaining sufficient moral and material support for ongoing community maintenance and development is a lack of understanding by mainstream government of community priorities and worldviews and UHS's primary health care strategies. Health bureaucrats and funding bodies appear to have difficulty comprehending and accepting the fundamental role of local Culture in all aspects of health planning and delivery.

“We have problems getting people to understand how we want to run, how these mob want to run it, how the community want to run it”

DISCUSSION

Deficits in Aboriginal health are readily measured and well known. Likewise, data on the conventional ‘social determinants’ are routinely collected and, at least in part, easily understood with respect to their relationships with physical influences on health. Information on the more subtle influences, positive and negative, of Aboriginal social and cultural factors are not readily available, making the interpretation of biomedical outcome data problematic and effective intervention difficult. Thus we sought to draw on local knowledge to identify protective factors operating at Utopia community in order to a) contextualise mortality and morbidity rates observed from 1988 to 2004 and b) increase knowledge relevant to chronic disease management. The data presented predominantly refer to positive aspects of community life and, in particular, the services provided by UHS. While this in one sense may constitute ‘bias’, as noted above the deficits in Indigenous health outcomes and service delivery are adequately covered elsewhere in the literature. Clearly there are serious issues to be addressed at Utopia – housing data show inadequate community infrastructure for example, probably contributing to risk of conditions such as rheumatic heart disease. We consider the current data as a contribution to balance in presentation in the broader literature on Aboriginal health, and as a source of information about potential points for intervention.

Most of the *a priori* themes noted ahead of conducting focus groups were acknowledged as important in the course of discussions, albeit that discussion was brief in some cases. Examples of the latter were specific stories of experiences of heart disease, and the roles of kinship, obligation and avoidance in health. Ethno-anatomy and ethno-taxonomy were not discussed in detail. Decentralisation was a major theme of the discussions, as it contributes to exercise of local Authority, prevents social problems associated with ‘mix-up’, and enables better nutrition. All of these factors were included in the definition of ‘health’ presented by community members. In addition however, there was a strong focus on the role and activities of UHS in supporting Homeland communities and incorporating aspects of traditional Law and Culture in their protocols. This responsiveness to community direction was reflected in UHS's outreach model of service provision, its staff orientation emphasising culturally appropriate behaviour, and support for Traditional medicine and healing practices. As a result, trust in and good communication with UHS were identified as enablers of health, and participation in preventive health checks promoted. This emphasis on health service provision comes at a time of forced regionalisation of health services (NT Government

Department of Health, 2011) and a long history of pressure on UHS to centralise its services to a more conventional model of clinical service delivery. In this context, the emphasis given to explication of UHS's role in clinical and community functioning is not surprising. The outreach model implemented by UHS is consistent with the Australian Government Department of Health and Ageing's strategies to increase service access for Aboriginal people under the Closing the Gap agenda (Australian Government Department of Health and Ageing, 2010). PHC at Utopia also operationalises many of the factors that promote sustainable chronic disease management identified as important in 'remote' Australia, such as: a flexible implementation strategy that takes account of local conditions; high level of community engagement; effective communication; and effective use of monitoring and evaluation data (Wakerman et al., 2005).

The themes identified in focus groups provide some context and explanation for the paradoxically good clinical outcomes at Utopia, where conventional measures of the 'social determinants of health' score poorly (see elsewhere in this report). 'Employment', in addition to being a source of greater income, can represent engagement in meaningful activity. Examples of the latter emerging from focus group discussions included production of traditional medicines, hunting, and participation in ceremony and engagement in community governance, in other words the (usually unpaid) work of culture. Health service access is another area in which Utopia scores poorly when using an indicator based solely on geographic proximity to a health service. However the data clearly demonstrate that other aspects of 'access' are more important for facilitating delivery of appropriate services. These factors included responsiveness to community priorities and worldview, staff orientation, good communication and support for traditional healing practices. Accessibility is thus maximised, and participation of community members in preventive health checks as well as acute care is enabled.

We accept the validity of the information provided from the focus groups for a number of reasons. Firstly, it represents local Indigenous knowledge from people connected to this Country since humans first appeared in the land (approximately 500 centuries in Western historical terms). Privileging this knowledge is consistent with a research approach that seeks to resolve the complex social, historical, political, psychological and biological influences on health (Brown et al., 2006), and to avoid imposing Western epistemology and ontology that assume their own superiority over other worldviews (Smith, 1999; Sherwood, 2009). Secondly, the data are consistent with a model of health and comprehensive primary health care that includes social connection, mastery and control, and health service accessibility, all of which are associated with better health outcomes elsewhere. An analysis of archival documents identified a relatively high degree of social cohesion and collective efficacy that has been maintained throughout the history of European contact in the region, due to the nature of relationships and interactions with European culture and key individuals which have, however, simultaneously resulted in dependence on western food sources and other factors reflected in poor socioeconomic indicators (Anderson and Kowal, in press). In a comparison of individual level and community level interventions in the published literature, Lomas concluded that interventions to increase social support and social cohesion prevented more deaths from heart disease than a risk-factor modification approach (Lomas, 1998). Finally, we did not set out to identify protective factors that are explicitly generalisable to other Indigenous communities, nor did the key informants (LJ and AB) purport to speak for other communities, only to tell the story of Utopia community and the social processes important for their own wellbeing, yet the data resonate strongly with information from elsewhere.

Regarding analysis of focus group transcripts, the four university-based researchers who extracted themes independently of each other in the first instance were by and large in concordance, including MG who had no prior relationship with the community, UHS or the majority of the other authors. The focus groups themselves were unconventional in a Western academic sense (see 'Methods'). We note however that the purpose of this qualitative research was not to produce data which can be statistically generalised to other populations, but to describe the social processes involved in modulating disease risk at this site. Liamputtong and Ezzy (2005) note that the purpose of non-probability sampling is to identify cases which will provide a textured and sophisticated account of all aspects of a phenomenon, in this case, the role of culture as a determinant of health and illness at Utopia. Willis et al. (2005) identify certain characteristics of focus group discussions in Aboriginal community-based research relevant to the present context, which are that they: enhance community control over the definition of the situation; provide the community with the capacity to speak with one voice and enhance consensus and the building on ideas; highlight who has authority to speak and who dominates; allow for the generation of solutions to problems of real concern; allow the agenda to be set by the participants; and facilitate discussion of sensitive topics.

The majority of the authors of this report are either community members themselves or have a long standing professional relationship with UHS. Given the history of research in Aboriginal health in Australia and the misuse to which it has been put, some information of the type presented can only be gained through developing a long-term relationship built on trust between researchers and community members. Does this result in 'bias' or greater 'expertise'? We have explicitly documented the roles and background of each investigator and their relationship to the community as a means of facilitating interpretation of the results presented. Certainly, the exclusion of local knowledge and a focus exclusively on biomedical outcomes would have biased this study, or at least encouraged ignorance, by excluding a major source of information not available anywhere else. Its inclusion goes some way to addressing a factor identified as a barrier to good health at Utopia – a lack of understanding of the role of community priorities, worldview and service provision at Utopia on the part of Government.

Hence the influences on health at Utopia are more complex than indicated by a social determinants model that includes conventional indicators of employment, income housing and education, and PHC is more complex than indicated by clinical indicators of service delivery and geographical indicators of access. The strength of Law and Culture as an underlying driver of 'health behaviours' and the manner in which health services are delivered reflects a degree of agency/autonomy that makes service delivery culturally appropriate and is in itself health promoting. It is an example of the operation of local sovereignty.

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SOCIAL AND POLITICAL DETERMINANTS OF HEALTH OUTCOMES

David Moore

Introduction

The research in this study was aimed at finding out some of the social and political determinants of health outcomes for people living at Utopia community. To what degree are health outcomes related to the way in which the UHS functions and to what degree are these good health outcomes related to the lifestyle of the outstations?

Methodology

The methodology of this research follows the 'ethnographic interview'. Respondents representing four locations in the Utopia region were asked three key questions:

How and why did the Urapuntja Health Service start?

How does Urapuntja Health Service work culturally?

What effect does the Urapuntja Health Service have on people's health?

Respondents were encouraged to respond in their own languages: Alyawarr and Anmatyerr. The responses have been translated into English and interpreted and analysed.

Albert Bailey, Casey Holmes and Frank Holmes at Antarriginnya

How and why did the UHS start?

The story of the clinic starts with the beginnings of the outstation movement in 1978. People came back from Murray Downs. They had been living on a Pastoral lease, in an area which was like a paddock. Paddock-arl artew. Whitefellers were on the outside of the paddock. The clinic started at Three Bores. At the time, Albert Bailey was at Ali Curung, building the police station.

Some Alyawarr people were living at Elkedra Station. They were forced to leave Elkedra. Artyeler-they alperlewew. Johnny Driver lerrp-anem irrew-wety. Johnny Driver-el amernel arntarnt-arenh. Johnny Driver had given the people rations. When he became ill, he said that he could no longer look after and feed the Aboriginal people at Elkedra. Welfare-arenyel akarrilew Alekarenge-warl "Welfare moved everyone to Ali Curung". Different language groups settled at Ali Curung, including people from the west. There were high levels of conflict because the mixing of different groups, expressed by Albert as apmwel-areth yanheley 'that was bad state of affairs'.

The changes in Indigenous policy started with Mr. Whitlam. The handover of land began with going around and viewing of sacred sites. Aboriginal people took the judges and lawyers right all around all the sacred sites, "apmer ngkwenh nthenh?" Sacred sites arerl-apaynteyew 'looking around at sacred sites'. Atnwenhey-alhew- showed them around. They took the lawyers and judges. Nthakenh changemiley-angenh. Akely-rnem akalty-anthaynteyew 'It shouldn't be changed. We need to keep teaching the young people.'

How does UHS work culturally?

Awank-akerran anenh, aley aneyel mwerr-antey. Anewantherrenh-angkwarr. Traditions have been maintained and are in place today. We continue to do things our way.

Arreng-wenh, arrwekeleny-angkwarr. 'Working through grandfather's way and traditions'. There are sacred sites which can't be abandoned. Arrkngertelengkw are the sacred places on country need to be maintained and people need to live locally to do that task.

Aboriginal land is just like a series of separate blocks, amentew-ament irrpwerlwenhan. Artwewenh amentew-ament. Apmelerr ayntenh-angkwarr-antey. Each estate is separate. That is the customary way. Irrpwerlel iterl-areyel. Aboriginal people know about those land arrangements. We can't sit down ingwer-wenh, on land belonging to other people. Only landowners and people who marry locals can stay in that place.

Waylpel iterrew pwelek-angketyarr-kety. The European settlers were concerned for their cattle. Pastoral Lease-wety aylpenyirrew. Indigenous no longer wanted to live on pastoral leases. They sought 'open country'. Apmelerr ayntenh arrwekeleny-angkwarr 'those are the customs of our ancestors'.

Casey said that "If we all came to together in one place, we would be worried about all of our sacred sites". These sites are dispersed across the region and managed by different groups.

What effect does it have on people's health?

The outcomes of good governance are lower levels of conflict. Local autonomy and control by landowners is important. If a visitor causes problems for local families, it's possible to tell them, "Apmerr ngkwenhel aney-alpa!" "Go back to your place".

The respondents stressed that recently governments have taken little notice of traditional landowners. The result has been awerrey-angenhant-arey 'mutual misunderstanding' and a feeling that the traditional landowners haven't been heard. This has resulted in frustration and distrust of government. The clinic is seen as an organization which listens to landowners and takes their views into consideration when making policy.

Harold Nelson at the clinic

How and why did the UHS start?

Harold came back to Utopia after Cyclone Tracey in 1974. He had been living at Bagot Reserve. He was then working on a number of station properties, building houses and working for a union in Darwin. Apmerr akely-rnem Outstations. Keep happy and hunting and family. The establishment of outstations allowed people to stay away from drunken mobs.

How does UHS work culturally?

If people are mixed up in one area, trouble will be happening all the time. There are still problems. Some workers are 'spoiled from grog'.

What effect does it have on people's health?

Being able to freely hunt animals such as kangaroo and perentie is a 'better way'. This is seen as 'freedom', analogous to private landowning. If different groups are mixed up in one

area, trouble will be happening all the time. It is in these places that drinking tends to proliferate. In the outstations, troublemakers are told, “You go back to your own area.”

Lenny Jones at the Clinic

How and why did the UHS start?

The first clinic was at Three Bores. Arntety-akertel wayemilem, rernem awelhem ‘If there is a sick person in camp, they call and the clinic answers’. As there are few private cars in the outstations, this is very helpful.

How does UHS work culturally?

Concern for looking after the money and medicines well.

Apmer amentew-ament, apmer akely-akely. ‘Separate living places, outstations’.

There is a need for succession planning of the older generation, for the younger people to take control, a high cultural priority. Ilwenty-kety rernem arntarnt-aretyek. ‘When we pass away, the younger generation will take responsibility’.

Awelheyneyel intem-antey. It’s important that the CEO and staff of the clinic listen to people and take notice of them.

During this discussion, Lenny showed me a Cultural Business vehicle which is being used for traditional cultural activities such as hunting and gathering bush medicines. It clear that the UHS takes a positive attitude to hunting and gathering activities and provides material support to assist landowners to participate in these activities.

What effect does it have on people’s health?

Local knowledge and understanding is important. Arleng-arenyel ilpertileyelarl-kety, arraty iterl-arey-angenh. Visitors without local knowledge might think the wrong way and make mistakes.

Change-irrey-angenh arrangkw, anyent-antey aneyel. Irrkatyel aneyel. ‘We don’t want to make changes, keep it the same’.

Mwentyel arntarnt-arem, atwerrerrl-ane Kerr ‘work carefully, in case of violence’.

Lena Pula, at Alparra with other senior women

How and why did the UHS start?

I worked for the clinic in Dr Toby’s time. Neyl atanthetyart, checkup-iletart ‘giving needles and checking up on patients’. Aleyan alakenh arppemarl, Mulga Bore, Antarrengenyek-atwety. The same arrangements are still in place to provide services to Mulga Bore right up to Antarrengeny. There have been some changes, for example Ampilatwatja now has its own health service. And some places are arltwanem ‘empty’ such as Boundary Bore Outstation.

How does UHS work culturally?

An aspect of the clinic's success is the governance arrangements in which people are looked after in separate living areas. Akalkant-arey menty 'continue to live in separate homeland living areas'. Mwerr anetyel apmerel 'people do well at home'.

What effect does it have on people's health?

People don't want to live in Alice Springs. If people are mixed up in one place, they will fight with each other. Pweytilenty arntetyirrem 'forcing people together leads to illness'. People should be on their own homelands because atwerrerrl-ane Kerr 'violence'.

Awelhetyel - the clinic listens to people, in contrast with other organizations in the area.

CONCLUSIONS

Integral to the foundation of the Urapuntja Health Service was the outstation movement and its attempt to allow Alyawarr and Anmatyerr people to re-settle on their own homelands. Distance from stores and fatty foods, availability of bush tucker and bush medicine are often cited as reasons why health outcomes are favourable at Utopia. However, it's apparent that none of the respondents seem to think that these factors were as important as those of good governance. The value of land ownership and autonomy to mental health, harmony and cultural continuity has often been understated. These are the social and political determinants of health.

All respondents indicated that wellbeing was the result of political and social harmony. Respondents see the role of the UHS as to provide strong clinical governance. This is done in a way which is sympathetic with the aspirations of the local landowners. Treating patients in an environment which is familiar and comfortable to them is highly valued. To the extent that people recognize traditional authority structures and follow traditional law, the Utopia model recognizes and is sympathetic to traditional ways. Good governance results from doing things in way that makes sense locally. According to respondents, good governance leads to lower levels of disputes and conflicts. The result is better health outcomes.

PROVIDING ACCESS TO PRIMARY HEALTH CARE AT UTOPIA COMMUNITY

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INTRODUCTION

Elsewhere we have reported that a conventional indicator of health service accessibility – residence within 25 km of a PHC service – indicates that the majority of members of Utopia community have apparently poor access to Urapunjta Health Service (UHS; Figure 1). In contrast, focus groups conducted at Utopia identified a number of aspects of service delivery by UHS that act to facilitate good engagement of the service with community members, such as regular outreach, staff orientation and training, employment of local community members, and incorporation of traditional healing practices (Rickards et al. this report).

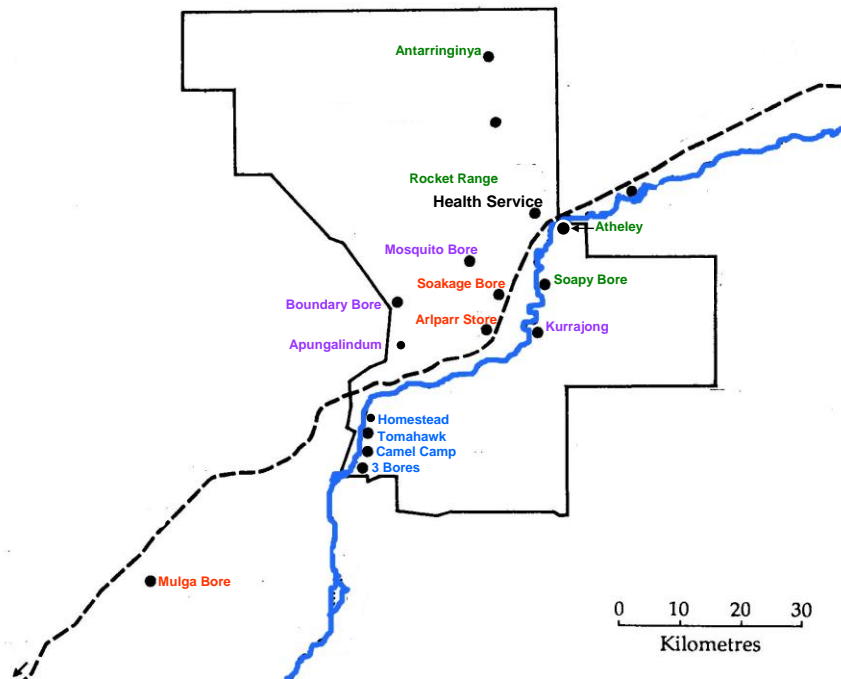


Figure 1. Homeland communities serviced by UHS. Colours indicate communities visited on the same day each week by a UHS team according to the Homeland visiting roster c2006.

To further investigate accessibility of services at Utopia, here we report data from a qualitative investigation with staff of UHS, which sought to identify barriers and enablers of access to care for Aboriginal people with chronic conditions within the context of: the geographical organisation of the community to which the health service provides care, that is, a group of 16 remote homeland communities in Central Australia (Figure 1); a decentralised outreach model of primary health care service delivery; Aboriginal people making up a large majority of the population, a considerable proportion of whom have English as a second or third language; high levels of poverty in the population; a considerable burden of illness,

especially chronic disease, in the population; and access to hospital and other specialist medical treatment is available several hundreds or thousands of kilometres away.

METHODS

UHS is a participant in the Kanyini Vascular Collaboration (Peiris et al., 2009), a project established by Baker-IDI Heart and Diabetes Institute and The George Institute for Global Health in 2005. It brings together a network of researchers, Aboriginal Community Controlled Health Services, community members and policy advisers for the common purpose to improve Indigenous health outcomes. *Kanyini* is a term used by a number of language groups in Central Australia, including the Pitjantjatjara and Pintubi language groups, and its closest English equivalent translation is “to have, to hold and to care” (Institute for Aboriginal Development, 2001). Over the last five years a program of research has been conducted Australia-wide in partnership with health services in urban, rural and remote New South Wales, Queensland and the Northern Territory. The research program includes a series of discrete but inter-related studies. These are: an audit of chronic disease identification, prevention and management in Aboriginal and Torres Strait Islander primary care services (Peiris et al., 2009); a randomised controlled trial of a fixed-dose combination ‘Polypill’ strategy to maximise the delivery of evidence-based, long-term therapies among individuals at moderate to high cardiovascular disease (CVD) risk (Liu et al., 2010); and a qualitative study of knowledge, attitudes, practices and perceived needs of patients, communities, health care providers and policy advisers with respect to the prevention and management of chronic disease in Indigenous people (The Kanyini Qualitative Study; KQS).

The KQS is an in-depth exploration of barriers and enablers to care for Indigenous Australians with chronic disease. A theoretical framework incorporating the concepts of health care accessibility, candidacy and the Aboriginal caring praxis of *kanyini* underpin the Study. The objectives of the KQS are:

1. To understand patients’, communities’, health care providers’ and policy-makers’ views regarding barriers to and enablers of care;
2. To determine the key structural and organisational components of health services that affect their accessibility and the quality of care provided;
3. To explore the components of clinical interactions between health care providers and service users that affect perceived quality of care; and
4. To explore how barriers to care are experienced, understood and expressed differently in various health care settings, and between Aboriginal community members and health practitioners, with a view to developing integrated interventions in chronic disease across health care sectors.

Seven Indigenous and non-Indigenous Urapuntja Health Service staff including the Chief Executive Officer, Cultural Liaison Officer, Aboriginal Health Workers, General Practitioner and a Registered Nurse were interviewed as part of the KQS. There was a mix of male (3) and female (4) staff interviewed who had been employed by the Health service for varying lengths of time, from six months through to more than 15 years. Interviews with these staff were conducted in May and July 2009. Four staff were interviewed individually while the remaining three were interviewed together as a group. The thematic analysis of the seven staff interviews presented here was undertaken at the request of UHS to contribute to *Revitalising Health for All*.

RESULTS

Several key themes emerged from the interviews with the seven staff and these can be organised into three key thematic areas: 1) perspectives on maintaining health and wellbeing; 2) perspectives on providing care; and 3) perspectives on accessing and receiving medical treatment and care outside the community. All of these themes relate to the context in which Urapuntja Health Service is providing health care.

Perspectives on maintaining health and wellbeing

Several of the participants talked about what they believed, or had observed, contributed to Aboriginal people in the community being able to maintain health and wellbeing. These factors included having control over their health service, the association between culture and health and the Utopia homelands model.

Aboriginal Community Controlled Health Service Several participants spoke strongly about the fact that Urapuntja Health Service is an Aboriginal Community Controlled Health Service governed by a Board of local Aboriginal people. They believed that this was an indication that people in the community cared about their health, knew it was important and were taking control. One participant described how the outreach model of health service delivery was determined by the community:

...it's the community that set up the way that the service is delivered to them...they know that they haven't got vehicles to get to the health service, so they make the nurses and doctors and health workers go out to see them...not wait until they get here [to the health centre] at the last minute. So I think...they're very concerned about their health...

The employment of several Aboriginal people in the health service was also seen as a strength of the service with one participant describing it as an “investment in the community” and letting the community know that the health service was “a good safe place to come to” and that its agenda was more than just dispensing medication.

It's about these kids watching them [Aboriginal staff]. The example they are giving to their family, to come to work. So that's about accessibility for me...And so people will come and I've seen like some really positive changes in some of the young people, either working here or coming in generally...more young men will come up because they know there's young men here...their uncles, their fathers, their brothers, you know...health is a social condition.

Another participant described their role at the health service as ensuring that the:

...Aboriginal culture side of it is put together so it matches with the health service and we respect both sides of it. So we're not just using one side, we're using both sides, as culture is a big part of our health I reckon.

It was also reported that the Health Board was keen to lift the profile of the health service and let people know more about the positive outcomes it was achieving with the outreach model of service delivery that allowed people to live on their homelands and access good health care. Another participant suggested that Aboriginal people involved in the health service had been successful in convincing the government funding body to recognise the intrinsic link between culture and health through presenting the results of a study in Utopia that showed the protective effects of the homeland lifestyle with regard to the rates of cardiovascular disease in the population (Rowley et al., 2008). As one participant put it, the study “showed that our

cultural way was also part of our health” and that this was reportedly accepted and supported by the funders.

So there was awareness amongst some of the staff about the strength of the Urapuntja Health Service being under Aboriginal control and what had been achieved to maintain health and wellbeing as a result.

Culture, homelands and health The association between culture, country and health was clearly articulated by a number of the participants, as mentioned in the section above. However, when participants spoke about this association there was an emphasis on the benefits to people’s mental health of being connected to country and culture and that the benefits to physical health seemed to flow from that:

I mean living on your homeland is the best thing you could probably do...Living on the homelands, you’re home so your mind’s free...and your heart’s good...It’s just stress free, you know. Self empowerment as I call it, on your own homeland...You have that own belief in yourself...You’re the boss...look after your country and it’s just good, it’s excellent...because I thought once they knew they had a healthy mind, I think it’s a healthy body.

Whilst living on homelands, people had access to bush foods, exercise through hunting as well as access to bush medicines and Ngangkari, or traditional healers, all of which was conducive to health and wellbeing. This was clearly perceived even by those who worked ‘outside’ of, yet fully supported, traditional ways of healing:

...there’s a whole system of...the Ngangkari and the spiritual care that goes on. We’ve got no idea about that ‘cos we’re outside of the system...Just let it be, because it’s good and our idea is to work in with that and just support that.

This experience of living on homelands and feeling safe and well is explained by some Indigenous participants as Aboriginal people being “born in through a culture” and belonging to the land. This experience is disrupted if people need to travel to Alice Springs or beyond to access medical treatment:

And sometime they think their self you know, “I don’t belong to the hospital, I belong to the land that I wanted to go back and I can die anytime because I belong to the land” you know.

The impact of leaving home to access health care is discussed in more detail below. The challenges that this context of health and wellbeing present for a health service based on the Western biomedical model are considerable and the need to “walk in both worlds”, that is, to take into consideration these two worldviews and their understandings of health and wellbeing, is critical to achieving better health outcomes. This was recognised by all staff interviewed.

Perspectives on providing care in this context

All participants described aspects of providing care in this context and articulated the challenges of this work. Key themes that emerged around providing care included the challenges of the cross-cultural health care interface where there is a divergence of worldviews and understanding and a considerable burden of chronic illness. The importance of the ability and competency of the Aboriginal and non-Aboriginal health service staff to negotiate this space and build effective relationships were highlighted by several participants as were the benefits and challenges of the outreach model of health service delivery.

UHS model of service delivery: strengths, challenges and expectations all participants indicated that fundamentally they support the outreach model of health care that was adopted by UHS; some stated this more explicitly than others. The reasons for this support included that, for some, the model aligned with their personal philosophical views while for others it was because it was defined by the Aboriginal people themselves and supported the way they wanted to live. Others mentioned the opportunities the model provided for building relationships between the health practitioners and the community. One participant spoke very passionately about working with this model in this context:

And it's really nourishing. That's why we love this work...This is kind of, it's vibrant and it's real and it's fun and it's connected...Like you know you're alive.

There was also a sense that the staff needed to support and believe in the model to be sustained in their jobs as the participants recognised the considerable demands that the model placed on them. One participant said that staff needed to be “devoted” and love what they did to be there and also talked about new staff sinking or swimming in this environment. As another participant put it:

It's a big job. You have your ups and downs...it's pretty full on...it is a 24 hour job.

Another impact on staff discussed by one participant was that the staff did not have time to engage in networks, find out about new developments in health research or take up training opportunities and professional development due to the tight rosters and “extra energy” required to run the outreach service. However, this participant talked also about having the time to spend with the people during the outreach visits so that the service was “not just a lick and a promise.”

Several participants spoke extensively about the challenges in resourcing and sustaining the model to ensure that it provided the type of service and care that was expected by the community. It was reported that a lot of effort goes into maintaining the schedule of visits to each of the homelands but that “the wheels can come off too easily”:

So there are different runs. And it works when it works. But if some staff's sick or some staff's away, or there's been an emergency stuff in the night and you're up with people and drips and your plane can't come until...you know, all this – well then the thing gets lost. And then the people are who are expecting you to turn up that morning, for whatever reason you couldn't come... there're repercussions down the line...They just think...“Oh that rubbish clinic, they never come.” So then they lose faith in us.

The outreach model is more resource intensive than a centralised health centre model where the people visit the health centre, and with limited resources its vulnerabilities were acknowledged by some of the participants. One participant observed that when the health service is experiencing resourcing pressures the first thing to “get lost” is the systematic visits to the homelands rendering the clinic an emergency centre rather than providing comprehensive primary health care.

One of the key factors that some participants identified as stretching the health service was when staff left and there were new or short-term staff working at the health service who did not know the systems, the homelands or the people who lived there. As one participant observed:

that's why keeping staff and everything, without losing crucial people and having to fill those gaps, that's why that's a really important part of it.

The impact of the current significant burden of illness was also highlighted. Participants talked about the considerable increase over the last decade in the number of people in the community with chronic and complex illnesses. This increase in chronic and complex illnesses meant that the duration of an outreach visit to each of the homelands had increased and the workload was more demanding. At the same time it was reported that there had not been a similar increase in the staffing levels within the health service until very recently at the time of the interviews.

...we have reduced visits to two-weekly [fortnightly] for six or seven of the outstation runs...we have had to because of staffing. And because of workload...and the workload of the outstations is so big now that two nurses are better going to do it justice, and health workers. We pull in every single person who can help us. And the harder we're working, the harder the health workers are working, or the harder the drivers are working. So we do pull in quite a lot of help from the community.

Some participants acknowledged that while there were significant concerns about the impact of the Northern Territory Emergency Response (the Intervention) on communities and their human rights, it had resulted in increased funding for the health service to employ additional staff which would strengthen it against the vulnerabilities described above.

...we have to maintain the capacitants [sic] in our organisation that we do get there on the day we're supposed to come. So in other words if a chronic person knows that's a clinic day...they'll wait for the clinic. But then if the clinic didn't turn up...they're going to get pissed off. If we go higgledy piggledy because of our own reasons, even good reasons, then we lose a lot. It doesn't take long for chaos and lack of trust to come out of something really good. It's really hard to build up and really easy to lose it.

Trust between the health service and the community was highlighted by some participants and trust between individual staff and community members is discussed further below. Several participants commented that they believed the health service was perceived positively in the community because of the way it worked and the care it provided and how it enabled them to engage in their health. In describing the context of providing health care during the homeland visits one participant referred to the patience that people demonstrated when waiting to be seen by the health team:

I mean like yesterday, people waited, just sitting out on the verandah, talking and everything, for hours and hours while you're dealing with some things. Everyone sits and waits, no problems...It was nice in the sun and they were having quite a lot of good interactions, 'cos everyone's come from their own family groups and their houses...Not a lot of angst.

This contrasts to the situations described by participants above when the scheduled outreach visits do not happen as people are expecting and they become very frustrated and reportedly annoyed with the health service for letting them down. Another participant commented that people are

...worried about their health because they've realised that here, that health is a big thing. And that's why this health service has got so much expectation on it, from the community I think.

Some participants also noted that the outreach model has its critics and that one of the key criticisms is that it creates dependency within the community on the health practitioners. One participant admitted that when they began they did think that dependency was being created

but over time they have come to recognise that the strength of the model is that it gets staff out of the clinic and allows them to develop relationships with the people in the community because of the regular contact they have. Another participant believes strongly that the model does not create dependence but rather independence in that it supports the way people want to live and encourages them to have the confidence to deal with complex health issues in their own homelands rather than moving to live close to a health centre.

While participants supported and believed in the outreach model of health service delivery as an effective model to enable access to care in this context, they were honest about the model's vulnerabilities, the challenges they faced and the resources and energy it took to implement the model in this context.

Gaps in understandings Several participants talked about the gaps in understanding that existed between many Aboriginal people in the community, including some of Aboriginal staff at the health service, and the non-Aboriginal health practitioners. These gaps in understanding were believed to affect the way health services were accessed and delivered and what decisions people make about their health. When participants spoke about this issue, they were not talking about communication issues but more fundamental understandings of contributors to health and wellbeing and assumptions that are made that are not true. All of the Aboriginal staff participants spoke about their key roles in facilitating communication and better understanding between the people in the community and the non-Aboriginal health service staff.

There were two key issues that participants used to illustrate the issues around gaps in understandings: one was food available at the store and the second was with regard to post mortems. A couple of participants talked about how much people loved the food at the store and had developed a belief that the meat that you bought there was just as good for you as the meat that you get when you go hunting.

Some participants talked about the need to have more education about health and healthy lifestyle choices in the school and that this education should be delivered by the health service staff. Another participant believed that the health service staff just needed to keep repeating the health messages and eventually people would take these messages up.

The second issue relating to gaps in understanding was raised by one participant and focussed on post mortem procedures. This participant spoke strongly about the lack of understanding about these procedures that resulted in fear among people in the community, especially old people, about post mortem examinations. The participant believes that the health practitioners need to talk much more with the families about these procedures so that the families are clear about what will happen and what is required under the Australian law. It was also suggested that fear around these procedures was a factor in some people from the community not wanting to go to hospital when they needed treatment and that several of the non-Aboriginal staff at the health service were not aware of this lack of understanding or its impact.

One participant suggested that there should be more meetings between the health service and the community, not just with the Health Board, to discuss some of these issues where there are gaps in understanding on both sides. Another participant talked about the assumptions about level of health literacy that are made by health practitioners that need to be re-considered to reduce the gaps in understanding being perpetuated.

Relationships between health practitioners and people in the community: trust, respect and attitude

And it all works on relationships too.

The importance of relationships between health practitioners and people in the community in providing health care was emphasised by all participants, with the core components of effective relationships identified as mutual trust and respect. In addition, it was recognised that the attitude of the health practitioner needed to be conducive to working effectively in this context. As one participant put it, it's "[n]ot so much the job description, but the person description".

Several participants commented about the great health team that the health service had at the time of the interviews and how this had led to the development of trusting relationships with the community. The participants valued these relationships and were conscious of maintaining them.

And they [community] got trust in them [health team]. But it takes a lot to get their trust. The community that is, to get their trust, and that's where it comes down to, I think, is that the trust in the doctor and the nurses themselves...

Because it's just attitude of the staff member from the health service, and that's what we say...you got to talk to the community with respect...You give respect, they give respect. If you don't give respect, you don't get respect, and that's how I find it.

One participant commented that people in the community are always observing the health service staff to see how they work and interact with people and making their assessments about the attitudes of new staff. Several participants commented about the way some new staff speak to people in the community which did not show respect, describing it as "rough talk" and one participant talked about staff needing to remember who the bosses are out there – the senior lawmen and women who are the bosses for that country.

It was suggested that the quality of these relationships and interactions meant that some people in the community did exercise their choice with regard to which health practitioners they would see and those they would not. One participant commented:

...I've seen nurses come and I've seen nurses go. Seen doctors come, seen doctors go, and some of the community members didn't like them, because of their attitude. The way they were spoken to...and the first thing they [say] "Oh I don't like that person. I don't want to see that one", so it puts more stress on the other staff member, because that person, none of the community want to see that person. They want to see someone else.

Other participants talked about the reliance of the outreach model on the strong relationships that had been built up between the health service staff and the community for the model to work effectively. One participant commented "if we don't think it's important, then they don't think it's important" because of the trusting relationships that had been established. This underscored not only the importance of maintaining a good long term health team, but also the imperative to support and induct new staff well.

Trusting and respectful relationships were also identified as key to allowing health practitioners to have the important conversations with people about the difficulties they were experiencing in their lives and with their health – to be able to talk about all the challenges and contradictions. One participant offered the following:

...if you give people time and make time, they will always respect you...if you are going to be a good nurse; you have to be a good counsellor.

Another participant gave a compelling account of the importance of trust in supporting a person from the community through major surgery and the responsibility of ensuring that that trust was not broken:

...he got to the point where he was trusting all the people that were caring for him. And he basically sort of just handed himself over. And so we just made sure that...everything was set up so this was not going to fail...so I think probably more than a conversation about how this was going to get you better, it was more a conversation about trust, and about "Look I'm here for you. I'm not going to let you fall through the cracks."

Burden of illness and determining priorities Some participants observed the significant increase in the number of people in the community with chronic disease over the last decade. Participants described the impacts of this increase in burden of illness on the health service not only in terms of an increased workload overall but also an increase in the time required to manage individuals with complex chronic illnesses leaving less time to focus on preventative health and education. This was further complicated by the fact that there had reportedly been no increase in staffing levels until very recently.

One participant talked about the dilemma and tensions that this situation presents for the health service:

...there's very much that focus of getting out the meds for the chronic disease. We put a lot of energy that way...It is a big burden...So I guess it just goes back to that other thing about your sort of priorities. Like are we so prioritising the 50 year olds with chronic disease and we're forgetting about the young people?...the energy we put into chronic disease and the energy that we put into...adolescent sort of health and education and things like that, are sort of, I think we're a little bit out of balance...Have we got the gaze the wrong way?

Several participants agreed that there needed to be more work about healthy lifestyle choices done in schools by the health service and there was an opportunity for this identified with a new school being opened. However, it was agreed that an investment in additional health service staff was required to take up opportunities such as the one to work with the school as well as maintain work around chronic disease.

Perspectives on accessing and receiving medical treatment and care outside the community

Many people with chronic disease are required to leave the community if they are to access medical treatment in hospital or some types of specialist care. Participants described how, from their perspective, this journey for people to access medical treatment is filled with anxiety and fear as people enter foreign and uncomfortable environments that present many barriers and offer few supports. The challenges for Urapuntja Health Service in coordinating care for people accessing medical treatment out of the community were highlighted. In addition, participants described other impacts people experience when they leave the community to access medical treatment.

Impact of leaving home for medical treatment There were three significant factors described by participants that they believed impacted upon people when they had to leave home to access medical treatment. These were actually leaving their country and families behind and experiencing a strong feeling of being 'homesick'; the dangers associated with being in Alice Springs for accompanying family members; and the fear of the hospital environment and not knowing what is going to happen.

Participants described people's connection to home and belonging to the country and surrounded by family which allowed people to feel safe and well, as described above. To leave that place to go to hospital several hundreds or thousands of kilometres away was significant and brought with it fear and sadness. Participants suggested that this was separate to any experience that they had in hospital:

Well I'll be honest with you, a lot of people don't like going to the Alice Springs Hospital, you know. I meant it's not because of the nursing staff and all that. It's just because they don't want to go at all because this is their home...

I think it's just the different environment too. Like, you know, going from here sitting there with your family, going into town and sitting there with strangers. That...plays on your mind too...It just says 'I want to go home'. And that's a bad...negative feeling right there straight away, 'I just want to go home'.

Some participants also talked about the issues for the family members who accompany the person as 'escorts' when they leave the community for medical treatment. Participants described that there are limited support services for these family members and suggested that sometimes these people were not staying in stable or safe accommodation which presented risks and dangers for them, especially in Alice Springs, related to alcohol, drugs and violence. These situations also presented considerable worry for the person in hospital:

...when they're in hospital and family there and ours mostly are walking around the street you know...See sometime them old people talk, they think a lot you know. 'Maybe when I get sick only I'm in safe you know. I'm in safe in hospital or dialysis or anywhere you know. Even and kids stay and family there, you know walking around or they're learning ganja or grog or anything you know.'

One participant observed the tensions that can exist for some people about what is best for them personally and what is best for the family when making decisions about whether or not to leave the community to access medical treatment. As one Aboriginal participant put it, "Aboriginal always joined up together." This raises the issues of competing priorities for patients as in some cases it was suggested that accessing medical treatment considered beneficial for the individual might actually result in increased problems for the family due to the risks associated with being in town. Participants suggested that these were not easy decisions for people and these situations could create stress within families over the best course of action.

Several participants talked about some community people's association of hospitals with death that understandably brought about fear and anxiety and questions about trust: can you trust the hospital? This again highlights the importance of relationships in providing care in this context and the fact that patients and hospital-based health practitioners have limited opportunities to develop trusting relationships due to the nature of the hospital environment.

One participant reflected on their role in talking with people who needed to go into hospital or see a specialist and providing them with some more explanation and an opportunity to better understand why is it was considered important and what it would involve. They thought this made a difference with people trusting it would be OK and increasing their understanding of what would happen. The idea that when people left the community for medical treatment they were going into environments that were foreign and uncomfortable for them and over which they had very little control was discussed by several participants:

But it's very different when you go into Alice. I mean even for myself to go into Alice Springs and into the hospital, it's a totally different environment. And, you know, out here you're a bit in control of things...But when you're somewhere else

you're not in control and you feel, you know, a bit down and out. And that's what happens to a lot of our clients because they're not used to the environment around there, they will get home sick and they just want to come home, you know. And of course every nurse and every doctor's going to be terrible, in the hospital [laughing].

Participants also discussed the important role of the health service in negotiating on behalf of people in these contexts and supporting them through these experiences and any decision-making, while ensuring:

... that the Aboriginal culture side of it is put together so it matches with the health service and we respect both sides of it.

The reality and challenges of people's journeys into the health care environments beyond the community from the participants' perspectives are explored in the next section.

Confidence, communication, language barriers and foreign environments: coordinating and providing care beyond the community several participants reflected on experiences where they have supported people through journeys into the health care systems outside the community. They talked about people's vulnerabilities and the challenges experienced when negotiating in environments that are so foreign to them. Challenges associated with communication and language barriers when English is not a person's first language were clearly articulated by many participants. Some participants also made reference to the lack of confidence that people have when entering these care environments and the critical role that the UHS staff have in not only facilitating communication and understanding but in also reassuring and encouraging people during these experiences.

Providing and coordinating care for people who have to leave the community for medical treatment is a key challenge is for the health service:

...we'll, you know, go to a lot of effort to get, pick someone up from their house and take them into Alice Springs, but then once they get to Alice Springs well we don't have any control over what goes on, and I think that's...a really big gap, so as a standalone service, I think we do really well, but I think there's a lack of cohesion between organisations and other agencies, that could be addressed.

There was an exceptional example described of the health service providing a staff member and an interpreter to accompany a young person and their family member to Adelaide to provide support and care while the person underwent major surgery. This example is an exception as the health service cannot resource this level of care in every case. More generally, participants described the reliance on communicating and liaising with other health service providers to coordinate people's care outside the community.

One participant talked about the need for "shared care" between UHS and health services in Alice Springs to ensure that people who have moved from the community into town, either for a few months or more permanently due to a family member requiring access to medical treatment such as dialysis, can still access health services. However, as this participant described people can fall through the gaps in these situations because "no-one really wants to hold it [responsibility]" for their care.

Another participant described how a person with chronic disease had moved from Utopia into Alice Springs due to a family member requiring dialysis. The participant reported that the health service worked for three years to get this person "into the system" in Alice Springs so that they could access health care and medications. The challenges associated with this delay in accessing care were identified as twofold: firstly, the limited resources health services in

Alice Springs have to provide encouragement and support for people from remote communities accessing these services; and secondly the person's lack of confidence to access services in a completely different environment where they did not feel comfortable.

As one participant concluded, "...it's just a glaring defect in the system which somehow from both sides we've got to work to solve it". This participant also noted that some larger Aboriginal Community Controlled Health Services had liaison officers employed in Alice Springs to support people and provide assistance; however this participant believed that UHS was not large enough to be able to resource such a position.

Within the hospital context, the challenges for some people associated with communicating and understanding information about their health was highlighted by one participant. It was acknowledged that even though there are liaison officers employed within hospitals they are not always available when they were needed:

...I mean they got liaison officers in the hospital there, but they're not always available...Some of the clients from out here, at Utopia...how do you think they're going to feel when they've got a nurse in town talking to them without no help...that's the hardest thing is trying to understand when someone's telling you what's wrong with you and then you don't know what's going on properly.

Some participants made reference to the challenges for people to navigate through these hospital or health care systems that operated so differently to the health service in Utopia. One participant even described their own stressful experience of going to an interstate hospital:

...I get a bit nervous. I get a bit scared. I don't know what's going on. Especially when I go interstate. If I got to go interstate to a hospital, I am lost. Because, you know, you got all these different levels of, you know, you got your green floor, your yellow floor in Adelaide and all that, and then you got all these names, Gum Room, or whatever it's called...I'm lost and I get scared...and you ask a staff member and they'll turn around and be grumpy with you, you know.

Other participants observed how some people find the health care organisations outside of the community "quite daunting" and called on the health service in Utopia to assist them to gain access and communicate their needs effectively. One participant described how they have received calls from people from Utopia who are in Alice Springs and need to access the hospital or the local health service to pick up some medication:

...there's people that ring from town and they're standing outside these big institutions and they're asking us to call the institution [and ask the staff] to go out and get them.

Another participant described that to assist in these circumstances the health service has implemented a "healthy card" which they provide to everyone on a care plan and it contains the person's Medicare number as well as their medications and the health service's telephone number. The idea is that the person can present this card to the health service in Alice Springs as a way of assisting the person to communicate the information they need in order to obtain the health care they require.

Participants discussed the role the health service often plays in keeping patients in hospital. They described how they receive calls from patients in hospital who express their desire to come home and indicate they are likely to discharge themselves. In these situations it was reported that the health service will often contact the hospital and talk through the issues with the staff to see what support or assistance the patient needs to remain in hospital until they are

discharged by medical staff. One participant also described what a challenge this can be when the person desperately wants to come home and expect the UHS staff to respond to their request:

...and it's very hard to say "No, you got to sit down, and you can sit down there another, a few more days"...Make him feel comfortable, you know, let him know that I do care...So put their minds at ease...

A couple of participants spoke about their perspective on Aboriginal people's expectations of care in the hospital environment. One participant believed that people just wanted to be treated equally and be provided care in the same way as everyone else. Another participant stated that from their perspective Aboriginal people had a different and somewhat lesser expectation of care. This participant suggested that Aboriginal people had a more fatalistic approach when they were diagnosed with an illness, adding that there had always been gaps in health services provided in Aboriginal communities which they believed contributed to expectations being lower, not only of what could be provided, but what services would be provided.

Impact of bad experiences A couple of participants spoke directly about bad hospital experiences and their impact on people in the community. One participant believed that when people do have bad experiences in hospital they are mostly a result of the way they are treated by staff and suggested that this experience impacts upon that person's willingness to go back to hospital. With regard to bad experiences in hospital and/or primary health care these two participants suggested that institutionalised racism was a contributing factor in some cases.

Because some of nurses that you get, that you do get in hospital are, some of them are pretty mean...I've experienced it for myself...Some of them can be a bit degrading to you...

...I think a lot of people are treated badly, have a bad experience in the hospital, and you know, they don't really want to go back.

DISCUSSION

Interviews with UHS staff members shed light on the reasons for the current good accessibility of UHS services, and also on potential reasons for why preventive health care activities vary depending on priorities of health service staff. Key factors that were identified by UHS staff as enablers of primary health care at Utopia included: the outreach model of service delivery; the attitude of health practitioners and their ability to establish relationships with the people in the community built on trust and respect; and having an effective team of both Aboriginal and non-Aboriginal staff that shared similar values and a commitment to the model of health service delivery.

At the same time the vulnerabilities associated with the model were identified by participants as a potential barrier to care. These vulnerabilities related to the level of human and financial resourcing of the health service at any point in time, as this determined if the schedule of outreach visits could be maintained. This point underscores the importance of the Urapuntja Health Service being able to present an argument, supported by evidence, of the benefits of the outreach model in delivering better quality care, chronic disease management and health outcomes for Aboriginal people to ensure that funders recognise the importance of providing adequate resources to support this model.

Other barriers were identified when it came to people being required to access health care outside the community. These barriers included the fact that people had to leave the community and their country, a place where they reportedly felt safe and comfortable, and be in foreign hospital environments where their ability and confidence to communicate and navigate was limited at a time when significant decisions and information about their health were being discussed. Participants described what they understood to be the fear and anxiety associated with being in such a foreign environment experienced by people and the inability of the hospital systems to address this effectively. Another concern for people accessing hospital and medical treatment in Alice Springs was the associated risks for the family members who accompany them as escorts. These risks were reportedly related to the limited social support services and accommodation available for family members with limited personal financial resources as well as the potential for exposure to an environment of drinking, drug taking and violence. The tensions between what was beneficial for the individual and what was beneficial for the family, it was suggested, were real for some Aboriginal people in their decisions to access care. The expectations on UHS staff to support clients in these circumstances are considerable and an increasing burden of chronic illness may be expected to divert attention away from preventive care in the absence of additional resources.

While language barriers in this cross-cultural care environment were identified as considerable challenges, especially given the fact that for many people in the community English is not their first language; several participants described issues relating to gaps in understanding between people and health practitioners. These gaps in understanding go deeper than language barriers and are related to people's understandings of health and wellbeing and factors that contribute to a healthy lifestyle based on people's beliefs, values and world views. Culture is a core part of health and wellbeing for Aboriginal people in the community and the challenge was how culture was recognised, respected and considered in the health care service that was based on, and funded according to, a Western biomedical model. The employment of a substantial number of local Aboriginal people is a key strategy used by UHS to drive a culturally accessible model of health care, underpinned by a community-controlled health board representing the Homelands making up Utopia community.

The outreach model implemented by UHS is consistent with the Australian Government Department of Health and Ageing's strategies to increase service access for Aboriginal people under the Closing the Gap agenda (www.health.gov.au/internet/ctg/publishing.nsf/Content/expanding-outreach). In addition to making clinical services accessible, it supports the social and physical benefits to wellbeing of Homelands living. PHC at Utopia operationalises many of the factors that promote sustainable chronic disease management identified as important in 'remote' Australia, such as: a flexible implementation strategy that takes account of local conditions; high level of community engagement; effective communication; and effective use of monitoring and evaluation data (Wakerman et al., 2005). The latter has included engagement with research institutions over several decades that allowed monitoring of population health trends before the advent of effective electronic PHC record systems, and the associated identification of certain benefits of decentralisation.

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ADDENDUM

Key Performance Indicators (KPIs) used routinely for Primary Health Care Services in the Northern Territory.

A summary of primary health care service delivery data for Urapuntja Health Service for the calendar year 2010 was derived from the KPIs reported back to Urapuntja Health Service by the NT Aboriginal Health Key Performance Indicator System team for the NT Aboriginal Health Forum. Comparisons are made with NT-wide data for remote Primary Health Care providers using Chi-square tests of observed versus expected numbers of cases (SMR Analysis Version 4.11.19; www.sph.emory.edu/~cdckms/exact-midP-SMR.html). Data presented relate to service provision for chronic conditions management and maternal and child health, specifically: pregnant women receiving a first antenatal check before 13 weeks gestation; women aged 18 to 70 years receiving a pap smear test; children under 5 years being weighed; children 6 months to 5 years screened for anaemia; persons aged 15 to 54 years receiving an adult health check (Medical Benefits Scheme [MBS] item 710 or 715 or an equivalent alternative adult health check); persons aged 55 years or older receiving an adult health check (MBS item 704, 706, 715 or alternative); diabetic clients having a HbA_{1c} test in the previous 6 months; children aged 6 months to 6 years fully immunized according to the National Immunisation Program Schedule (www.medicareaustralia.gov.au/provider/patients/acir/schedule.jsp); clients with Type 2 diabetes and/or coronary heart disease on a Chronic Disease Management Plan (MBS item 721, 723 or alternative 721, 723); clients with Type 2 diabetes and microalbuminuria who are prescribed an angiotensin converting enzyme (ACE) inhibitor and/or an angiotensin receptor blocker (ARB).

In 2010, UHS met or exceeded the screening rates for the indicators of women's, child and adult health reported for participating health services in the NT generally (Figure I). Screening of children for underweight was close to 100% and adult health checks were performed at 2-3 times the rate of other services in 2010. UHS achieved significantly greater screening rates than services in the NT in general for anaemia in children, adult health checks, and HbA_{1c} testing for diabetic clients. Likewise the KPIs for childhood immunisation, prescription of ACE inhibitors or All receptor blockers for diabetic clients with albuminuria (both of which were close to 100%), and Chronic Disease Management Plans for clients with type 2 diabetes and/or coronary heart disease were as good or significantly better than the figures for services in the NT generally (Figure II). Thus KPI data provide no evidence that the decentralised model on which Utopia community is designed is associated with a lower than expected level of PHC service accessibility, and some indicators are significantly better than expected.

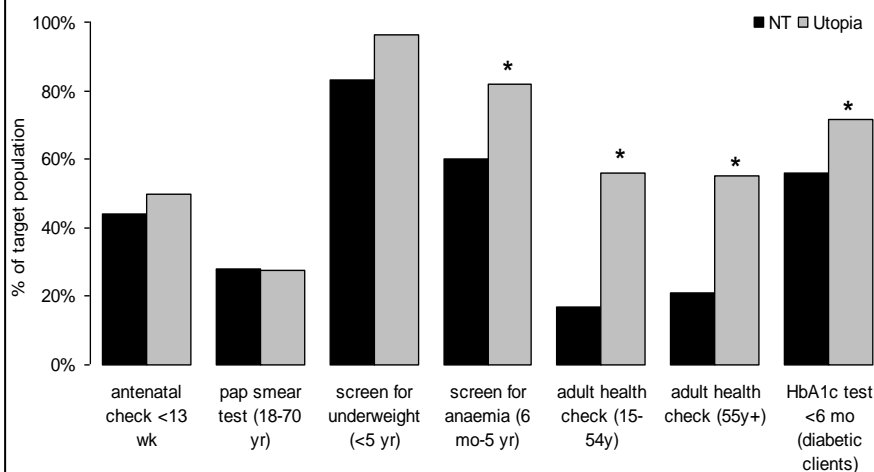
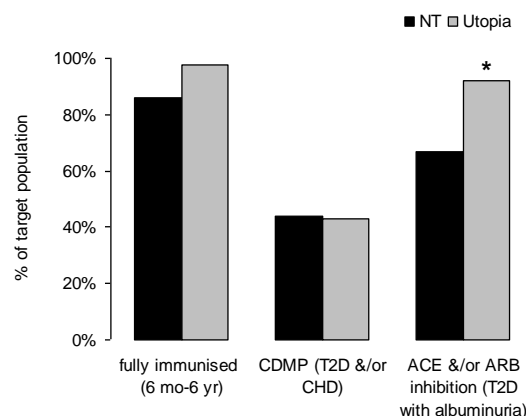


Figure I. Screening rates for Utopia residents and Aboriginal clients of NT PHC services, 2010. Asterisks indicate a statistically significant difference.

Figure II. Clinical intervention rates for clients of UHS and Aboriginal clients of other remote PHC services in the NT. Asterisk indicates a statistically significant difference.



CONCLUSIONS

Utopia community has come to prominence in recent decades for a number of reasons. Alyawarr and Anmatyerr people were among the first to acquire Land Rights under Western law in the 1970s; an internationally significant art movement emerged through the 1980s and '90s; and, less famously but nevertheless a major impetus for involvement in the current project, there was considerable national interest in reports of relatively good health outcomes among residents of the Homelands making up Utopia community. These events are not unrelated. They arose from the opportunities that local Aboriginal people had to exert a degree of agency in the way their community operates. This is reflected in the decentralised nature of the Homelands, in community control of the Urapuntja Health Service (one of the first Aboriginal medical services to be established in Australia), and underpinned by a relatively uninterrupted governance system based on local cultural imperatives. The successes for which Utopia is known have occurred despite poor socioeconomic development in the conventional sense, that is, low rates of employment and Western education, and high rates of poverty and overcrowding.

Explaining the social mechanisms driving these paradoxical outcomes is difficult - simplistic interpretations of the clinical and social determinants of health and of the indicators routinely used to monitor them do not provide useful tools for telling the story of Utopia. Neither do they inform useful intervention designs for responding to emerging health and social issues such as increasing rates of chronic illness, health and social policies imposed by Territory and Commonwealth Governments, and the cultural and economic effects of globalization. And if the strengths of the social processes driving the good outcomes for members of Utopia community are to help other Indigenous and mainstream communities, we need to be clear about how they operate.

In this report we have sought to shed some light on the complexity of the 'social determinants of health' at Utopia. The historical analysis by Anderson et al. highlights the earlier economic influences on current indicators of housing, education, employment and income. All of these indicators show the high levels of material poverty that are prevalent in the community. However it also demonstrates maintenance of certain social strengths that have allowed ongoing assertion of culture, identity and governance mechanisms that have buffered the negative effects of material poverty to a degree. Some of the social mechanisms at work are described by Rickards et al., and these include the exercise of authority derived from generations of connection to Country, access to traditional food sources, medicines and ceremony, and the implementation of community control of health service provision. The decentralised design of the community aids hunting of traditional foods and, at least in the past, has limited access to processed foods from the store. The latter was reflected in successful prevention of weight gain on Homelands remote from the store during the 1990s – a unique achievement at a time of otherwise rampant obesity. But as highlighted by Moore, a simplistic interpretation of 'remoteness' facilitating better diet and exercise behaviours misses another major factor – the opportunity to implement good governance that is also associated with living on Homelands. This extends to influencing the nature of clinical services delivered by Urapuntja Health Service. Again, assumptions about service accessibility that are based on geographic location of a clinic are false in the context of Utopia. Access includes the manner in which staff interact with community members, responsiveness to community priorities, and respect for and use of local knowledge. Uptake of clinical services that form part of Key Performance Indicators are determined by these aspects of service delivery. As reported Togni et al., the human and material resources required to achieve the high levels of access observed at Urapuntja Health Service are

considerable, requiring high levels of training for and commitment by staff members. High rates of adult risk factor screening at Utopia have been aided by engagement with research over several decades, with the accompanying resources for screening, feedback and advocacy that provides (albeit intermittently).

The parallels with Native American communities are difficult to ignore, where sustainable economic development never occurs in the absence of Indigenous sovereignty and good governance. Interventions to change the indicators of health and economic development without regard to their true social basis always fail, because of the cultural meanings of employment, education, housing and income over and above their implications for material resources, and the breadth of what is considered to be part of 'health'. These meanings are culturally specific. In the case of Utopia, the community has and continues to resist external pressures to implement health and social policies that meet others' priorities and cultural meanings but not their own.

Hence the story of health at Utopia is not one that is explained by simple interpretations of the meaning and effects of Homelands living, employment, education, health service delivery or self determination. Depending on any one of these factors to explain health outcomes is not meaningful, much less a basis for designing interventions. Clearly at Utopia, access to Country and the return to Homelands have been essential to allow genuine self-determination, but such a degree of access to and control over Country is not possible for the majority of Aboriginal People. And although participation in the paid workforce is low, and consequently so is income, there is nevertheless a high level of culturally meaningful activity occurring – an additional aspect of 'employment' that drives its association with better health outcomes in mainstream society.

Thus the shifting balance between external influences that are often negative and internal buffering mechanisms is reflected in changing health profiles at Utopia. Urapuntja Health Service is a major organization required to respond to these influences. It is both a major employer and health service provider, and in addition supports traditional healing practices and ceremony and advocates for community on various issues. In this way Urapuntja Health Service continues to deliver primary health care according to the vision articulated in the WHO's Alma Ata Declaration.

Kevin Rowley, Karmananda Saraswati, Ricky Tilmouth, Alex Brown, Sarah Doherty

"The longer I work here and live here, the less able I am to recognise single causes, rather the importance of country, connection (including with UHS and its staff), ceremonies, good traditional governance ("law"), and modern, all play a part. It is a tangible experience of wellbeing, being held by something wonderful, beyond words, but really good. Probably like playing in a footy team with Aboriginal and non-Aboriginal players creating goals together, and defending the goal desperately, together. A great feeling, doesn't get better, closes the gap in the truest sense."

K. Saraswati.